

Step





Breastfeeding Overview

Very few interventions have a greater impact on the health outcomes of a preterm or ill infant than simply providing optimal nutrition.

Nutrition for the infant begins in utero with the swallowing of amniotic fluid. Growth factors, nutrients, stem cells, and a host of immunological properties in the swallowed amniotic fluid are essential to the optimal development of the fetus (Underwood, 2013; Underwood, Gilbert, & Sherman, 2005). Growth factors found in the amniotic fluid more than double the weight of the intestinal tract (Meier, Engstrom, Patel, Jegier, & Bruns, 2010).

An infant delivered prematurely misses out on some of the benefits of the amniotic fluid. For this reason, the mother's expressed breast milk (EBM) becomes essential to significantly improving both short- and long-term health outcomes (Meier, Johnson, Patel, & Rossman, 2017). The breast milk expressed by a mother who delivers prematurely is different from the milk she would produce if her infant was delivered at term. This early "preterm breast milk" has similarities to amniotic fluid and is high in growth factors and immune cells known to decrease the infant's risk for serious infections, such as necrotizing enterocolitis (NEC; Meier et al., 2017; Underwood, 2013).

The American Academy of Pediatrics (AAP), along with the U.S. Department of Health and Human Services, recommends breast milk feedings for all infants, healthy or ill (AAP, 2012). In addition to lower rates of NEC and other infections, preterm infants who are fed breast milk have been shown to achieve enteral feedings more rapidly, have lower rates of chronic lung disease and retinopathy of prematurity, and have improved neurocognitive and visual acuity scores, to name a few benefits (Meier et al., 2017; Rodriguez, Miracle, & Meier, 2005; Underwood, 2013).

Improved outcomes translate to shorter hospital stays and cost savings for both families and healthcare facilities.



Mother breastfeeding infant baby. © vitalinka

In a study published in *Pediatrics*, researchers analyzed data cited by the Agency for Healthcare Research and Quality on health outcomes related to breastfeeding for 10 pediatric diseases. The researchers found that if 90% of families in the United States complied with the recommendation to breastfeed exclusively for 6 months, the United States would save approximately \$13 billion per year in healthcare costs (Bartick & Reinhold, 2010).

Given the numerous health benefits of breast milk for the vulnerable infant, healthcare professionals have an important role to educate and encourage mothers to provide their own breast milk for their infants regardless of their choice of feeding method. For the mother who intends to bottle feed her infant with formula, the healthcare professional must separate the feeding method from the nutrient to allow the mother to make an informed decision about providing breast milk for her infant. Many mothers may be willing to pump when offered this option even though they did not intend to directly breastfeed (Meier et al., 2017). Counseling the mother of a very-low-birth-weight infant has the potential to increase the incidence of breast milk feedings without increasing stress or anxiety to the mother (Sisk, Lovelady, Dillard, & Gruber, 2006).



Ensuring successful breastfeeding at discharge begins when the infant is admitted to the neonatal intensive care unit (NICU) and should continue throughout the hospital stay by educating mothers on its benefits and techniques. These mothers need information on the science of breast milk along with the specifics related to hand expression and pumping. They need instruction on the use of a double electric breast pump, collection of EBM, the storage and transport of EBM, and, when indicated, positioning for direct breastfeeding (Meier et al., 2010).

In addition, it is important to tell the mother that although feeding her baby exclusively breast milk provides the greatest protection for her premature infant, providing breast milk for even half of her infant's daily feedings has the potential to reduce the risk of serious infection by half (Corpeleijn et al., 2012). If the mother has insufficient EBM for her infant's nutritional needs, donor breast milk is the best alternative for the preterm infant (Kumar et al., 2017; Quigley & McGuire, 2014).

Hand Expression, Pumping, and Milk Storage

Early, frequent, and effective milk removal determines milk production (Morton et al., 2009). Initiation of hand expression, preferably within the first hour after birth, has been shown to increase overall milk volume at 6 weeks (Parker, Sullivan, Krueger, & Mueller, 2015). Every mother should receive instruction on breast massage and manual expression techniques. She should be instructed to combine hand expression with her pumping sessions if she is separated from her infant (Morton et al., 2009). In addition, providing the mother with an opportunity to hold her

infant skin to skin may enhance her body's enteromammary response and produce immunoglobulins specific to the bacteria and viruses of her infant and to those in the hospital environment, along with increasing her overall milk production (Gulla, Dahlo, & Eilertsen, 2017; Moore, Bergman, Anderson, & Medley, 2016; Riskin, Almog, & Kessel, 2010).

The following guidelines should be provided to the new mother separated from her infant:

- If the mother is stable, instruct her to hand express her milk within the first hour after birth and to continue massage and hand expression before or after each pump session.
- In combination with hand expression, initiate pumping with a hospital-grade electric pump. Instruct the mother on pumping techniques, including handwashing, cleaning pump equipment, and the storage, labeling, and transport of EBM.
- Instruct the mother to pump every 2–3 hours during the day and at least once at night for a total of eight sessions in a 24-hour period.
- Provide an opportunity for skin-to-skin care and pumping at the infant's bedside.
- Provide the mother with a log to keep track of her milk volume and pump sessions.

Instruct the mother to inform the neonatologist or neonatal nurse practitioner (NNP) if she is taking any medication while providing milk for her infant in the NICU. The provider, with the lactation consultant, will need to assess the compatibility of maternal medications with breastfeeding and the use of EBM.

Storage of Human Milk for NICU and High-Risk Infants

- Freshly expressed human milk is safe at room temperature for 4 hours.
- Milk can safely be refrigerated for 2–4 days.
- Time in freezer: 1–3 months; time in deep freezer: ≤ 12 months
- Human milk that is previously frozen and cold thawed but not warm: ≤ 24 hours in refrigerator
- Milk that is being fed to an infant via continuous feeding can be safely administered over a 4-hour period.
- Storage of fortified human milk: Milk with fortifiers should be given as soon as possible after the fortifier is added and as quickly as tolerated. Time in refrigerator: ≤ 24 hours

Refer to *Best Practice for Expressing, Storing and Handling Human Milk* (2011) from the Human Milk Banking Association of North America for additional information (www.hmbana.org).



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Breastfeeding Overview for Parents

Pacifier Use for the Preterm or Ill Infant

Nonnutritive sucking, or sucking without taking milk, has been shown to have many benefits for preterm or ill infants, especially when provided during gavage (tube) feedings. Nonnutritive sucking may be provided with a pacifier or at the emptied breast (called nuzzling). Although pacifier use during the early postbirth period has been linked with breastfeeding problems in the healthy full-term baby, pacifier use during tube feedings for preterm or ill infants does not cause problems. Discuss nuzzling during tube feedings with your infant's healthcare provider or neonatal nurse practitioner.

Protecting Your Milk Supply

In the early weeks following your baby's birth, the breast pump did the work of maintaining your milk supply. It is natural to think that once your baby starts to feed at the breast, you can stop pumping. In fact, most mothers are anxious to get rid of the pump and just breast-feed. Remember, your baby may not be strong enough to empty your breast, and you have worked so hard to get your milk supply where it is. It is important to continue to pump your breasts after your premature baby has nursed to make sure your breasts are empty. This will ensure you continue to make enough milk. Stopping too quickly may cause your milk to dry up.

Maintaining Your Milk Supply

The first 2 weeks after having your baby is a very important time to establish a good milk supply. Your baby will be fed eight times every 24 hours; therefore, you will need to pump at least eight times every 24 hours. This is necessary to send the right signals to your breasts to make milk.

If you are separated from your baby, you may want to consider renting a hospital-grade pump. Contact your insurance company and discuss pump options with a lactation consultant.

Consider the following ideas for maintaining your milk supply:

- Pump every 2–3 hours during the day and 3–4 hours at night for a total of eight pump sessions every 24 hours.

- Prior to pumping, massage your breasts to promote the flow of milk. Pump for 15 minutes (20 minutes if you have multiples). Continue to pump an additional 2 minutes once the flow has stopped to be sure to remove as much milk as possible.
- After pumping, express your breast milk by hand for several minutes. Hand expression has been shown to increase milk production. Ask your nurse or lactation consultant to teach you this simple technique.
- Continue to take your prenatal vitamins while pumping or breastfeeding.
- Drink plenty of fluids; eat three healthy meals and three healthy snacks every day.

Whether you choose to directly breastfeed or to pump only, this journey can be very difficult at times. You may even wonder if it is worth all of the effort. Every study shows that it is worth it. Babies who are ill or premature and receive breast milk have fewer infections, fewer developmental delays, and stronger immune systems than babies who receive formula. Providing breast milk to your baby is a gift of love that will have health benefits for you and your baby that will last for years to come.

Tips for Storing Your Milk for Your Infant After Discharge from the NICU

- Wash your hands with warm water and soap before handling pump parts or breast milk.
- Use clean bottles or plastic nursing bags to store your breast milk.
- Write the date and time on each new bottle of pumped milk.
- Once at home, freshly expressed breast milk is safe at room temperature for 4 hours.
- Frozen milk can be stored in the freezer for 3–6 months.
- Thaw frozen milk in the refrigerator or in cold water and use within 24 hours.
- Do not store expressed milk in the refrigerator or freezer door; temperature variation is considered warmer inside door space.
- Do not add fresh milk to milk that is already frozen.
- Do not thaw or warm breast milk in the microwave.



Getting Information from the Healthcare Team

A family-centered approach to care in the neonatal intensive care unit (NICU) has been shown to have a positive impact on outcomes. These include lower levels of parental stress, improved confidence in decision making, and increased trust in the healthcare team (American Academy of Pediatrics, 2012; Hendricks-Muñoz & Prendergast, 2014; Williams, 2016). In addition, parents who are included in direct patient care are less likely to suffer from depression and anxiety often associated with having an infant in the NICU (Obeidat, Bond, & Callister, 2009).

Upon the infant's admission to the NICU, parents should be presented with a list of opportunities to participate in the routine care of their infant, such as holding, changing, feeding, and bathing. Avoid giving parents a list of rules and restrictions, but instead provide guidelines on hand-washing, visits from family and friends, etc. Explain that parents are not considered visitors but instead are vital members of the healthcare team who work together with healthcare providers to promote healthy outcomes for their infant while in the NICU.

Having an infant in the NICU can be one of the most emotionally stressful times in a parent's life. The healthcare team should encourage activities such as *kangaroo care* (KC), an evidence-based practice benefitting both the infant and parent that meets the infant's needs for warmth, love, and contact. KC has the potential to decrease stress by replacing it with a wonderful experience that only the parent can provide (Gabriels, Brouwer, Maat, & Hoogen, 2015).

Each member of the NICU should consider the unit's physical layout and ability to maintain confidentiality when determining how best to include parents in rounds and to exchange information about their infant. Parents should be recognized as both experts on and advocates for their child.

The following are suggestions for parental participation:

- Encourage parents to learn as much as possible about their infant's health and medical condition.
- Encourage parents to perform KC.
- Encourage parents to be involved in direct care as much as possible, reminding them that they are their infant's most consistent caregivers.
- Encourage parents to ask questions and include them in patient care rounds and reports when possible.
- Encourage parents to keep a journal and to write down additional questions as they log daily activities.
- Encourage parents to take time to care for themselves.

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Getting Information from the Healthcare Team: Information for Parents

As parents, you are the most important people in your baby's life and in their care. Your baby's healthcare team needs you to help provide your baby's care. There are many ways that you can do this:

- Come to the neonatal intensive care unit (NICU) as soon as you can after your baby is born. Get to know your baby. Help us learn about his or her patterns, likes, dislikes, and communication. Let your baby hear your voice and feel your touch—they are comforting and familiar to your baby.
- Learn what care you can provide for your infant (for example, taking his or her temperature, diaper changes, bathing, feeding, and calming your baby).
- If the healthcare team uses words you don't understand, ask for an explanation.
- Talk with your baby's caregivers often. It helps to write down questions, anything that worries you, or things about your baby to share. Talk with your baby's bedside nurse and the doctor or nurse practitioner.
- Learn everything you can about your baby's strengths and differences.
- Talk to your baby's provider or nurse about when you can start kangaroo care. This is a special type of

holding in which your infant is placed on your bare chest and covered with a blanket. Many studies have shown benefits for both baby and parent from this type of holding. Kangaroo care provides warmth, love, and comfort to your baby and should happen daily when your baby is stable.

In this unit, the best way/time to participate is _____.

We ask that you respect the privacy of other babies and not ask questions about them or discuss them with others.

It's important to take care of yourself, because your baby needs you. Spend time talking with your family and friends each day. Discuss your feelings and concerns. Find friends or family who can help with other daily tasks or offer support. It might help to talk to a social worker or chaplain. Tell the staff if you are having difficulty eating or sleeping.

Don't forget to ask your NICU team for information about support groups or websites that might be helpful.

Step





Temperature Control

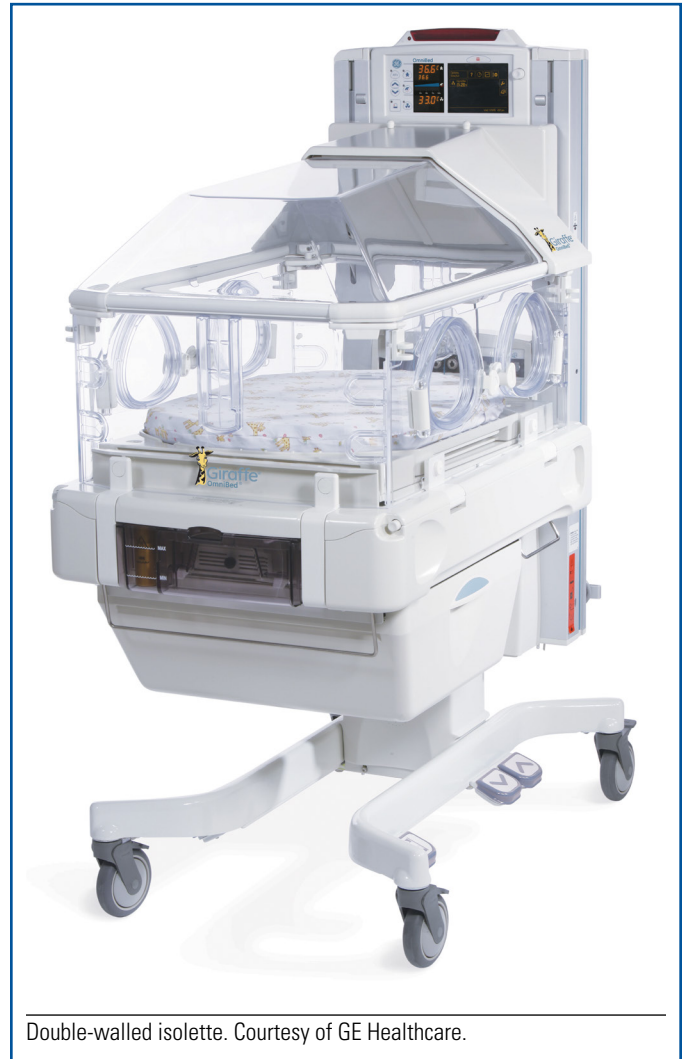
Thermoregulation is an important aspect of neonatal care that affects healthy newborns, as well as sick or premature infants. Infants need assistance with maintaining a neutral thermal environment, in which the least amount of an infant's energy is needed to maintain a normal body temperature. Maintaining this temperature requires a balance between heat that the infant produces and heat that is lost.

At birth, an infant loses heat rapidly due to exposure in a cold delivery room (convection) or through the evaporation of fluid from the infant's skin. An infant's core body temperature can drop 2°C to 3°C in the first 30 minutes of life. An infant may lose heat quickly when placed directly on cold surfaces, such as a scale or an X-ray plate (conduction), as well as through radiation, such as through walls or windows. In order to maintain temperature after delivery, an infant will metabolize brown fat stores, glycogen stores, or both. Infants who are born early have fewer brown fat stores than healthy newborns. By being exposed to heat losses for an extended period of time, these stores may become depleted, causing the infant to develop cold stress. When an infant experiences cold stress, blood vessels throughout the body will constrict, causing systemic vasoconstriction. Vasoconstriction prevents blood flow and oxygen from being delivered to tissues, which increases the risk for organ and tissue damage. This can lead to increased oxygen needs, infection, hypoglycemia, increased risk for blood pressure alterations, and potentially intraventricular hemorrhage when rewarmed.

Here are some ways to minimize heat loss in an infant:

- Increase the temperature of the delivery room and use prewarmed surfaces while stabilizing the infant.
- Heat respiratory gases (oxygen being breathed in from a ventilator or nasal cannula).
- Place a warm blanket on a scale or X-ray plate prior to use.
- Use a radiant warmer or double-walled isolette (shown at right) to reduce radiant heat losses.

- Use humidity to reduce heat loss through evaporation in very premature infants.
- Use developmental care, including facilitated tucking, to minimize surface area exposure.



When an infant is able to maintain temperature without radiant heat, he or she can be dressed in clothes and a hat, swaddled, and placed in an open crib.

It also is important to avoid overheating the infant while trying to maintain the infant's neutral thermal environment. If the infant is too warm or warmed up too quickly after being cold, he or she may experience further physiological changes such as increased heart rate and



respiratory rate and the risk of dehydration and altered acid-base status. A sustained increase in body temperature can cause apnea, bradycardia, and oxygen desaturation.

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Temperature Control: Information for Parents

Babies can sometimes have a hard time keeping their temperature in the normal range. Full-term babies have a layer of fat under their skin that helps them stay warm. When babies are born early they don't have as much fat under their skin.

Right after birth, your baby can get cold very quickly. The best way to keep your baby warm is to dry your baby; give your baby a warm, dry bed; and place a hat on his or her head.

In the neonatal intensive care unit (NICU), one of the beds that can be used is called a radiant warmer. It is like an open crib, with a heater on it that helps your baby stay

warm. Another bed your baby may use is called an isolette or incubator. This gives a preemie or sick baby extra heat to help keep his or her temperature where it should be.

When your baby is older and bigger, he or she can be dressed in clothes or a T-shirt, wrapped in a blanket, and put in an open crib or bassinet. This is one of the milestones along the journey to home.

It also is important to make sure your baby doesn't get too warm. Dressing your baby in too many clothes, covering your baby in too many blankets, or covering your baby's face can make him or her too warm. For more information related to this subject, see Safe Sleep in Step 6.



Double-walled isolette. Courtesy of GE Healthcare.



Babies can be wrapped in a blanket and placed in an open bassinet. © iStock.com/madisonwi

Things to remember when going home:

- If your baby's body temperature is lower than 97 °F (36 °C), undress your baby, place him or her skin to skin on your chest, wrap yourselves in blankets, and call your baby's provider. You also should call the provider if your baby's temperature is higher than 100.4 °F (38 °C).
- If your baby's hands or feet are cool or look pale or blue, warm them with a blanket. You also can add a layer of clothing. If the color of your baby's hands and feet does not improve, call your baby's provider.
- Dress your baby in layers. To avoid overheating, add only one more layer of clothing than you are wearing if



Babies can be dressed in layers, but no more than one additional layer than you are wearing. © tirc83/Getty Images

the temperature is cool, and remove a layer of clothing if your baby is warm. Use sleepers when you can.

- Remove clothes when they are wet or dirty.
- Keep your baby away from drafts and windows as much as possible.
- Keep the crib away from drafts, windows, and outside walls by placing your baby's crib on the inner wall of the room.
- Always place a hat on your baby when you go outside in cool or windy weather.



Pain Management

Infants who are born sick or premature and are admitted to the neonatal intensive care unit (NICU) frequently endure painful procedures during their stay. Procedures such as routine care, heel pricks, blood draws, intravenous catheter insertions, respiratory interventions (suctioning or intubation), and surgical procedures are painful stimuli that can have negative effects on the infant. A growing body of evidence shows that infants who experiencing repeated painful stimuli may develop emotional, behavioral, or learning difficulties. In addition, parents of infants receiving care in the NICU report that one of the greatest sources of parental stress is the worry that their baby is experiencing pain.

The prevention or reduction of pain an infant experiences should be the goal for all caregivers, as well as an expectation of the parents. Pain assessment tools are used to measure pain responses in neonates because of the infant's inability to report pain. These tools may measure physiological indicators (e.g., heart rate, respiratory changes) and behavioral indicators (e.g., facial expressions, body movements, crying). An infant's pain should be assessed routinely, as well as before and after procedures.

Pain prevention strategies in neonates include nonpharmacological interventions and the use of pharmacologic

agents. The most effective way to alleviate pain is to reduce or eliminate unnecessary procedures. Other methods to reduce pain include developmental interventions performed by the caregiver or a parent. For routine care procedures, nonpharmacological interventions may be sufficient to reduce or prevent pain in an infant.

Nonpharmacological interventions include

- containment or facilitated tucking (swaddling, positioning)
- nonnutritive sucking (use of pacifier with oral sucrose or breast milk)
- kangaroo care or skin-to-skin contact with mother
- maternal presence during procedure
- decreasing light and noise to provide calming environment.

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Pain Management: Information for Parents

Pain management is an important part of care in the neonatal intensive care unit (NICU). While your baby is in the NICU, the doctors and nurses are doing everything they can to make sure your baby is comfortable and not in any pain. Although it is natural for you to be worried that your baby is hurting, there are many ways to prevent pain and make potentially painful procedures more comfortable.



There are many ways to lower pain without using medications. This is called *nonpharmacological pain management*. This includes

- wrapping the baby snugly in a blanket
- holding the baby skin to skin, also called *kangaroo care*
- offering the baby a pacifier to suck on

- letting the baby nurse at the breast before, during, and after a painful procedure
- keeping the baby distracted with rocking, gentle touch, soft sounds, and low light
- giving the baby a solution of sugar water on their tongue or on a pacifier.

If your baby's providers think that a necessary procedure will cause more pain, they can use many safe and effective medications to help relieve that pain. This includes everything from applying numbing cream to the skin to offering medicines to stop the pain.

If you're worried that your baby is in pain, you can ask the NICU nurses to help you learn how to tell if your baby needs something (Is your baby hungry? Does he or she need a diaper change?) or if he or she is hurting. After going home, you can continue following these tips to help your baby if you think he or she is in pain:

- Wrap your baby in a blanket to provide comfort and to help him or her feel safe.
- Give your baby a pacifier or offer breastfeeding.
- Provide skin-to-skin care by holding your baby with their bare skin up against yours (*kangaroo care*).
- Keep lights and noise down to provide calm.
- Talk to your baby's provider about medicines that can help with pain.



Developmental Care

What Is It and Why Is It Important?

Preterm infants are hospitalized in a care environment that is very different from the maternal womb, where optimal growth and development of the fetus occurs. Therefore, the application of developmental care principles in the neonatal intensive care unit (NICU) is critical to improve neurodevelopmental outcomes of preterm infants. *Developmental care* is a strategy to help reduce the amount of environmental and sensory stress that a premature infant is exposed to after birth.

Developmental care practices can be predictive of long-term neurobehavioral outcomes in preterm infants. In one study (Montirosso et al., 2012), infants from NICUs with high scores in infant-centered care had higher attention and regulation, less excitability, less hypotonicity, and lower stress scores than infants discharged from lower scoring units.

There are many aspects of developmental care. These include family-centered care principles such as

- open visitation and kangaroo care (shown below)
- infant behavioral or “cue” monitoring
- positioning (providing boundaries and avoiding “W” or “M” placement of extremities)



Kangaroo care. Courtesy of Joan Smith, MSN NNP-BC, and Mary Raney, MSN NNP-BC, St. Louis Children's Hospital.



Supportive positioning without confinement. Courtesy of Joan Smith, MSN RN NNP-BC, and Mary Raney, MSN RN NNP-BC, St. Louis Children's Hospital NICU.

- handling (avoiding the “preemie flip,” when infants are turned rapidly; telling infants when they will be touched)
- bathing (should be a family intervention)
- helping infants regulate themselves.



Swaddling with pacifier. Courtesy of Joan Smith, MSN NNP-BC, and Mary Raney, MSN NNP-BC, St. Louis Children's Hospital.

Remember, there is no time when developmental care is *not* appropriate because routine care is never innocuous to neonates.



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Developmental Care: Information for Parents

As a preemie, your baby needs special care and attention. While your baby is in the neonatal intensive care unit (NICU), the staff will try to create an environment that is safe, quiet, and more like being in the womb than being in a noisy, busy hospital. They will do this by keeping the lights low, using soft voices, and positioning your baby's body so that it is cradled in the isolette. Bright lights and loud noises may bother your baby, especially if he or she is very premature or very sick.

The staff will be very gentle with your baby. This is because a premature baby's skin can be very fragile and sensitive to touch. You also may find that your baby needs to be held or positioned in certain ways to be calm and comfortable. Learning the best way to care for your baby now can help him or her grow and develop down the road.

Most of the time, preemies and sick babies are asleep. It is best to avoid waking them because they need sleep to grow and get well. As babies get closer to full term and get stronger, they will be able to stay awake for longer periods of time. Preemies and sick babies are very sensitive to overstimulation. Try to focus on one of your baby's senses at a time. For example, touch your baby and then talk to him or her—not both at the same time.

Babies develop the sense of touch early, so they can be very sensitive. Ask your baby's nurse to help you use touch in a positive way. This might include

- using a constant, firm but gentle touch; a back-and-forth touch like stroking or massaging can be too much for a premature baby
- gently cupping one hand under the head and another hand on the bottoms of the feet to support a fetal position

- using skin-to-skin contact (also called *kangaroo care*) as soon as your baby is ready, putting your finger in your baby's hand so he or she can hold it.

Babies use taste and smell to know who their parents are while they are in the womb. They continue to use these senses to get to know you during their NICU stay as well. Be sure to not wear perfumes or scented lotions. Some mothers can place a cloth that smells like their breast milk in their baby's isolette. This smell is unique to you and can help your baby connect and bond with you.

Over time you also will learn to read your baby's cues. *Cues* are things your baby does that show what he or she is feeling. Ask your NICU nurses to teach you what your baby is saying by the way he or she is acting. Learning to read your baby's cues will help you care for your baby when you go home together. For example, you will learn the difference between an angry cry and hungry cry. Also, you'll know whether your baby, when given a pacifier, either just doesn't like it or needs you to hold it in his or her mouth. Eventually, you will be the expert and will know what your baby needs to grow and develop.



Mother and baby enjoy skin-to-skin time. ©University of Texas Southwestern Medical Center. Reprinted with permission.



Parenting in the NICU

Having an infant in the neonatal intensive care unit (NICU) can be a stressful time for parents. Infants are admitted to the NICU for a variety of reasons, including prematurity, infection, and respiratory complications. Most of these are unexpected and distressing for the family. Parents of a sick or premature infant can experience many emotions and display different responses to their baby being in the NICU.

Common emotions and responses to having an infant in the NICU can include

- fear of the unknown
- guilt for having the baby early or feeling responsible for what happened
- grieving the loss of a typical birth experience and not having a healthy baby
- feeling helpless to comfort their infant
- fears their infant will experience pain
- frustration over being separated from their infant
- fear of the future and the financial burden a NICU admission can cause.

Parents can see the NICU as a foreign and overwhelming environment, and many have reported that the inability to hold their baby and protect him or her from experiencing pain is a great source of stress. It is important to help reduce parents' stress by giving them opportunities to be involved and to have some control in their infant's care.

Remember, parents often don't know what to ask and can be so distraught that they don't remember what was said to them. Be patient—parents may ask the same question several times.

Parents can be involved in their infant's care by

- asking questions (multiple times, if needed)
- providing routine care, such as taking their baby's temperature and changing his or her diaper
- being present and placing their hands on the baby to help console him or her during painful procedures
- providing skin-to-skin contact (kangaroo care)
- holding or feeding their baby when he or she is medically stable.

It has been shown that facilitating quality parent-infant interaction during the infant's stay in the NICU can help parents acquire a sense of confidence when taking their infant home.

Remember, too, that it is important to include fathers. Although fathers may have some of the same feelings about having a sick baby, they will outwardly react differently in most cases. Just because the father appears to have it all together does not mean he does.

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Parenting in the NICU: Information for Parents

Having a baby born very early or sick can be distressing for parents. The neonatal intensive care unit (NICU) can be a scary place because of all of the sounds and machines that are used. You may have many overwhelming feelings about your baby being sick: you may be feeling sad, guilty, scared, or worried about your baby and what is going to happen.

Mothers and fathers often have many of the same feelings about having a sick baby, but they will show those feelings differently—and that's OK. Be patient with each other. It's OK to ask questions—and you can ask the same question again if you don't understand or don't remember the answer.

At first, your baby may be too sick to hold, and noise and lights may be too much for him or her. One way you can help your baby is to gently touch or talk to him or her in a quiet voice. You play a very important role in your baby's care and ongoing development. Your presence at the bedside is very comforting to your baby, who knows your

voice and scent. Your voice can help your baby be calm so he or she can grow and get better. Once your baby is feeling better, the nurse will show you how to place your hands on your infant to help your baby feel secure.

As your baby feels better, the nurse will let you know when to help with your baby's care. Being involved in your baby's NICU care will help you feel more comfortable caring for your baby once you go home. There are many ways you can interact with your baby during the NICU stay, including talking, reading, and singing. You can change your baby's diaper, take his or her temperature, and possibly hold your baby. You also can give your baby skin-to-skin care, called *kangaroo care*. This will help you get to know your baby and help your baby be calm and quiet.

As your baby gets bigger and stronger, you will get to hold your baby more and feed him or her. When your baby is able to do these things, you are one step closer to going home!



Newborn Screening

Newborn screening tests look for serious developmental, genetic, and metabolic disorders so action can be taken during the critical time before symptoms develop. Most of these illnesses are very rare but treatable if caught early.

In the United States, individual states regulate newborn screening, so the diseases screened for vary considerably from state to state. Most states require three to eight tests, but organizations such as the March of Dimes and the American College of Medical Genetics suggest more than two dozen additional tests.

The most thorough screening panel checks for about 40 disorders. All 50 states screen for congenital hypothyroidism, galactosemia, and phenylketonuria (PKU).

Screening tests do not diagnose illnesses. They identify which babies need additional testing to confirm or rule out illnesses. Remember, a negative screen does not mean that the disease is not present—it may mean that the baby was screened too early or that there were insufficient amounts of metabolites in the blood to reach the threshold for a positive result (sensitivity of the test). If the baby is showing signs and symptoms of concern, always do follow-up testing. If follow-up testing confirms that the infant has a disease, appropriate treatment can be started right away, before symptoms appear.

Normal values for each screening test may vary depending on how the test is performed. Each state laboratory should have established “normal ranges” for the newborn screening program and individual tests.

Each state has independent screening programs. To find out specifics on your state screening program, visit <http://genes-r-us.uthscsa.edu>.

Screening tests in state programs may include

- amino acid metabolism disorders
 - arginosuccinic acidemia
 - citrullinemia
 - homocystinuria
 - maple syrup urine disease
 - PKU
 - Tyrosinemia type I
- biotinidase deficiency
- congenital adrenal hyperplasia
- congenital hypothyroidism
- cystic fibrosis (see also neonatal cystic fibrosis screening)
- fatty acid metabolism disorders
 - carnitine uptake deficiency
 - long-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency
 - medium-chain acyl-CoA dehydrogenase (MCAD) deficiency
 - trifunctional protein deficiency
 - very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
- galactosemia
- glucose-6-phosphate dehydrogenase deficiency (G6PD)
- organic acid metabolism disorders
 - 3-hydroxy-3-methylglutaric aciduria (HMG)
 - 3-methylcrotonyl-CoA carboxylase deficiency (3MCC)
 - beta ketothiolase deficiency
 - glutaric acidemia type I
 - isovaleric acidemia
 - methylmalonic acidemia
 - multiple carboxylase deficiency
 - propionic acidemia
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Critical Congenital Heart Defects (CCHD) Screening

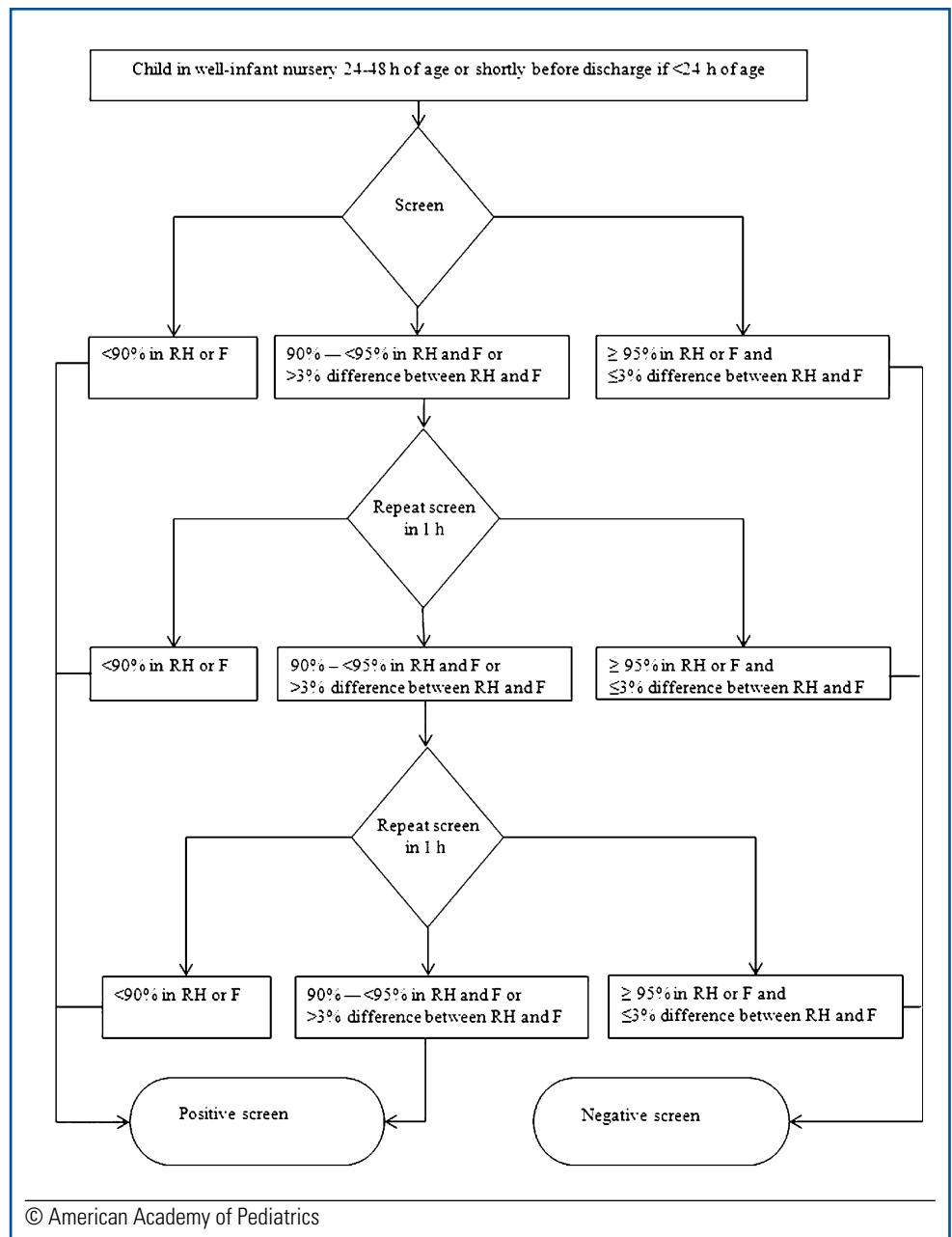
Approximately 18 of every 10,000 babies are born with a critical congenital heart defect (CCHD). CCHD is life threatening and requires intervention in infancy. However, CCHD is not always detected prenatally or upon exam in the nursery. As a result, some infants with CCHD are discharged from the nursery to home, where they quickly decompensate. To improve the early detection of CCHD, the Secretary of Health and Human Services recommended that CCHD screening be added to the uniform newborn screening panel (American Academy of Pediatrics, 2017).

Screening with pulse oximetry can identify a number of types of CCHD, including coarctation of the aorta, double outlet right ventricle, Ebstein anomaly, hypoplastic left heart syndrome, interrupted aortic arch, pulmonary atresia, single ventricle, tetralogy of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, tricuspid atresia, and truncus arteriosus.

Current published recommendations focus on screening infants in the well-baby nursery and in intermediate care nurseries or other units in which discharge from the hospital is common during an infant's first week of life, although not all states require this screen. Timing the screening around the time of the newborn hearing screening can help improve efficiency.

A pulse oximeter is used to measure the percentage of hemoglobin in the blood that is saturated with oxygen (Centers for Disease

Control and Prevention, 2017). A failed screen occurs when there is an oxygen saturation measure that is less than 90% (in the initial screen or in repeat screens); oxygen saturation is less than 95% in the right hand and foot on three measures, each separated by 1 hour; or a greater than 3% absolute difference exists in oxygen saturation between the right hand and foot on three measures, each separated by 1 hour. Any infant who fails the screen should have an evaluation such as an echocardiogram for causes of hypoxemia.





A passed screen occurs when the oxygen saturation measure is greater than or equal to 95% in the right hand or foot with an equal to or less than 3% absolute difference between the right hand and foot. Pulse oximetry screening does not detect all CCHDs, so it is possible for a baby with a passing screening result to still have a CCHD or other congenital heart defect.

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Newborn Screening: Information for Parents

All newborn babies are given tests before they leave the hospital to identify possible serious or life-threatening conditions that they may have, even if they don't have symptoms. Serious diseases are rare. Some disorders can slow down an infant's normal physical and mental development in a variety of ways. Parents can pass along the gene for a certain disorder without even knowing that they carry the gene. Most disorders can be treated if found early, but not all disorders found during screening can be treated.

The following are excellent resources if you need more information about genetic screening:

- National Newborn Screening and Genetics Resource Center: www.genes-r-us.uthscsa.edu
- American College of Medical Genetics: www.acmg.net
- March of Dimes: www.marchofdimes.com/pnhec
- Baby's First Test: www.babysfirsttest.org

Most tests use a few drops of blood collected on a special sheet of paper by pricking the baby's heel. If a screening test suggests a problem, your baby's provider will follow up with more testing. If those tests confirm a problem, the provider may refer you to a specialist for treatment. Even though these conditions are considered rare and most babies are given a clean bill of health, finding disorders early and giving proper treatment can make the difference between lifelong challenges and healthy development for your child.

Although individual states may not perform all screening tests, parents can have additional tests done by qualified laboratories at large medical centers. Private laboratories also offer newborn screening. Parents can find out about

extra newborn screening tests from their provider or the hospital where their baby was born, as well as through organizations such as the March of Dimes.

An abnormal result means that the baby should have additional testing to confirm or rule out the condition, but remember, normal value ranges may vary slightly among different laboratories. Talk to your baby's provider about the meaning of your specific test results.

Critical Congenital Heart Defects (CCHD) Screening

Congenital heart defects are heart conditions that a baby is born with. Critical congenital heart disease (also called CCHD) is a group of severe congenital heart defects. These defects can affect the shape of a baby's heart, the way it works, or both. Babies with CCHD need treatment within the first few hours, days, or months of life. Without treatment, CCHD can be deadly. Your baby may be tested for CCHD as part of newborn screening before he or she leaves the hospital after birth (older than 24 hours), though not all states require this screen. Babies are screened for CCHD with a small machine called a pulse oximeter (also called pulse ox) that uses sensors attached to your baby's hand and foot. This testing is painless and only takes a few minutes.

The pulse oximeter checks your baby's oxygen level in the blood. Low levels of oxygen in the blood can be a sign of a CCHD. If a low level of oxygen is detected in your baby's blood, your baby's doctor may order further testing, such as an echocardiogram (a heart ultrasound), to check for any severe congenital heart defects.

Step





Kangaroo Care

Kangaroo care, or skin-to-skin care, involves having an unclothed infant (wearing diapers only) lay directly on a parent's chest. Instruct the parent to remove all jewelry and not wear any perfume, and discourage the use of cell phones during this time. If a parent is a smoker, ask him or her to bring a clean shirt to the hospital and change into it before participating in skin-to-skin care. You may have to ask them to wash their chest prior to kangaroo care, as well.

A standing transfer is preferred because it is less disruptive for the baby. The family member can prepare himself or herself while the nurse prepares the baby. The process of providing kangaroo care will take at least 1 hour, so the infant and family member should be prepared for this extended experience.

Nurse preparations are as follows: change the diaper, then assess and record the infant's status, including temperature, oxygen saturations, vital signs, breath sounds, and position of indwelling tubes. Suction the endotracheal tube if necessary. Place a blanket under the infant and position supine next to the door of the isolette. The family member can then open his or her shirt, place his or her hands under the blanket, and draw the baby toward his or her chest. If the infant is intubated, ask for help from another nurse or a respiratory therapist to help

maintain tubes and lines in place. Disconnecting briefly from the ventilator during the transfer process is advised. Alternatively, the family member can be seated and the nurse can perform the transfer, placing the infant on the family member's chest. The infant is then covered with a warm blanket and a hat is placed on the infant's head. Position the baby flexed with the head in a sniffing position to maintain the baby's airway. Help the family member get into a comfortable position.

Once the baby has settled into place, continue to frequently monitor the baby, including vital signs and respiratory status. Set the isolette temperature to maintain a neutral thermal environment until the baby is returned to the bed. Benefits of this activity include pleasant sensory stimulation to the infant, increased oxygenation, stability of respirations, and enhanced bonding. Other benefits include regulation of heart rate, temperature, and a decrease in infections. This activity can be continued at home after the infant is discharged.

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Kangaroo Care: Information for Parents

Kangaroo care is a way of holding a baby so that there is skin-to-skin contact with the parent. It is used to help form the special mother-baby bond following sudden separation during the birth experience. Kangaroo care is important for fathers, too!

There are many benefits to kangaroo care, including keeping your baby warm, helping your baby gain weight, improving your baby's heart rate and oxygen level, and increasing the mom's milk supply, as well as increasing the special antibodies in the breast milk that help protect your baby from infection. Some research shows long-term effects include helping with your baby's brain function and growth.



Skin-to-skin care. Courtesy of Susan Ise, BSN RN, and Alyssa Kendrick, BSN RN.

Here's what you need to know about kangaroo care:

- This type of holding your baby usually begins before a feeding and continues for the duration of the feeding. Talk to your nurse about how kangaroo care is done in your baby's unit.
- Please shower and put on clean clothes before coming to the hospital.
- You will hold your baby for at least 1 hour and up to 3 hours.
- Use the bathroom before kangaroo care.
- You will open your shirt. (Button-down shirts work well and can be left at the bedside. Moms will want to remove their bras.)
- A standing transfer is easiest for the baby. The nurse will initially assist you in preparing the baby for transfer. He or she will place a blanket under the baby and secure any tubes that may be necessary. You will stand next to the baby's isolette, place your hands under the blanket, and draw the baby toward your chest. Once you have the baby secure against your chest, you can step backward toward the chair and sit. Alternatively, the nurse will place your baby on your chest after you sit down. Some units may have special chairs designed just for kangaroo care.
- Your baby will be covered snugly with a blanket.
- Do not wear chains or necklaces.
- No loud conversations with visitors should take place during this time.
- For the safety of your baby, please do not sleep while holding your baby. Your nurse will check on you and your baby frequently during kangaroo care.
- Use of cell phones is not recommended during your visit in the neonatal intensive care unit.
- Do not smoke until after visiting your baby.

As soon as your baby is stable enough to hold, you may start kangaroo care. We strongly encourage this special type of holding at least once per day. The wonderful thing about kangaroo care is that you can continue it even after you are home.



Skin Care

Promoting the neonate's skin integrity is a priority for the neonatal nurse. The preterm infant's skin is thinner than a full-term infant, making it more susceptible to problems. The neonatal nurse must therefore exercise caution when handling and cleansing the neonate's skin.

One of the most important steps nurses and visitors in the NICU can take is to wash their hands with antibacterial cleansers before making contact with the preterm infant (Gardner, Carter, Enzman-Hines, & Hernandez, 2011). This helps decrease the spread of all infections, especially methicillin-resistant *Staphylococcus aureus* (MRSA).

The nurse should perform a thorough skin assessment at least once a day and more frequently as needed to identify any skin breakdown and promote skin integrity. Consider using a valid and reliable assessment tool to provide an objective measurement of skin condition, such as Neonatal Skin Condition Score (NSCS), Braden Q Risk Assessment, Starkid Skin Scale, or Neonatal Skin Risk Assessment Scale (Association of Women's Health, Obstetric and Neonatal Nurses [AWHONN], 2013).

Bathing

Bathe infants according to facility protocols, such as sponge bathing, tub bathing, or swaddled bathing. The tub that is used for bathing the neonate should be disinfected before and after each use. When bathing an infant, create a neutral thermal environment so that the infant is less likely to lose heat. Precautions such as keeping the bath water temperature between 38 °C and 40 °C, keeping the room temperature warm, and using prewarmed towels can help prevent the infant from becoming hypothermic. The duration of the bath should be kept to a minimum to ensure that the infant stays physiologically stable (AWHONN, 2013).

For preterm infants younger than 32 weeks, gently cleanse skin surfaces with warm water only during the first week of life. Use soft materials and avoid rubbing the skin; instead, squeeze water onto the skin during

rinsing. Use warm sterile water when breakdown is evident (AWHONN, 2013). Skin cleansers with the least irritating formula should be chosen, and antimicrobial soaps should be avoided whenever possible. Infants should be bathed every few days or as needed. Shampooing once or twice a week usually is adequate.

Vernix

Residual vernix does not have to be removed after birth because it acts as a protective skin barrier and allows the infant to better adapt to the dry extrauterine environment. The World Health Organization recommends leaving vernix intact after the infant is initially dried following birth. Vernix helps to protect against infection; is a natural, water-containing barrier cream; helps with wound healing; and does not affect auxiliary temperature readings. Vernix should be left in place to naturally wear off with normal care (AWHONN, 2013). Scrubbing vernix after delivery may cause skin breakdown because it could damage the fragile epidermis of the neonate.

Cord Care

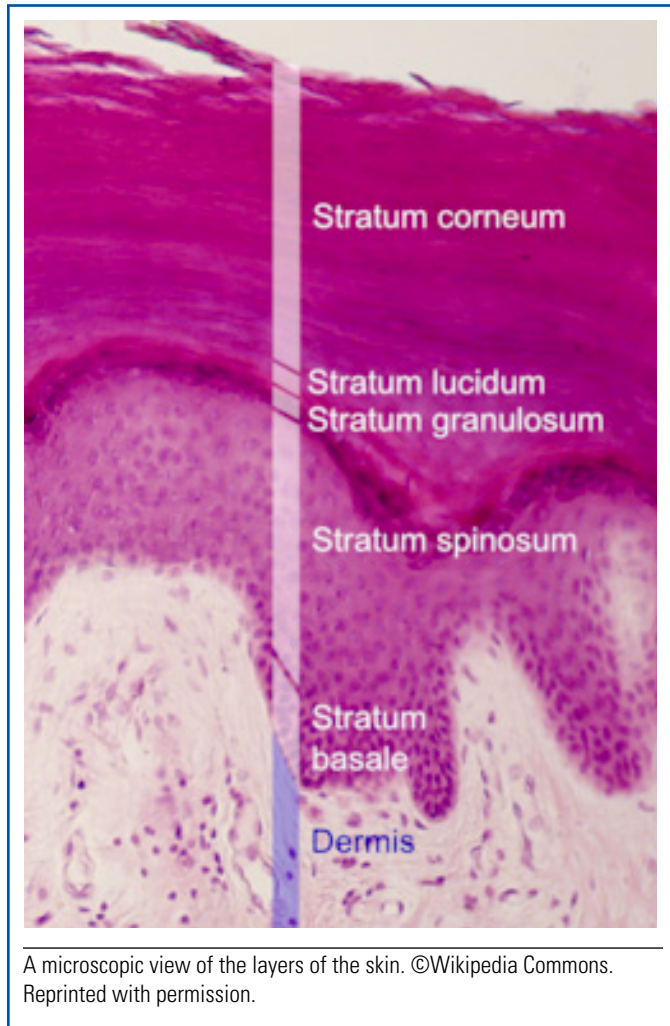
After birth, the neonate's umbilical cord should be cleansed with tap water to remove debris and thoroughly dried as part of the first bath. The routine use of antimicrobial sprays, creams, or powders on the umbilical stump has not been shown to be more effective in preventing infection than allowing the cord to dry naturally (Gardner et al., 2011). If the cord becomes soiled, it can be cleaned with water and dried with absorbent gauze to remove excess water. The diaper should be folded down and away from the umbilical stump to keep the stump clean and dry. Current evidence shows that cord separation time is shorter with dry cord care than by applying isopropyl alcohol to the cord daily. Research also shows that triple dye on the umbilical stump had the longest separation time compared with dry cord care and alcohol cord care (AWHONN, 2013).

Emollients

Emollients help protect the integrity of the neonate's skin by keeping it hydrated and should be used at the first sign



of dryness. The emollient should be applied gently to the skin to prevent skin irritation and breakdown (AWHONN, 2013). The container should be kept away from contamination and ideally should be provided in unit dose or patient-specific containers.



Transepidermal Water Loss (TEWL)

Because preterm infants have a smaller stratum corneum, which controls evaporative heat loss, they are more likely to develop transepidermal water loss (TEWL; Gardner et al., 2011). Current American Academy of Pediatrics (AAP) Neonatal Resuscitation Program guidelines recommend increasing the temperature in the room the baby will receive care to approximately 23 °C to 25 °C (74 °F to 77 °F), preheating the radiant warmer, placing a hat on baby's head, and for babies born at less than 32 weeks gestation:

- placing a portable thermal mattress under a blanket on the radiant warmer
- wrapping the baby in a polyethylene plastic wrap or bag up to their neck. Drying the body is not necessary (AAP, 2016).

Monitor the baby's temperature frequently to maintain an axillary temperature between 36.5 °C and 37.5 °C. TEWL in extremely-low-birth-weight infants at 23–26 weeks of gestation is reduced by half when the relative humidity is increased from 20% to 60%. High humidity has been shown to reduce fluid requirements and improve electrolyte balance in preterm infants when compared with historical control groups.

Provide humidity at levels of more than 70% relative humidity for the first 7 days of life. After the first week of life, gradually decrease relative humidity to 50% until the infant is 28 days old. Consider continuing 50% humidity until 30–32 weeks postconceptual age (AWHONN, 2013).

Skin Disinfection

Decontamination of the infant's skin before invasive procedures is a common practice in the NICU. According to AWHONN's *Neonatal Skin Care Evidence-Based Practice Guideline*, 3rd edition, the U.S. Food and Drug Administration has issued a labeling change to manufacturers of skin antiseptics containing chlorohexidine gluconate (CHG). The new label warns that CHG-containing skin antiseptics should be used with caution in premature infants or infants less than 2 months of age, as these products may cause chemical burns. At the same time, case reports of CHG/alcohol skin disinfectants and dressing causing skin injuries are becoming more frequent; therefore, the selection of skin disinfectants for extremely preterm infants remains a dilemma for clinicians (AWHONN, 2013).

AWHONN (2013) suggests considering the potential for systemic toxicity if skin disinfectants are absorbed through the skin and suggests wiping off all skin disinfectants after use with sterile water or saline as quickly as possible after the procedure is complete.

No disinfectant agent comes without risks, but it is important that the nurse understands the possible risks



and uses the most current evidence to guide his or her nursing practice.

Adhesives

When adhesives are removed, they can alter skin barrier function by stripping the epidermis and causing skin breakdown (AWHONN, 2013). Nurses should select medical adhesives that cause the least trauma while effectively securing medical devices with one of the many choices available. Silicone-based skin barrier films should be used to protect the skin from medical adhesives; they do not sting when applied, rapidly evaporate, and do not leave a residue (AWHONN, 2013). Medical adhesives should be removed slowly using moistened gauze or saline wipes. AWHONN (2013) suggests avoiding the following products whenever possible: alcohol/organic-based products, oil-based solvents, enhancing bonding agents, and adhesive bandages after drawing laboratory samples.

Penile Care

With an uncircumcised penis, the foreskin should not be forcibly retracted; doing so can cause tearing, which can lead to adhesions (AWHONN, 2013). After a circumcision has been performed, the nurse should closely inspect the skin and remove any skin disinfectant still present with sterile water or saline. Following the circumcision, the penis should be covered with petroleum gauze for at least 72 hours to promote healing. With a circumcision that involves a plastic device, petroleum use should be determined by the provider doing the procedure. Some believe it should not be used because it may cause the device to move out of place; others will suggest the use of petroleum to prevent adhesions. Once the plastic device falls off, place petroleum jelly over the tip for up to 2 weeks. This will keep the foreskin lubricated while healing. The newly circumcised penis should be cleansed with only water for the first 3–4 days because soaps can be more irritating to the skin.

Diaper Dermatitis

Diaper rash can occur after 1–3 weeks of life and can be caused by prolonged contact of the skin with urine and

feces. To care for a diaper rash, use soft cloths and water or disposable diaper wipes that have no added detergents or alcohol (AWHONN, 2013). Breastfeeding also decreases the chances of diaper rash because breastfed infants have stools that are less caustic to their skin than formula-fed infants. Using petroleum-based lubricants or skin barriers containing zinc oxide at every diaper change for infants at risk for developing dermatitis can help decrease diaper dermatitis (AWHONN, 2013). Keep in mind that vigorous rubbing to remove traces of these barriers should be avoided because doing so can cause more damage to the skin. Diaper dermatitis can be complicated by a fungal infection and should be treated accordingly with antifungal ointments or creams. The use of powders should be avoided due to the risk of promoting bacterial and yeast growth (AWHONN, 2013). Most important for preventing diaper dermatitis is keeping the skin dry and maintaining a normal skin pH. Diaper changes every 1–3 hours during the day and at least once at night are necessary to maintain skin integrity.

Skin Excoriations

Specific measures that can minimize the risk of skin breakdown include using devices (such as gelled mattresses and pads) to help prevent pressure sores, applying transparent dressings over bony prominences (knees and elbows), and applying petroleum ointments to the groin and thigh of very-low-birth-weight infants (AWHONN, 2013). Skin excoriations can be cleansed with warmed sterile water or saline to gently debride the wound, and moistening helps with the healing process.

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Skin Care: Information for Parents

Your baby's nurses will look at your baby's skin to make sure it is not broken or red. Your baby has very fragile skin that has to be touched gently. As your baby gets older, his or her skin will not be as fragile. Talk with your baby's nurses about ways to protect your baby's skin while moving him or her.

Remember to always wash your hands with soap and water for at least 15 seconds before touching your baby. You should scrub your hands very well while washing them and clean underneath your fingernails. Also, clean between each of your fingers and the top of your hands. You also should wash your hands after changing your baby's diaper and before you make your baby's bottle. Washing your hands will help prevent your baby from getting an infection. Others caring for your baby will need to do this, too.

Your baby's nurses will tell you about the different things that they will do to or use on your baby's skin. The nurses will show you how to help take care of your baby's skin until you go home.

Bathing

You may see your baby's nurses clean the bathtub before and after a bath. This is done to help prevent infection. The soap used on your baby should be fragrance-free to help protect his or her skin. You may find that your baby's nurses use only water when giving your baby a bath. This is because your baby was born early, and soap is not needed right now. Later on, your baby will get a bath with soap. You do not need to give your baby a bath more than once every few days. By not bathing your baby every day, you are helping to keep his or her fragile skin safe and not dried out.

Vernix

Your baby may have a white, cheesy covering on his or her skin called vernix. This is normal and is a natural covering to keep your baby's skin moist and free from infection. Scrubbing this covering off can hurt your baby's

fragile skin. Instead, the covering is left in place until it comes off by itself.

Cord Care

After your baby is born, the umbilical cord is clamped and cut, leaving a stump. If it becomes dirty, this stump can be cleaned with water and dried well. It is not necessary to use alcohol wipes to clean the cord. The best way to keep your baby's cord free from infection is to make sure that it does not get dirty from your baby's diaper. You should fold the front of your baby's diaper down when changing him or her to make sure the stump does not get wet. You should look at the cord daily to make sure it is not red or hot or has any drainage. These are signs of infection, and you should tell your baby's provider or nurses if you see them.

Cream to Protect Your Baby's Skin

The nurses may put a clear cream on your baby's skin, which will help keep it from becoming too dry. When your baby's skin is too dry, it can crack more easily. Talk with your baby's nurse or medical provider about creams or lotions that can be used on your baby's skin. If you apply the clear cream to your baby's skin, make sure the container does not get dirty because this can raise the risk of a skin infection.

Water Loss

Your baby's skin is very thin and fragile. Because of this, your baby's skin can dry out very easily. Depending on how early your baby was born, he or she may have been wrapped in a plastic bag from the shoulders down right after being born. This helps keep the baby warm and his or her skin moist. Remember that your baby can get cold very easily. The plastic bag also will help prevent that. Your baby also might have been placed into an *isolette*, which is a special "house" that keeps your baby warm and lets the nurses keep track of your baby's temperature. Sometimes when your baby is in the *isolette*, the nurses will keep the air humid inside of it, which helps keep your baby warm and his or her skin moist.



Keeping Your Baby Free from Infection

Your baby may need to have his or her skin cleaned with a special cleansing product before certain procedures are performed. This helps protect your baby from an infection. Feel free to ask any questions about the special cleansing products or the procedures being performed.

Tape

Since your baby has very fragile skin, you may see your baby's nurses use different kinds of tape on your baby. The nurses may put a protective piece of tape on your baby's skin and then put another kind of tape on top of that. This helps keep your baby's skin intact. When the nurses remove the tape, they will do it slowly and may use water to keep your baby's skin from breaking.

Your baby's nurses also may leave the tape in place even though your baby may not need it anymore. This is because the nurses are waiting for the tape to come off by itself. This will help keep your baby's fragile skin intact and protect your baby from getting an infection.

For Baby Boys

You may or may not decide to have your baby boy circumcised. This procedure is used to remove skin toward the tip of the penis. Caring for your son differs based on whether or not you choose to have your son circumcised. For a natural penis, you should not pull the skin down to clean around your baby's penis. This can cause your baby's skin to tear. Instead, leave the skin in place and gently clean around the penis if needed.

For circumcised boys, the tip of the penis may seem raw or yellowish. When gauze is used, it should be changed

with each new diaper to reduce the risk of infection. Use petroleum jelly to keep the gauze from sticking to the diaper. Sometimes a plastic ring is used for circumcision. This should drop off within 5–8 days. It may be recommended that you use petroleum jelly on the tip of the penis with either procedure to keep the foreskin lubricated; be sure to follow the instructions from the hospital. The penis should be fully healed about 7–10 days after circumcision.

Diaper Rash

Diaper rash is when your baby has redness and irritation around his or her buttocks. To prevent a diaper rash, frequently change your baby's diaper, especially after they poop. To care for a diaper rash, clean the area with soft cloths and water. You also can clean the area with diaper wipes that are chemical-free. Your baby also may have a special cream that should be applied each time the diaper is changed. Sometimes, your nurses will tell you not to wipe off all of the cream, but to only gently wipe around the buttocks. This will keep your baby's skin intact and allow it to heal.

Other Skin Information

Depending on how early your baby was born, you may see your baby's nurses use special products to keep your baby's skin from tearing, including placing special pads underneath your baby or placing clear coverings on your baby's knees or elbows. Ask your baby's nurses about ways you can help keep your baby's skin from tearing.



Newborn Jaundice

Newborn jaundice, or hyperbilirubinemia, develops when red blood cells (RBCs) are broken down and release bilirubin. The liver helps metabolize bilirubin so it can be excreted in urine or stool, but when the rate of RBC breakdown exceeds the rate of elimination, it results in a buildup of bilirubin in the body.

Jaundice can be the result of excessive numbers of RBCs breaking down (as in Rh or ABO incompatibility), bruising, polycythemia, or a slow rate of metabolism and elimination—as can occur with an infection, lack of enzyme activity, dehydration, or constipation.

Bilirubin buildup can manifest itself as a yellowish color of the sclera and skin of an infant. This skin color progresses in a cephalocaudal pattern (head to toe). Jaundice becomes particularly harmful when the level of the bilirubin in the blood is too high because it can cross the blood-brain barrier and deposit into the cells of the brain and spinal cord, resulting in bilirubin encephalopathy.

The goals of assessment and therapy are to initiate phototherapy and prevent the bilirubin from climbing to dangerous levels. In the event that it rises and approaches critical levels, an exchange transfusion can be done. This process consists of removing small volumes of blood while replacing them with fresh, whole donor blood or normal saline (in the case of polycythemia). Infants of Chinese, Japanese, Korean, Native American, and Greek descent are at higher risk for having hyperbilirubinemia.

Methods to determine the level of bilirubin present include transcutaneous instruments and sampling the serum. The transcutaneous assessments have not proven reliable beyond a certain level and thus have limitations associated with the instrument. Serum assessment is more reliable when the levels are elevated. Visual inspection alone is not sufficient to determine bilirubin levels. Even if a test is in the normal range, based on the infant's age (in hours) and the rate of increase, the bilirubin level can rise and cross into a dangerous zone (see figure on next page).

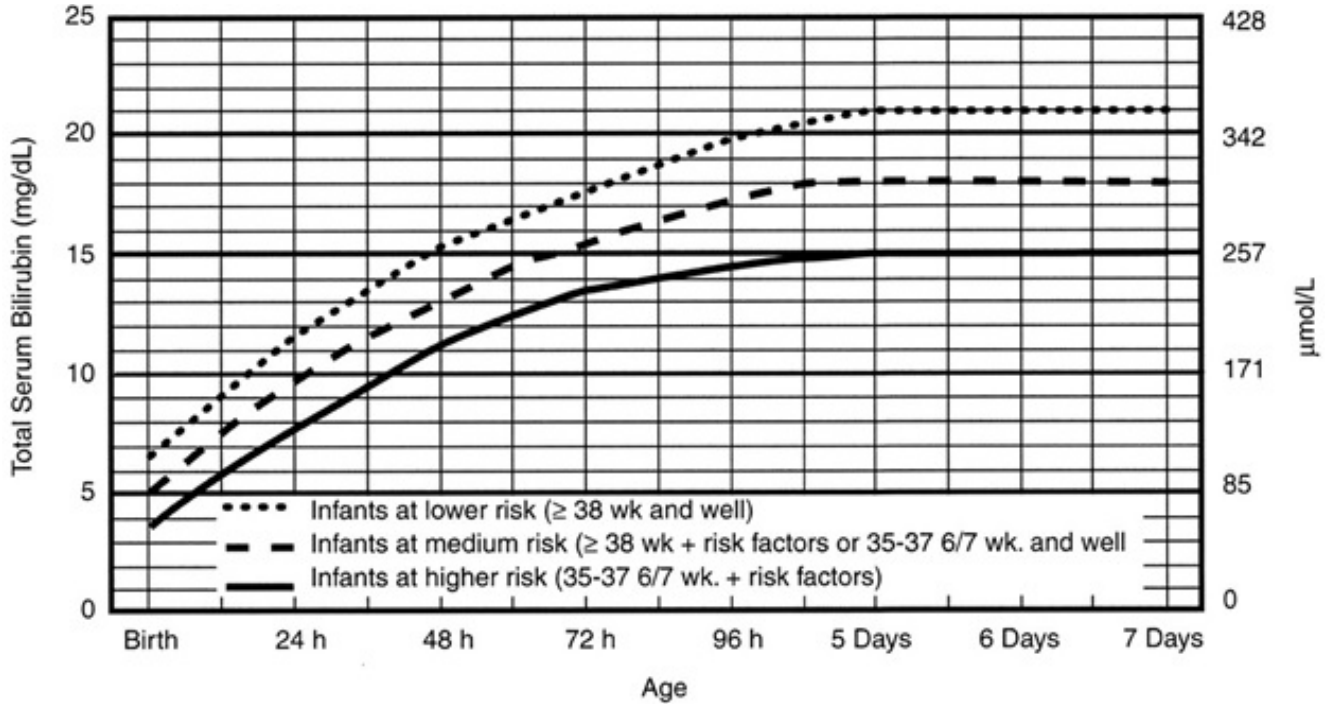
An infant with significant risk factors and climbing levels is not a candidate for early discharge. When an infant is discharged, it is necessary for parents to keep appointments for jaundice evaluation and further bilirubin tests. It is important to give regular feedings (every 2–3 hours) to promote an active pattern of stooling and to provide adequate hydration and elimination. Parents need to be informed of signs indicating that the bilirubin level is too high, including fussiness, limp or floppy tone, stiffness in arms or legs, arching of the neck or back, high-pitched cries, or sleepiness. Any change in level of response (consciousness) should be reported immediately.

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Hyperbilirubinemia Levels



- Use total bilirubin. Do not subtract direct reacting or conjugated bilirubin.
- Risk factors = isoimmune hemolytic disease, G6PD deficiency, asphyxia, significant lethargy, temperature instability, sepsis, acidosis, or albumin < 3.0g/dL (if measured)
- For well infants 35-37 6/7 wk can adjust TSB levels for intervention around the medium risk line. It is an option to intervene at lower TSB levels for infants closer to 35 wks and at higher TSB levels for those closer to 37 6/7 wk.
- It is an option to provide conventional phototherapy in hospital or at home at TSB levels 2-3 mg/dL (35-50mmol/L) below those shown but home phototherapy should not be used in any infant with risk factors.

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Newborn Jaundice: Information for Parents

When an infant's skin has a yellowish or orange color, this is known as *jaundice*. Jaundice occurs when red blood cells are broken down, giving the baby's skin a yellowish color. Bilirubin is a pigment that is released from the red blood cells. The liver helps break down the bilirubin so it can be removed from the body in the stool, but when the rate of breakdown exceeds the rate of elimination, it leads to buildup of bilirubin. Sometimes special lights are used on infants whose levels are high. This is called *phototherapy*. These lights work by helping to break down bilirubin in the skin. The infant is placed under artificial light in a crib or isolette and will wear only a diaper and special eye shades to protect the eyes. Treatment can last 1 to 2 days, and further testing called a bilirubin test will be done. Babies who were born early, bruised during delivery, or have a different blood type from their mothers have a higher risk of getting jaundice. Jaundice becomes harmful when the level of bilirubin in the blood is very high.

The only way to know the level of bilirubin in the blood is to test the baby's blood. Even if a test is normal, the bilirubin level can sometimes rise. When a baby is sent home, a follow-up appointment with your baby's provider will be made. This appointment will help decide if an additional bilirubin test is needed.

If your baby is more mature and able to feed normally, it is important to feed your baby every 2–3 hours. Frequent feedings will help your baby poop more often so that the bilirubin is removed from his or her body. You can check for jaundice by pressing a fingertip on your baby's nose, cheek, or forehead. When you remove your fingertip, the pressed area should look lighter for a few seconds before turning pink. If the area is yellow after your fingertip is removed, this shows that your baby has jaundice. This process can be repeated on the upper chest and tummy area. Jaundice starts in the face, moves down to the tummy area, and then spreads to the legs and feet.

Look for signs that show your baby's bilirubin might be too high, including fussiness, stiffness in arms or legs,



arching of the neck or back, high-pitched cries, or sleepiness. Phototherapy is used to prevent your baby's bilirubin from rising. The light waves in phototherapy change the bilirubin in skin to a substance that is easily removed in the urine or stool. If your baby is under the lights, it is important to keep his or her eyes covered (to protect him or her from the light) and have as much skin exposed as possible. Phototherapy is safe and can sometimes be done at home.

Step

4



Basic Baby Care

Basic baby care incorporates the daily routines of elimination, cord care, and bathing. It is an essential part of discharge education, but it includes a lot of information that may overwhelm parents. When teaching basic care, it may be a good idea to break up the content and set priorities by following the parents' cues.

Elimination

Elimination patterns will be determined by breastfeeding or formula-feeding patterns of the infant. It is important to be aware of elimination patterns to distinguish problem signs from normal elimination. Normal elimination includes six to eight voids per day. Changes in the color and consistency of the stools will depend on feeding type. Formula-fed infants will have fewer stools compared with breastfed infants. The stools of formula-fed infants are pasty to semiformed; breastfed infants' stools will be looser, with some consistency in the texture. Instruct parents to cleanse the genitals daily and with diaper changes, noting any skin irritations. Infrequent diaper changes and diarrhea can contribute to diaper rash, so diapers should be checked often. Over-the-counter zinc oxide ointments may be used if diaper rash is noted.

Cord Care

The umbilical cord should be kept clean and dry. In recent years, the use of triple dye and alcohol for cord care has been shown to prolong separation time. Signs of infection should be noted with each diaper change, and the cord should fall off around 10–14 days after birth. A granuloma often is seen once the cord separates, appearing as a small, raw, red polyp. The granuloma may need to be treated with silver nitrate by the infant's provider if it does not heal on its own.

Bathing and Skin Care

Bathing is an opportunity to observe the infant's skin condition. Daily bathing is not recommended because it alters the skin's pH, disrupts the integrity of the skin,

and may cause excessive dryness. The infant's age will determine if a sponge bath or tub bath is appropriate. All infants should be bathed with a sponge until their cord falls off and heals.

Unscented, mild baby soap (avoid alkaline soaps) should be used for cleansing the skin to protect the pH. The newborn's skin has an acid mantle that is formed from the epidermis, superficial fat, and amniotic fluid, which can be a medium for bacterial growth when altered by alkaline soaps. Steps to prevent heat loss are an important part of bath time. If the infant is stable, immersion bathing is appropriate and has been found to lessen heat loss as well as crying. Developmental bathing, in which the infant is swaddled while in the tub, with only one body part unwrapped at any one time, is recommended for premature infants. Dry the infant immediately after bathing to prevent further heat loss.

Bathing is a task that allows parents to bond with and get to know their infant. This increases parental feelings of competency and confidence and will lower overall anxiety. Bath time also is a good opportunity for parent-infant interaction. Parents should talk to their infant and engage their infant in play activities.

Clothing

A common concern parents have is how to dress their infant. It is best to recommend that parents dress infants as they would dress themselves. Keep in mind that overdressing may cause overheating and is linked to increased risk of sudden infant death syndrome, and an uncovered head leads to excessive heat loss in cold weather.

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Basic Baby Care: Information for Parents

It is important to understand how to care for your baby to meet his or her basic needs. Basic care activities such as diaper changes, cord care, and bathing are a good time for parent-baby interaction and will be part of your daily routine with your baby. While caring for your baby, you can talk and play with him or her. The nurses will help teach you how to care for your baby while in the neonatal intensive care unit (NICU) so you are ready to continue caring for your baby when you go home.

Elimination and Diaper Changes

Your baby will need his or her diaper changed several times a day. You should check your baby's diaper often and with each feeding. The number of dirty diapers and poop consistency depends on your baby's feeding method.

- The first poop a baby has is called meconium. Meconium often is black and tarry and will last a few days.
- Formula-fed babies may have as few as one poop every other day, and poops may be pasty to semi-formed in consistency.
- Breastfed babies may have three or more poops a day and poop may be loose in consistency, like mustard mixed with cottage cheese.
- You can expect six to eight wet diapers a day.
- Clean the genitals daily and as needed with each diaper change using unscented, nonalcohol-based, mild soap; baby wipes; or a washcloth and water. For girls, clean the genitals by separating the labia and gently washing and rinsing from the pubic area to the anus. For uncircumcised boys, gently wash and rinse the tip of the penis. When gauze is used for circumcised boys, it should be changed with each diaper to reduce the risk of infection. Use petroleum jelly to keep the bandage from sticking to the diaper.
- Secure the diaper with the tabs, making sure the diaper does not cover the cord.
- Wash your hands after each diaper change.

Cord Care

- Clean around the base of the cord, where it joins the skin, with soap and water.
- Keep the cord dry.

- Do not bathe your baby in a tub until the cord falls off and is healed.
- You can expect the cord to fall off between 10–14 days after birth.
- If you notice signs of infection (foul odor, redness, drainage), report them to your baby's provider or nurse.

Bathing and Skin Care

Bathing gives you a chance to clean and observe the condition of your baby's skin. Your baby's skin is sensitive. Use unscented, mild baby soap for bathing. Sponge or spot bathing often is done until your baby's umbilical cord falls off and heals. As your baby gets older, you can give your baby a tub bath. A daily bath is not necessary, but you should clean the face, behind the ears, the neck, and the diaper area daily. While your baby is in the NICU, talk to your baby's nurse if you want to give your baby a bath. The nurses will help you coordinate a time for the bath.

Here are some tips for giving your baby a bath:

- Make sure the room is warm and free of drafts.
- Gather your supplies (soap, washcloth, drying towel, receiving blanket, diaper, and clothes).
- Bring your baby to the bathing area when the supplies are ready.
- Never leave your baby alone on a bathing surface or in bath water.
- Water temperature should feel pleasantly warm to the inner wrist. Do not hold your baby under running water. The temperature can change and your baby could be scalded or chilled quickly.
- When sponge bathing, undress your baby and swaddle in a towel with the head exposed. Uncover the parts of the body you are washing, taking care to keep the rest of your baby covered to prevent him or her from getting cold. Wash, rinse, and dry each part of the body.
- If tub bathing, position your baby on his or her back in the tub with just enough water to touch the chest.
- Start by washing your baby's face. Do not use soap on the face. Wet the washcloth. Wash around the eyes from the inner edge of the eye (by the nose) to the outer edge. Use a separate part of the washcloth for



each eye. Report any eye drainage to your baby's nurse or provider.

- Wash the rest of the face. Clean the ears and nose with the washcloth. Do not use cotton-tipped swabs because they can cause injury.
- Add soap to the washcloth and wash the body with soap.
- Lift your baby's shoulders to expose the back of the neck (be sure to hold the head) and clean between the skinfolds. Gently lay your baby on his or her back and lift the chin to expose the front of the neck. Clean between the skinfolds.
- Wash the arms and legs and be sure to clean between the fingers and toes.
- Wash the chest and back. Be sure to support the head and neck.
- Wash the diaper area last and be sure to clean between the skinfolds.
- To wash the baby's hair, wrap your baby in a warm towel with the head exposed. Hold your baby in a

football position supporting the head and neck with one hand and using your other hand to wash the hair with soap. Rinse soap completely and dry with a towel.

- Unscented, nonalcohol-based lotion may be used after bathing. Ask your baby's provider or nurse for suggestions on skin care products.
- Newborn fingernails and toenails are usually soft and flexible. You should use a nail file or emery board to shorten and smooth the nails once a week or as needed. This is the safest method.

Clothing

Dress your baby as you would dress yourself. Add or take away clothes as necessary. Your baby's clothes should be washed separately using an unscented, mild laundry detergent to protect his or her sensitive skin. Your baby also is prone to sunburn and should be kept out of direct sunlight. Ask your baby's provider about the use of sunscreen.



Choosing Your Baby's Provider

The American Academy of Pediatrics recommends that every infant with special healthcare needs have a medical home. They use the term *medical home* to describe an individual or team of providers that is prepared to coordinate the many needs of infants in a way that is family-centered and culturally effective, while providing education and making use of community resources (American Academy of Pediatrics, n.d.).

All infants need a healthcare provider or group to be their primary care provider and provide the services of a medical home. Depending on where the infant lives and what his or her care needs are, this provider may be a pediatrician, a physician who provides family care, or a nurse practitioner. When an infant is born prematurely, parents may not have had time to choose a primary care provider. Parents should begin their search as early as possible and meet the primary care provider before discharge, if possible. When picking a provider, parents should consider the following issues:

- Does the provider accept their insurance or form of payment? Are they accepting new patients?
- Where is the provider located? Does the family have appropriate transportation to reach the provider?
- Does the provider understand the parents' culture and beliefs? Is the provider easily able to communicate with the parents?

- Does the provider have the knowledge and skills to care for the infant? Is the provider willing to coordinate potentially complex care needs? With which hospitals is the provider affiliated? With which hospitals are they on staff and can provide in-patient care if needed?
- Does the provider have separate "sick" and "well" waiting areas, or does the provider schedule fragile patients at specific times?
- How long does it take to get an appointment? What if the parents just need advice? Is there a "nurse line" parents can call with questions?
- Does the provider offer lactation support after discharge through the office?
- Will parents always see their primary care provider?
- How do caregivers contact the provider after hours or on weekends?

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Choosing Your Baby's Doctor When Going Home: Information for Parents

Picking a doctor to care for your baby after you have gone home is an important decision. You may need to see this person often, and you will be dependent on him or her for advice, medical care, and help as you coordinate your baby's care. Start looking for a doctor before your baby is ready to go home. This will give you time to find someone you are comfortable working with to make taking your baby home less stressful.

Here are some things to consider when picking a doctor:

- What types of doctors have offices close to your home? Are there pediatricians, family practice doctors, or nurse practitioners?
- How far are you willing to travel to see a doctor? Ask your baby's nurse what kind of special care your baby might need when he or she goes home.
- Consider asking friends and family for suggestions. The social worker in the NICU also might be able to help you identify a few doctors to consider.

Here are some questions to ask potential doctors:

- Is the doctor on your insurance plan? Is the doctor accepting new patients?
- Can you set up an appointment and meet the doctor before bringing your baby home?
- Does the doctor have experience caring for babies with your child's conditions, such as prematurity, feeding

problems, or lung issues? Is the doctor comfortable coordinating the specialty care your child may need after going home?

- Does the doctor have separate "sick" and "well" waiting areas or another way to make sure your baby stays well while at the office?
- With which hospitals is the doctor working? Will they care for your baby if he or she has to be admitted to the hospital again?
- What are the doctor's hours? If the doctor is part of a group, do you always see your own doctor or nurse practitioner? How long is a typical appointment? Are weekend hours available?
- What if you need to talk with someone after hours? Does the doctor offer a "nurse line" for questions?
- How are emergency calls handled?
- While you are breastfeeding, is there someone at the office who can help you with questions or provide support?

Discussing these topics with your doctor before bringing your baby home can help you feel more comfortable with your doctor and make coming home less stressful. Don't forget to schedule your first appointment within a few days of going home. Once you choose your doctor and make your appointment, be sure to give that information to the NICU team so they can share information about your baby with your new doctor.



Home Safety: Information for Parents

Below are some tips and warnings to help ensure your baby's safety when you return home. Be sure to check that all electrical outlets are working.

Medications

- Keep your baby's medicine bottles away from other small children.
- Discuss any home medications with other caregivers and share instructions on the medication sheet you received.

CPR

- Enroll all caregivers in a cardiopulmonary resuscitation (CPR) class.

Bathtub Safety

- Don't rely on baby bathtubs, bathtub rings, pool noodles, floaties, or other air-filled toys to keep your baby above water. These items cannot replace adult supervision.
- Before you begin bathing, have all supplies within arm's reach.
- Prevent your baby from being burned by the water by testing bath water temperature with your inner wrist or a bath thermometer. The water should be lukewarm or no warmer than 37.7 °C to 40 °C (100 °F to 104 °F) and deep enough to allow your baby to settle into the water with his or her body well covered. Move your hand through the tub to mix any hot spots. Wash your baby's face with clean water only. Don't use soap on face until they are older—your doctor will tell you when it is alright to do so. Clean your baby's body and then shampoo the hair with a new clean cloth.

Kitchen Safety

- Put your baby down before handling hot objects.
- Do not hold your baby while cooking.
- Always follow the instructions for how to prepare formula. Formula that has been warmed up in the microwave can burn a baby's mouth. Test the warmth of the formula on your wrist before giving it to your baby.
- Your baby's food should be barely warm.

- Keep hot items, such as coffee, out of reach.
- For burns, run cool water over the burn right away, then call your baby's doctor.

Baby's Room Safety

Babies spend much of their time sleeping; therefore, the baby's bedroom should be the safest room in the house.

- All healthy babies younger than 1 year should sleep on their backs at nap time and at night.
- The safest place to sleep is in a crib with a firm mattress covered by a fitted sheet.
- Infants should never sleep in an adult bed or on a couch.
- Keep pillows, quilts, comforters, sheepskins, and stuffed toys out of your baby's crib.
- When your baby is awake, give him or her at least an hour of tummy time each day.
- Never leave your baby on a bed, couch, or changing table due to the risk of falling.
- Use a crib that meets current standards. It should not have a drop side or any raised corner posts or cutouts where loose clothing could get snagged and strangle your baby. Also, the slats should be no more than $2\frac{3}{8}$ inches apart, and the mattress should fit snugly to prevent entrapment.
- Tighten all screws, bolts, and other hardware securely to prevent the crib from collapsing. Only use hardware provided by the manufacturer.
- Check the paint on the crib. Peeling paint could be harmful if swallowed.
- Keep the crib away from windows. Keep window blind cords, rosaries, or strings away from the crib.
- Do not put your baby to bed with a bottle.
- Do not attach a pacifier to a string or chain while in bed.
- Cover the mattress with a snug-fitting crib sheet with elastic corners and nothing more. Do not use a sheet, or part of one, from a larger bed.



Crib safety. © Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/sids/images/lady-parent-baby.jpg>

Reduce the Risk of SIDS and Suffocation

- Babies up to 1 year should always be placed on their backs to sleep during naptime and at night.
- If your baby falls asleep in a car seat, stroller, swing, infant carrier, or infant sling, he or she should be moved to a firm sleep surface as soon as possible.

Changing Table Safety

A changing table makes changing diapers easier, but falls from such a high surface can be dangerous. Never leave your baby alone on a changing table. Here are a few more tips:

- Choose a sturdy changing table with a 2-inch guardrail around all four sides.
- The top of the changing table should curve inward, like the inside of a circle, so the middle of the table is slightly lower than the sides.
- Buckle the safety strap, but never leave a baby alone, even if he or she is strapped.
- Keep supplies within reach—but out of the baby's reach. Never let your baby play with a powder container. If the container is open and your baby shakes it, he or she is likely to inhale particles of powder that can be harmful to his or her lungs.
- If you use disposable diapers, cover them with clothing. Babies can suffocate if they tear off tiny pieces of the plastic liner and swallow them.

Fire Safety

- Test the smoke alarms monthly and replace the battery when you change the clock for daylight savings time.

- Create a fire escape plan and practice it. If the door is blocked or on fire, is there another way out? Do you need a window ladder? Who will get the baby? Where will you meet outside?
- Do not put electric cords under rugs. Do not overload sockets.
- Keep space heaters away from anything that can catch fire. Never use the oven to heat your home. Blow out candles when you leave the room.
- Keep a fire extinguisher in the kitchen and post emergency numbers near the phone.
- Do not let anyone smoke in your home. If you smoke, go outside, but never leave your baby alone.
- Install a carbon monoxide (CO) detector on each floor of your house. CO is a toxic gas that has no odor, no taste, and no color. It comes from appliances or heaters that burn gas, oil, wood, propane, or kerosene.
- In the event of a fire, take your baby to a neighbor's home and call 911.

Babysitters

When leaving your baby with a babysitter, place emergency phone numbers near the phone and show them to the babysitter so he or she knows how to reach you.

Include the following:

- parents' phone numbers
- neighbors' phone numbers
- emergency 911
- Poison Control Center 800.222.1222
- your baby's doctor and phone number
- your home phone number and address
- your baby's birth date, health insurance information, preferred hospital, and consent for emergency medical treatment if you are away overnight.

Sun and Outdoor Safety

Babies who are younger than 6 months old should stay out of the sun. Use a hat and a carriage cover. Ask your baby's provider about the use of sunscreen.

- Use netting on the stroller to protect your baby from bug bites.
- Before you put your baby into a car seat, make sure the car seat is not too hot from the sun. A hot car seat can hurt your baby.



- Use the car seat every time your baby rides in a car or taxi. Use sunshades for car windows to protect your baby from the sun.

Water Safety

As your baby grows, remember these things:

- Because toddlers can drown in 1 inch of water, empty wading pools or buckets and turn them upside down when not using them.
- Many drownings of young children occur in bathtubs, usually when the caregiver leaves “for just a minute.” Never leave a child in the tub, even with a sibling.
- In a household with toddlers, always put the toilet lid down and use toilet locks. Keep bathroom doors closed and latched so children can’t play in the bathroom.
- Plan ahead and buy latches for cabinets, drawers, doors, and toilets. Cover electrical outlets with safety covers.

Resources

Centers for Disease Control and Prevention: Water Injuries

www.cdc.gov/HomeandRecreationalSafety/Water-Safety/waterinjuries-factsheet.html

Healthy Children: Reduce the Risk of SIDS and Suffocation

www.healthychildren.org/English/ages-stages/baby/sleep/Pages/Preventing-SIDS.aspx

Healthy Children: Make Baby’s Room Safe

www.healthychildren.org/English/safety-prevention/at-home/Pages/Make-Babys-Room-Safe.aspx

Healthy Children: Safety for Your Child: Birth to 6 Months

www.healthychildren.org/English/ages-stages/baby/Pages/Safety-for-Your-Child-Birth-to-6-Months.aspx

Healthy Children: Bathing and Skin Care

www.healthychildren.org/English/ages-stages/baby/bathing-skin-care/Pages/default.aspx



Postpartum Depression

Pregnancy and postpartum are two of the most vulnerable periods in a woman's life, and there is a wide range of diverse responses to the hormonal changes that occur during this time. All healthcare professionals who care for women and infants during the first year following childbirth should be aware of the early warning signs of postpartum depression (PPD) and postpartum psychosis (PPP) and provide available resources for referral if necessary. There is hope that with early intervention, the potential harm to families through isolation and neglect may be minimized and the devastating cases of suicide and infanticide may be prevented. Studies indicate that PPD not only responds well to treatment but also may be preventable (Dennis & Dowswell, 2013; Earls, 2010).

PPD is a mood disorder affecting approximately one in seven women, with approximately 8% having mild to moderate depression and 7% having a more severe depression ("Pregnancy," 2016). Unlike the *baby blues*, a term used to describe feelings of sadness, anxiety, and fatigue that usually only last 1–2 weeks, PPD impacts the mother's ability to enjoy or perform her normal activities of life. She may have extreme feelings of worthlessness, anxiety, irritability, and confusion. In addition, the mother may report changes in her eating and sleep patterns. Most new mothers suffer from some degree of sleep deprivation, but women with PPD often have difficulty getting to sleep, have disrupted sleep, and often wake early and are unable to get back to sleep (Hunt, 2017; Kennedy, Beck, & Driscoll, 2002). An early warning sign of more serious depression is if the mother feels overwhelmed combined with suicidal ideation; this should not be ignored. Feeling overwhelmed is normal after childbirth, but feeling suicidal is not. Being overwhelmed or distressed for longer than 2 weeks should be a warning sign that the patient requires an evaluation for depression.

It is estimated that at least 50% of PPD cases go unrecognized; therefore, there is a need to identify tools for early detection (Littlewood et al., 2016). The American

College of Obstetricians and Gynecologists, the American Academy of Pediatrics, and the U.S Preventive Services Task Force recommend universal screening with a validated screening tool during pregnancy and again during the postpartum period. The goal of screening is to know when to provide early treatment (Cox, Holden, & Sagovsky, 1987; Earls, 2010; Committee Opinion No. 630, 2015). The Edinburgh Postpartum Depression Screen is one example of a validated tool (Cox et al., 1987). This 10-item questionnaire is easily performed in the clinic waiting room and scored by the nurse or technician. Another tool, endorsed by the UK National Institute for Health and Care Excellence, is a two-question screening tool referred to as the "Whooley" questions (Littlewood et al., 2016). This ultra-brief screen is currently undergoing additional research to validate it. Screening tools are not intended to be diagnostic but instead to provide a guideline for referral.

Screening can be performed at 6 weeks, 3 months, and 6 months. Although exact percentages vary, it has been reported that 40% to 90% of PPD cases occur within 3 months after childbirth ("Pregnancy," 2016). Nonetheless, women should be carefully assessed throughout the first year after childbirth, as PPD can occur up to 1 year postpartum (Kingston, Tough, & Whitfield, 2012). The family practice physician or pediatrician is in an ideal position to perform ongoing screenings.

It is important to note that approximately 5% to 7% of postpartum women have abnormal thyroid levels (Sylvén et al., 2013). Hypothyroidism is associated with depressed mood and may be a causative factor for PPD in some women and therefore should be ruled out.

Postpartum psychosis (PPP), an extreme condition affecting one to two in 1,000 new mothers, is characterized as being out of touch with reality. Major risk factors include personal history of PPD or psychosis, a family history of depression, and the presence of bipolar disorder (Kingston et al., 2012; Thrugood, Avery, & Williamson, 2009).



PPP requires hospitalization—one in every 250,000 new mothers affected by PPP engages in infanticide, with many of those mothers going on to commit suicide (Thru-good et al., 2009).

Treatment strategies for any perinatal mood disorder require a multidisciplinary approach. The earlier the mother is treated and the more multifocused the strategy for treatment, the better and faster her recovery will be (Wisner et al., 2004). If a treatment strategy is not working after about 3 weeks, the mother should consider a different approach.

Several studies have indicated that when breastfeeding is going well, oxytocin and prolactin hormones are elevated and proinflammatory cytokine hormones are low, women experience lower rates of depression (Kendall-Tackett, 2010). Discontinuing breastfeeding is not recommended unless breastfeeding appears to be a contributing factor. If medication is necessary, several antidepressants are considered compatible with breastfeeding and should be considered (Wisner et al., 2004). In addition, breastfeeding may help to minimize the negative effects depression has on the infant's development. When a mother is breastfeeding, even when feeling detached, she will hold and engage with her infant (Kendall-Tackett, 2010).

As healthcare professionals we have an opportunity to provide the support and resources mothers need to help them enjoy motherhood. What mothers do is important, and when we support and nurture the mother, we support and nurture the child as well.

What can the family do?

- Listen without giving advice or fixing the problem
- Offer hope that she will recover
- Help with daily care: nourishment, bathing, sleep, exercise
- Take care of the baby as much as possible
- Hire a housekeeper
- Provide support for the partner (who may be experiencing PPD as well)

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Resource

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The Baby Blues and Postpartum Depression: Information for Parents

There are few things more troubling to a new mother than having feelings of sadness, excessive worry, and irritability after the birth of a baby. These disturbing feelings can be frightening, leading you to believe you are not a good mother. The truth is that the hormonal and chemical changes that occur during and after pregnancy cause many women to feel these emotions.

Following the delivery of a baby, hormones that were very high in order to maintain the pregnancy, come crashing down. Often called the “baby blues,” these emotional changes usually start within the first 5 days after birth and are gone by 2 weeks. Unfortunately, for some mothers these emotions last longer than 2 weeks and may be associated with one of the most common complications of childbirth: postpartum depression.

Risk factors for postpartum depression include having a history of depression before or during the pregnancy, birth complications or a difficult labor, an infant with health problems, stressful events in the past year, relationship problems, financial difficulties, and breastfeeding problems. If feelings of sadness, anxiety, confusion, loss of enjoyment in life and difficulty sleeping or eating persist beyond 2 weeks postpartum, you should contact your healthcare provider and reach out to people in your support system for help treating the depression.

Research shows that treating postpartum depression with medication alone is not as successful as a multifocused treatment approach. A multifocused approach may include counseling (individual and/or group therapy), medication, rest, exercise, good nutrition, and the removal of additional stressors such as housekeeping, cooking, and child care. Following an evaluation by a therapist, you may be prescribed an antidepressant medication. If breastfeeding, the mother should ask her healthcare provider to prescribe a medication that will work with breastfeeding. If a treatment strategy is not working after about 3 weeks, you may want to consider a different approach.

There is no way to predict when the symptoms of depression will go away. What we do know is that the sooner treatment begins, the sooner the symptoms seem to resolve. Treatment for postpartum depression has an excellent recovery rate. You should remember there is hope and until then, surround yourself with people who support you while making the journey back to enjoying life again.

Step

5



Oral Feedings

Assessment of oral feeding readiness traditionally begins once a baby nears 34 weeks gestation, although in some instances this assessment may begin sooner. Babies whose mothers plan to breastfeed may already be nuzzling at the breast; others who aren't being breastfed are receiving oral stimulation with a pacifier. Both of these methods are used during gavage feedings.

Oral stimulation and nonnutritive sucking promote feeding success and develop positive feeding experiences. Oral stimulation is best achieved when the infant accepts the pacifier, rather than inserting the pacifier into the mouth when the mouth is closed and the infant is not rooting. Oral care for infants who are not eating by mouth (NPO) or are intubated should be provided gently by letting the infant allow entrance when his or her mouth is open. When cleaning the lips, the use of the mother's pumped breast milk or donor milk with a 2-in. x 2-in. gauze pad or swab stick may be preferred over commercial saline wipes, which may be taste aversive to the infant.

As the baby begins weaning off of intravenous fluids and feedings are being initiated, this is a good time to start discussing oral feeding and feeding readiness with parents. Some hospital institutions have developed parent education about infant-driven feeding or cue-based feeding protocols; other institutions rely on feeding orders for volume and how many times per shift a baby may take a bottle or breastfeed. Whatever the case may be at your institution, early discussions of oral feeding with parents facilitates improved comfort levels once oral feedings begin.

Feeding assessment, which includes hunger cues and physiologic stability, consists of factors that indicate whether a baby is ready to feed. Observing for desaturations and stress cues such as hiccoughs, bradycardia,

or fingers splayed before, during, and after oral feeding are important assessment criteria. These stress cues determine the start of a feed, the need for pacing during a feed, and the end of a feed. Remember not to push an infant to suck and swallow if they fall asleep during a feed. This is usually a sign that they are finished, even if they have not completed the volume. Parents should be instructed in how to identify physiologic signs and be involved as much as possible. Medical staff should encourage consistent parent participation.

The assessment skills that you have learned regarding feeding readiness and stress cues will help you determine the significance of feeding difficulties, should they arise. Infants who have been hospitalized long term or have chronic lung disease, those born with cleft lip and palate, and those who remained NPO for long periods of time due to gastroschisis or other gastrointestinal complications are considered to be at risk for feeding difficulties. When identifying potential problems, lactation, speech and language therapy, and occupational therapy referrals should be made as a proactive approach to ensure babies continue to safely advance with oral feedings. Identifying feeding problems and initiating safe interventions early will allow the baby to continue to progress, having fewer opportunities for oral aversion and less chance of a physiologic setback.

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Oral Feedings: Information for Parents

You will learn a lot about feeding your baby. You play an important part in your baby's feedings.

Tube feeding is when your baby is getting your breast milk, donor milk, or special formula through a tube that goes into the mouth or nose and ends in his or her stomach. A pacifier may be dipped into milk and given to your baby during feeding times. A pacifier dipped into milk makes your baby happy during the tube feeding. Sucking on a pacifier gives your baby practice for either the bottle or your breast. Never force the pacifier into your baby's mouth.

Feeding should always be a happy time for you and your baby. If your baby is not ready to suck from a bottle or your breast, there are other things your baby can do. Your baby can rest his or her mouth at your breast if you want to breastfeed. Your baby can rest his or her body skin to skin with mom or dad during the tube feeding.

Your baby has to learn how to coordinate sucking, swallowing, and breathing when eating. Your baby may not begin to learn how to do this until they are close to 34 weeks gestation. The nurses and feeding therapists in the neonatal intensive care unit (NICU) will work with you to teach you how to feed your baby safely. You will also learn about feeding readiness. If your baby is stable, you and the nurse will decide if your baby is awake and moving around enough to eat from a bottle or breast. Both parents and caregivers should be comfortable with bottle feeding. Mothers should be comfortable with breastfeeding. Your baby should gain weight every day and finish the full feeding by bottle or breastfeeding. Once they can do these things, they can go home.

If your baby has problems during breastfeeding, the nurse will call a special nurse who may be able to help. If your baby has problems bottle feeding, the nurse will call the feeding specialist. If problems are found, the NICU team will work together to help your baby eat better. A video of your baby while swallowing may be made to see if the mouth or throat is not working right. The video also will show if food is going into the baby's lungs (also called

aspiration). The fluid may just be going up and down the baby's throat (also called *reflux*). During the video, milk may be thickened like a milkshake. The best thickness will show no reflux or aspiration on the video. Your baby's provider may decide to let your baby rest and go back to tube feedings until your baby is a little older. He or she may decide that a thickened feeding will help keep your baby safe. If your baby needs thickened feedings, as your baby grows and gets a little older the video will be done again.



Courtesy of Amy Gates, Hand to Hold.

Once oral feedings are started, it will be very important you to visit as much as possible. As parents, you will be the ones feeding your baby once you go home. If you plan to have other caregivers help you at home, they need to come to the NICU with you to learn how to feed your baby. Once you are home, contact your baby's provider for any feeding issues your baby might have. Things like not eating well for more than two feedings in a row, spitting up more than usual, not waking up for a feeding, or not breathing during a feeding need to be shared with your baby's provider as soon as possible.



Hearing Screening

Because early detection of hearing loss is so critical to positive outcomes, the National Institutes of Health made a statement in 1993 recommending universal newborn hearing screenings within the first 3 months of life for neonatal intensive care unit patients as well as full-term infants. Since this statement, forty-three states and territories including Puerto Rico and the District of Columbia have mandated hearing screens for all infants. Universal hearing screening is a recommendation of the American Academy of Pediatrics. Early detection of hearing loss is key in preventing later speech and communication disorders, as well as any potential developmental problems stemming from poor speech and hearing loss.

There are two types of hearing loss, conductive and sensorineural, though a mixture of the two also is possible. *Conductive hearing loss* usually occurs when fluid in the outer or middle ear blocks sound or when there is a structural abnormality of the outer or middle ear. *Sensorineural hearing loss* involves the inner ear or damage to the nerves from the inner ear that carry sound to the brain. Sensorineural hearing loss may be caused by structural abnormalities to the inner ear, maternal infections such as cytomegalovirus and rubella, or a genetic condition passed on to the baby from a parent. Hereditary causes are the main source of sensorineural hearing loss. It is very important for family history to be reviewed, especially any family history of hearing loss, prior to the hearing screen.

There are currently two forms of hearing screen tests: the Otoacoustic Emission (OAE) and the Auditory Brainstem Response (ABR). The OAE involves placing small probes in both ear canals, which release external sounds and stimuli and then measure internal cochlear sounds. If the cochlea is not functioning, there will either be no internal sounds recorded or the sounds will be too low to be recorded. The ABR involves placing earphones on both

ears and electrodes all over the baby's head. Sounds are released and electrical signals across the electrodes are recorded. If hearing is present in the baby, the responses are recorded as low-level stimuli. With hearing loss, the responses are recorded as high-level stimuli. Your hospital or institution has chosen at least one of these testing measures for universal hearing screening for all newborns.

The best testing results occur when the baby is sleeping or not active. Parent education should focus on the type of hearing test used at your institution (OAE vs. ABR), test time, an explanation that the procedure is pain free, and the importance of follow-up testing at outside referral centers when further testing is required. According to data analyzed by the National Institute on Deafness and Other Communication Disorders, as many as 50% of babies who fail the in-hospital screening are lost to follow-up (National Institutes of Health, 1993). Hospital staff plays a critical role in improving these odds. Reinforce with parents that even though their infant passed the hospital hearing screen, hearing may change due to illness or medications used while hospitalized, or both. Routine screenings throughout childhood are important.

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Hearing Screening: Information for Parents

Hearing is very important for the normal development of all babies. Every year, about 12,000 babies are born with hearing loss in the United States. Even a small hearing loss in one ear can affect your baby's communication skills. When babies cannot hear well, they may develop problems talking and understanding words. For this reason, all babies will have a hearing test before going home.

The hearing test is a painless procedure that is done when your baby is sleeping or still and quiet. This test measures how well the outer and inner ear work. It takes 10–20 minutes, unless the test has to be repeated. Special probes or earphones are placed in or around both of your baby's ears and connected to the hearing screening machine. This will be used to test both ears.

If your baby does not pass the first hearing test, it will be repeated. If your baby is awake and moving too much or if your baby has fluid in his or her ears, the test will need to be repeated. If your baby does not pass the hearing test, your baby's provider will refer you to someone who specializes in infant hearing. This specialist is called a *pediatric audiologist*. The audiologist has special skills and experience giving hearing tests and explaining what the results mean. Be sure to make and keep all appointments with your baby's primary provider, as well as any hearing test appointments. Although hearing loss is serious, the sooner you know about it the sooner you can find help—and the better the outcome will be for your baby. If you need help and information, contact your state's early hearing detection and intervention program.

Your baby's hearing continues to develop over time. Even if your baby has passed the hearing test in the hospital, you will still need to watch your baby's milestones of development. Some babies will require periodic hearing tests after they go home from the hospital. Talk to your provider about the milestones of development for hearing and talking. You can find more information at www.HealthyChildren.org. Under the tab "ages and stages," select baby 0–12 months. Visit www.babyhearing.org for more information.



A newborn undergoes a hearing screening. © Getty Images



Immunizations

The Centers for Disease Control and Prevention (CDC) and the American Academy of Pediatrics have worked together over the years to develop an immunization vaccination schedule based on long-standing practice and current evidence-based research.

According to the CDC, “Vaccines are the best defense we have against infectious diseases; however, no vaccine is 100% safe or effective. Differences in the way individual immune systems react to a vaccine account for rare occasions when people are not protected following immunization or when they experience side effects” (CDC, 2013). Vaccines are tested and then approved by the U.S. Food and Drug Administration.

The National Childhood Vaccine Injury Act (NCVIA) was passed by Congress in 1986 to provide the public with information regarding vaccine safety and health concerns and to reduce government liability (CDC, 2013). The NCVIA also gave the medical community resources and guidelines for administering immunizations and reporting vaccine reactions. The resources developed include the vaccine information sheet (VIS), which all healthcare providers must provide to parents before requesting consent for each scheduled immunization. Each VIS contains a brief description of the disease as well as the risks and benefits of the vaccine. The CDC develops and distributes the VIS to state and local health departments and posts it on the CDC website. The NCVIA also calls for a compensation program to assist those who have been injured from immunizations and a review committee to monitor information on vaccine side effects (CDC, 2013).

It is important for healthcare providers to educate parents about diseases and viruses that may be harmful to children. Parents should remember that breastmilk has immunologic benefits to help as well. It also is important that

the mother receives pertussis vaccination during pregnancy or at delivery to protect the baby. All family members and caregivers of infants younger than 6 months of age should receive the flu vaccine as well.

Newborns are immune to many diseases because they have antibodies from their mothers and these antibodies increase with breastfeeding. However, this immunity lessens during the first year of life. Infants and young children do not have “maternal immunity” against some diseases, such as whooping cough. Immunizing individual children also helps to protect the health of our community, especially those who cannot be immunized. That population includes children who are too young to be vaccinated (e.g., children younger than 1 year cannot receive the measles vaccine but can be infected by the measles virus), who cannot be vaccinated for medical reasons (e.g., children with leukemia), and those for whom vaccination is not successful.

By visiting www.cdc.gov/vaccines, healthcare providers can review information about preventable diseases and vaccines that prevent them. Content is designated specifically for healthcare providers and parents of infants and toddlers.

Immunization schedules may be printed directly from the CDC website and given to parents. Copies of immunization records and immunization injection dates should be included in the electronic health record printed discharge instructions and given to parents to share with their pediatric provider.

Reference

The Centers for Disease Control and Prevention (CDC). (2013). Vaccines and Immunizations. Retrieved from www.cdc.gov



Immunizations: Information for Parents

The diseases that immunizations (vaccines) prevent can be dangerous—even deadly. Vaccines reduce the risk of infection by helping the body’s natural defenses to develop immunity (or resistance) to disease.

When germs, such as bacteria or viruses, invade the body, they attack and multiply, causing an infection. The immune system (our natural system of defenses) has to fight the infection, but once this happens, the fighting cells can remember that infection to fight it in the future. Vaccines help develop these fighting cells by imitating an infection, but this imitation infection doesn’t cause illness. It causes the immune system to have the same fighting response as though it were a real infection, so the body can recognize it and fight it in the future. Sometimes, the vaccine can cause minor symptoms, such as fever. These minor symptoms are normal and should be expected as the body builds immunity.

Like any medication, vaccines can cause side effects. The most common side effects are mild (such as redness and swelling where the shot was given) and go away within a few days. If your baby experiences redness, soreness, and swelling where the shot was given, you can ease those

symptoms with a cool, wet cloth. Pay extra attention to your baby for a few days after vaccination. If you see something that concerns you, call your baby’s provider.

While your baby is in the hospital, the neonatal intensive care unit team will follow the vaccine schedule for your baby and make any necessary changes due to your baby being born early. The vaccine recommendations for the first 6 years of life are shown below.

A medicine called Synagis (palivizumab) also will be recommended if your baby was premature and born before 35 weeks to help prevent your baby from getting a respiratory virus called RSV.

The nurses will give you information on the specific shots your baby needs and will explain the possible side effects. They will ask for your written permission before giving your baby any shots.

A vaccine shot schedule and a record of the shots your baby received while in the hospital will be given to you before you go home. Vaccine shot records will be needed for public day care centers and public schools. It’s very

FIGURE 1: Recommended immunization schedule for persons aged 0 through 6 years—United States, 2012 (for those who fall behind or start late, see the catch-up schedule [Figure 3])

Vaccine ▼	Age ►	Birth	1 month	2 months	4 months	6 months	9 months	12 months	15 months	18 months	19–23 months	2–3 years	4–6 years	
Hepatitis B ¹	Hep B	Hep B	Hep B			Hep B		Hep B						Range of recommended ages for all children
Rotavirus ²				RV	RV	RV ²								
Diphtheria, tetanus, pertussis ³				DTaP	DTaP	DTaP	see footnote ⁴	DTaP					DTaP	
<i>Haemophilus influenzae</i> type b ⁴				Hib	Hib	Hib ⁴		Hib						Range of recommended ages for certain high-risk groups
Pneumococcal ⁵				PCV	PCV	PCV		PCV				PPSV		
Inactivated poliovirus ⁶				IPV	IPV			IPV					IPV	
Influenza ⁷								Influenza (Yearly)						
Measles, mumps, rubella ⁸								MMR		see footnote ⁹			MMR	Range of recommended ages for all children and certain high-risk groups
Varicella ⁹								Varicella		see footnote ⁹			Varicella	
Hepatitis A ¹⁰										Dose 1 ¹⁰			HepA Series	
Meningococcal ¹¹								MCV4 — see footnote ¹¹						

This schedule includes recommendations in effect as of December 23, 2011. Any dose not administered at the recommended age should be administered at a subsequent visit, when indicated and feasible. The use of a combination vaccine generally is preferred over separate injections of its equivalent component vaccines. Vaccination providers should consult the relevant Advisory Committee on Immunization Practices (ACIP) statement for detailed recommendations, available online at <http://www.cdc.gov/vaccines/pubs/acip-list.htm>. Clinically significant adverse events that follow vaccination should be reported to the Vaccine Adverse Event Reporting System (VAERS) online (<http://www.vaers.hhs.gov>) or by telephone (800-822-7967).

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important that you make routine well-child appointments for your baby to see his or her provider. They will help manage your baby's vaccines and make sure the shots are given when they are needed. One of the best ways you

can build your baby's immune system is to follow up and ensure that your baby receives all of the shots and medicines recommended for his or her age.

Step

6



Car Seat Testing and Safety

When discharge is anticipated, the infant's nurse will notify the family of the need to bring in the car seat to be used for transportation upon discharge from the hospital. Car seat evaluation usually is done for infants born at less than 37 weeks. Ideally, the car seat would be brought to the neonatal intensive care unit (NICU) approximately 48 hours before anticipated discharge. Parents of preterm infants should be advised to choose an "infant only" car seat. The nurse should encourage the parents to bring the base of the car seat in to the hospital when car seat testing will occur.

Parents should be encouraged to refer to their car's owner manual and car seat's instructions for information about how to install the car seat prior to performing the car seat evaluation (once again, it would be ideal to not have to learn how to put the car seat together on the day of their infant's discharge). The parents should confirm that the car seat is not subject to manufacturer recall and that it meets Federal Motor Vehicle Safety Standards (FMVSS).

The car seat should not be used as an infant carrier. An infant car seat is a rear facing seat only and has a convenient removable carrier that connects to a base installed in the car. This car seat provides the best fit for newborns and smaller babies and can be used from 4 lbs to 40 lbs, depending on the model. A convertible seat is a larger and heavier seat and can grow with your child. The recommendations for use are birth to 50 inches tall. For premature babies, this car seat might be too large to start with. You can use it rear facing until your child is at the 2-year recommendation, then forward facing until the weight limit, and then you can convert to a booster seat. This type of car seat stays in the car.

The parents can verify a car seat's compliance with FMVSS at www.safercar.gov/parents/CarSeats/Car-Seat-Safety.htm?view=full. Some local law enforcement agencies can provide a car seat inspection. Parents should be encouraged to reach out to their local law enforcement

agency for an inspection prior to the infant being discharged.

During the car seat testing, the infant is positioned in the car seat in the riding position and monitored with a cardiorespiratory monitor and pulse oximeter for 90–120 minutes or for the duration of travel to home if longer than 90 minutes. The nurse documents any episodes of apnea, bradycardia, and desaturations as well as any stimulation or intervention that is needed.

To pass the car seat evaluation, the infant should have no instances of apnea, bradycardia, or oxygen desaturation during the observation period. For a failed evaluation, the nurse should then notify the appropriate medical team member for a full evaluation of results. A car bed may be indicated for infants who experience apnea, bradycardia, or oxygen desaturation during the observation period. If a car bed is considered, another evaluation time period should occur.

Recently, car seat testing and evaluation has been in question as it remains unclear whether performing infant car seat challenges actually helps to identify at-risk infants or whether it causes false concern and unnecessary testing and interventions. This is due to prolonged time in a semi-upright position, which can lead to lower oxygen saturation levels in both the preterm and term infant.

What nurses can do for NICU infants and their parents is to ensure that the parents know how to safely and correctly position their infant in the car seat. This may require further education for the nursing staff. The nurse should recommend that another adult sits in the back seat next to the infant for observation when traveling. The parents also should be advised that the car seat is to be used only for transportation purposes and not as an infant seat in the home.



The American Academy of Pediatrics advises parents to keep their infants and toddlers in rear-facing car seats in the back seat of the vehicle until age 2 or until the child reaches the maximum height and weight for their seat. A rear-facing child seat does a better job supporting the head, neck, and spine of infants and toddlers in a crash because it distributes the force of the collision over the entire body.

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Car Seat Testing and Safety: Information for Parents

If your baby was born before 37 weeks, he or she may participate in a car seat test, also known as a “car seat challenge,” before being discharged from the hospital. This test will last about 1–2 hours, during which your baby’s heart rate and breathing will be monitored. This test will determine if your infant can tolerate being in a car seat for a car ride.

Your baby should ride rear facing and in the back seat of your car until he or she is 2 years old or exceeds the maximum weight and height requirements for the car seat, as this is the safest position. Make sure you have read all car safety seat instructions as well as your car’s instruction manual to learn how to install your car seat properly *before* the day of discharge. Many fire departments, police stations, and hospitals have fitting stations with certified child passenger safety staff available to help parents and families determine if their car seat is installed correctly.

Never use a baby carrier in the car instead of a car seat. An infant car seat is a rear-facing seat only and has a convenient removable carrier that connects to a base installed in the car. This car seat provides the best fit for newborns and smaller babies and can be used from 4 pounds to 40 pounds, depending on the model. A convertible seat is a larger and heavier seat and can grow with your child. The recommendations for use are birth to 50 inches tall. For premature babies, this car seat might be too large to start with. You can use it rear facing until your child is at the 2-year recommendation, then forward facing until the weight limit, and then you can convert to a booster seat. This type of car seat stays in the car.

Make sure the straps in the car seat are properly positioned, secured, and fit snugly against your baby’s chest. You should only be able to fit two fingers in between your baby and the straps. Loose straps do not provide maximum safety. Every car seat has an expiration date; check to see when your car seat will expire. If you cannot

find the expiration date on the car seat, contact the manufacturer.

When you are driving with your baby, try to bring another adult with you who can sit in the back seat to watch your baby. When you are traveling without another adult, remember to take your baby out of the car. Remember, you are never to leave your baby alone in a car.

More tips for keeping your baby safe on the car ride:

- Use car seats and seat belts on every single trip you take, even if it’s just down the street.
- Never use a car seat that has been in a car crash. To find out more, visit www.nhtsa.gov.
- Do not use a second-hand car seat, such as one from a garage sale or one from a friend or family member





because you do not know if it has been damaged in a crash or recalled.

- Never use padding or other products that did not come with your car seat.
- Never use a car seat that has been recalled. Make sure that when you purchase your baby's car seat that you fill out and return the registration form. This will ensure that you are informed of any recalls for the seat you purchased.
- For current, up-to-date information, visit www.safekids.org/ultimate-car-seat-guide.



Cardiopulmonary Resuscitation (CPR) Training

Healthcare professionals caring for high-risk infants and their families are responsible for preparing parents and families for safe discharge and transition to home. Discharge education for these patients should cover safety at home, including cardiopulmonary resuscitation (CPR) training. This education can decrease parents' and families' worry about discharge to home. Families must be evaluated to determine what form of education is appropriate to meet their needs. Learning disabilities or language barriers among family members must be recognized and taken into consideration. Education should be tailored to these family members. There are several potential educational styles for infant CPR, including in-person, written, and video instruction.

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Cardiopulmonary Resuscitation (CPR) Training: Information for Parents

The American Academy of Pediatrics suggests all parents learn infant cardiopulmonary resuscitation (CPR) before their babies leave the hospital. For some families, CPR training is required before their baby can be discharged. CPR training for infants and children may be offered through the Red Cross, American Heart Association, local libraries, a local hospital, or local emergency services. You will learn basic CPR skills to help your baby until emergency responders arrive. If an emergency happens, CPR can save your baby's life by reestablishing blood flow to the heart, brain, and other organs and restoring breathing.

CPR may be necessary in many different emergencies, including suffocation, accidents, near drowning, and suspected sudden infant death syndrome. CPR works best when started as soon as possible, but you must first decide if it's needed. CPR should only be done if your baby is not breathing, has no heartbeat, or is not responding.

Although you may feel very anxious as your baby is being prepared for discharge from the hospital, becoming familiar with emergency procedures will help decrease your fear and increase your confidence when taking your baby home. Partner with the neonatal intensive care unit team early in your baby's hospitalization to help prepare you for your baby's safe transition to home. If your family is having trouble understanding the steps in infant CPR, stop your instructor and ask questions.

After learning infant CPR, review the steps often. It is common for parents to be concerned that they will not remember the steps to CPR in an emergency. When calling 911, explain the issue you are having. They will try to walk you through it by phone until the team arrives. Remember, CPR training is provided so you can give life-saving care and increase your child's chance for survival in case of emergency until emergency responders can take over.



Safe Sleep

Sudden unexpected infant death, also known as *sudden unexpected death in infancy*, is a term used to describe any sudden and unexpected death, whether explained or unexplained (including sudden infant death syndrome [SIDS] and ill-defined deaths), occurring during infancy (American Academy of Pediatrics [AAP], 2016). Approximately 3,500 sleep-related infant deaths occur annually in the United States from causes such as SIDS, ill-defined deaths, and accidental suffocation and strangulation in bed (AAP, 2016). At the beginning of the “back to sleep” campaign in the 1990s, the number of sleep-related infant deaths decreased. Today, the number of infant sleep-related deaths has plateaued. The AAP recommends a safe sleep environment that can reduce the risk of all sleep-related deaths (AAP, 2016).

It is important that the healthcare team establish a safe sleep environment in the hospital setting and that all healthcare professionals, especially nurses, receive appropriate education and training on a safe sleep environment so they can serve as good role models (Patton, Stiltner, Wright, & Kautz, 2015).

The AAP’s recommendations to reduce the risk of SIDS and other sleep-related infant deaths include

- Place the infant on his or her back to sleep for every sleep.
 - Infants should be placed in a supine position for every sleep until they reach 1 year of age.
 - After birth, place infants on their backs to sleep as there is no evidence that placing infants on their sides after delivery will promote clearance of amniotic fluid.
 - Once home, preterm infants also should be placed supine.
 - Hospitalized preterm infants should be kept predominantly in the supine position, at least from the postmenstrual age of 32 weeks onward so they become acclimated to supine sleep before discharge.
- Use a firm sleep surface.
 - Infants should be placed on a firm sleep surface that is covered with a fitted sheet. No pillows and no mattress toppers should be used for infants younger than 1 year.
- AAP Task Force on Sudden Infant Death Syndrome cannot make a recommendation for or against the use of bedside sleepers.
- Infants should not sleep on beds because of risk of entrapment and suffocation.
- Sitting devices, such as car seats, strollers, swings, infant carriers, and infant slings, are not recommended for routine sleep in the hospital or at home, particularly for infants younger than 4 months of age. Always make sure the infant’s nose and mouth are clear of obstruction when using infant slings and cloth carriers.
- Breastfeeding is recommended.
- The infant may sleep in his or her parents’ room, but on a separate surface designed for infants. There should be no bed-sharing.
- No soft objects or loose bedding should be placed in the infant’s sleep area.
 - Sleep clothing such as a wearable blanket is preferable to blankets or head coverings.
 - Bumper pads are not recommended.
- Consider offering a pacifier at nap time and bedtime.
 - Use a pacifier when placing an infant to sleep. It does not need to be reinserted if the pacifier falls out of the infant’s mouth.
 - Pacifiers should not be hung around the infant’s neck and should not be attached to stuffed toys.
- Avoid smoke exposure during pregnancy and after birth.
- Avoid alcohol and illicit drug use during pregnancy and after birth.
- Avoid overheating infants.
 - Generally, dress the infant in no more than one additional layer than an adult would wear to be comfortable in that particular environment.
 - Overbundling and covering of the infant’s face and head should be avoided.
- Pregnant women should have regular prenatal care.



- Immunizations should be done in accordance with recommendations from the AAP and Centers for Disease Control and Prevention.
- Avoid the use of commercial devices that are inconsistent with safe sleep recommendations. Examples of such devices include wedges and positioners.
- Do not use home cardiorespiratory monitors as a strategy to reduce the risk of SIDS.
- Supervised, awake tummy time is recommended.
- There is no evidence to recommend swaddling as a strategy to reduce the risk of SIDS.
 - A swaddled infant has a high risk of death if placed in prone position or rolls to prone.
 - Swaddling should be snug around the chest but allow for ample room at the hips and knees.
 - No evidence exists on whether keeping arms in or out if swaddled has an effect on SIDS risk.
- Staff of newborn nurseries and neonatal intensive care units should endorse and model the SIDS risk reduction recommendations from birth.

- Media and manufacturers should follow safe sleep guidelines in their messaging and advertising.
- Primary care providers should actively participate in the Safe to Sleep® campaign.
- Continue research and surveillance on the risk factors, causes, and mechanisms of SIDS and other sleep-related infant deaths.

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Safe Sleep: Information for Parents

Sudden infant death syndrome (SIDS) is the sudden, unexplained death of a baby younger than 1 year who doesn't have a known cause of death, even after a complete investigation by healthcare professionals, law enforcement personnel, and the community. SIDS is the leading cause of death among babies between 1 month and 1 year of age. Most SIDS deaths occur in babies between 1 month and 4 months of age, and the majority (90%) of SIDS deaths occur before a baby reaches 6 months of age.

The Safe to Sleep® campaign, formerly known as the Back to Sleep campaign, focuses on actions you and others can take to help your baby sleep safely and to reduce

your baby's risk of SIDS and other sleep-related causes of infant death.

Learning about SIDS and safe sleep for babies is important for all caregivers—not just parents. Grandparents, aunts, uncles, babysitters, child care providers, and anyone else who might care for babies should learn more. Simple actions can make a big difference.

What Does a Safe Sleep Environment Look Like?

You can reduce your baby's risk of SIDS and other sleep-related causes of infant death in the following ways.

Use a firm sleep surface, such as a mattress in a safety-approved* crib, covered by a fitted sheet.

Do not use pillows, blankets, sheepskins, or crib bumpers anywhere in your baby's sleep area.

Keep soft objects, toys, and loose bedding out of your baby's sleep area.

Do not smoke or let anyone smoke around your baby.

Make sure nothing covers the baby's head.

Always place your baby on his or her back to sleep, for naps and at night.

Dress your baby in sleep clothing, such as a one-piece sleeper, and do not use a blanket.

Baby's sleep area is next to where parents sleep.

Baby should not sleep in an adult bed, on a couch, or on a chair alone, with you, or with anyone else.

*Always use the most up-to-date safety information for your crib.

Courtesy of the Safe to Sleep public education campaign; www.nichd.nih.gov/sts/about/environment/Pages/look.aspx.

Step





Respiratory Syncytial Virus

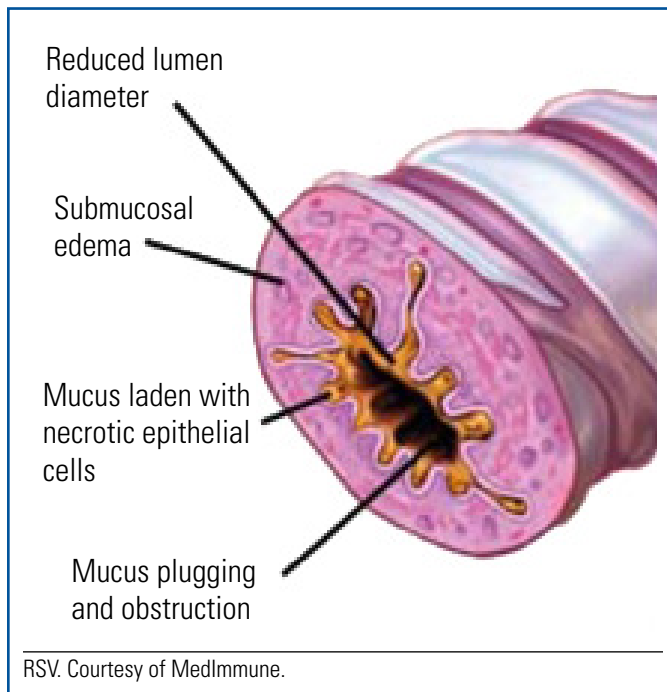
Respiratory syncytial virus, or RSV, is a common illness of the lungs and breathing passages affecting high-risk populations, especially babies born prematurely who are less than 2 years of age.

- By age 2, most children have had or been exposed to RSV.
- In healthy children, RSV is like a cold. It can be more serious for those in high-risk groups, such as
 - children more than 4 weeks premature at birth
 - twins or other multiple births
 - children younger than 2 years born with lung or heart disease
 - children who weighed less than 5.5 pounds at birth
 - school-aged brothers and sisters
 - children who attend day care
 - children who live in a crowded home environment
 - children with a family history of asthma
 - children who are exposed to tobacco smoke and other air pollutants.

RSV can be dangerous for premature babies—even those who did not require oxygen or positive pressure ventilation in the neonatal intensive care unit—because they do not have fully developed airways. In addition, they may not have received antibodies to help fight off RSV and other viruses because they were born early.

It is important that parents understand prior to discharge that it is essential during this first year of life to take specific precautions to decrease their baby's exposure to RSV. Precautions include continued proper handwashing and limiting their baby's exposure to crowds and school-aged children. Healthcare professionals should discuss day care arrangements with parents and other intended caregivers. For infants with severe chronic lung disease or heart defects, traditional day care may not be the best alternative. The healthcare professional can help parents explore other options (e.g., private day care).

RSV infections usually begin in the fall and end late in the spring. Unfortunately, RSV has several strains, so even if



a baby has had it once during RSV season, there is still a chance he or she can get it again. We each will have RSV several times in our lifetime.

RSV is very contagious. It can be spread through the air when a person coughs or sneezes. RSV also can spread by touching an object that has the virus on it. In fact, the virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours. Handwashing and proper cleaning are the best ways to help prevent the spread of RSV. Synagis (palivizumab) is an immunoglobulin injection that helps prevent RSV. Synagis is not a vaccine, but it helps to prevent or lessen the symptoms should the infant contract RSV. The National Perinatal Association and the American Academy of Pediatrics each offer dosing guidelines. Follow the dosing guidelines of your institution.

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Respiratory Syncytial Virus: Information for Parents

Respiratory syncytial virus, or RSV, is a virus that can make your baby sick. There are times of the year when your baby has more chance of being around people with the virus, usually from fall through spring (October through March). RSV can cause a mild cold, but it also can lead to a more serious sickness and a stay in the hospital. Babies born early and children younger than 2 years have the greatest risk for RSV. This is because babies born early, even those who did not need any help breathing while they were in the neonatal intensive care unit, do not have fully formed lungs. Also, their bodies may not be able to fight RSV and other viruses.

Symptoms of RSV

RSV usually causes a mild cold with a runny nose and fever. However, RSV also can make your baby very sick. Call your baby's provider right away if your baby has any of these symptoms:

- cough that does not go away, gets worse, or produces yellow, green, or gray mucus
- wheezing (a high-pitched whistling sound when breathing)
- trouble breathing or breathing faster than usual
- blue color on the lips or around the mouth
- high fever
- thick nasal discharge that is yellow, green, or gray.

There are ways to protect your baby. RSV is very easy to spread through coughing and sneezing. The virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours. During RSV season, wash your hands well and avoid crowded places (like malls and churches) and school-age children. Speak with your baby's provider about your day care plans. You might have to tell other people what RSV is and how dangerous it can be for your baby. Your baby's provider can help with this by giving you some handouts to help you discuss RSV with friends and family.

Handwashing and keeping your baby away from sick people is a good way to protect your baby. There also is a medication that can help lower your baby's risk of getting an infection. Synagis (palivizumab) is an immunoglobulin injection that helps prevent RSV. Synagis is not a vaccine, but it helps prevent hospitalization due to RSV. It is indicated for preterm infants (less than or equal to 35 weeks gestational age), children with bronchopulmonary dysplasia, and children with certain forms of congenital heart disease.

More resources can be found here:

www.nationalperinatal.org/rsv_awareness

www.infanthealth.org/rsv

www.littlelungs.com



Protecting your baby from **Respiratory Viruses:**

What parents need to know this RSV and flu season



RSV (Respiratory Syncytial Virus) and flu infections affect the lungs and can cause serious breathing problems for children and babies.

Certain diagnoses - like prematurity, chronic lung disease, heart conditions - can make children and babies more vulnerable for serious complications.



You can limit the spread of these viruses by washing your hands often with soap & water or using alcohol-based hand sanitizer.

The fewer germs your baby is exposed to, the less likely they are to get sick. Limit visitors. Avoid crowds. Stay away from sick people.



Immunizations save lives. Get your flu shots and stay up-to-date with your family's vaccinations, especially pertussis.

There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect the most vulnerable babies. Talk to your doctor.



www.nationalperinatal.org/rsv

Protecting Your Baby from Respiratory Viruses. © National Perinatal Association. Reprinted with permission.



Preventing Infections

Neonatal intensive care unit graduates have a higher rate of rehospitalization than the average newborn population. Common reasons for unexpected readmission are poor weight gain, feeding problems, dehydration, and upper respiratory infections. Healthcare providers should encourage parents to discuss with extended family and friends the precautions they should take to ensure the continued good health of their premature infant. Parents will need to ask for respect of their boundaries and support during preparation for discharge.

The best preventive measure is good handwashing. Everyone who interacts with the baby at home should learn about and practice good handwashing. Placing soap by all sinks and cleansers or hand gel in any rooms in which the baby may be cared for will help ensure good hand hygiene. You can use hand sanitizers to kill germs on hands when soap and water are not available, but keep them out of the reach of children and use as directed. Sanitizers containing high levels of alcohol can pose as a potential hazard. The American Academy of Pediatrics (AAP) recommends that parents use the same caution with hand sanitizer as with any other possibly poisonous item.

Cleaning

The baby's room, including the changing table, needs to be cleaned thoroughly. It is important to remove dust and dirt but avoid the use of harsh smelling cleaning products. Harsh cleaning solutions and insecticidal sprays can leave residual odors that may irritate or even harm the baby. All cleaning items should be stored out of the reach of children.

Sleeping

The baby should always be placed on his or her back for sleep. The National Institutes of Health (NIH) confirmed that studies demonstrate the benefits of infants sleeping on their backs. "Placing infants to sleep on their backs not only reduces their risk of Sudden Infant Death Syndrome, but also appears to reduce the risk for fever, stuffy nose, and ear infections" (NIH, 2003). Breastfeeding may reduce the risk of SIDS. See Safe Sleep for additional information on safe sleeping precautions.

Contact with Others

The AAP Committee on Environmental Health has identified these problems associated with secondhand smoke exposure: decreased lung growth, decreased lung function, and increased frequency of lower respiratory tract infections and respiratory symptoms. Research also clearly shows that exposure to smoke can cause ear infections and related hearing problems, increased incidence of hospitalization related to bronchitis or pneumonia, and increased risk for sudden infant death syndrome.

The following precautions will reduce the possibility of exposure to illnesses, especially during the cold season:

- not allowing smoking in the home, including vapor e-cigarette use
- asking anyone who is ill or feels that they may become ill to postpone their visit
- teaching everyone to do proper handwashing prior to touching the baby
- limiting the frequency—and duration—of guest visits (outside family included)
- limiting initial contact with small children (other than those who already live in the house).

RSV Prevention

Respiratory syncytial virus (RSV) is a very contagious virus spread easily through the air when a person coughs, sneezes, or touches an object that has the virus on it. In fact, the virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours. Handwashing and proper cleaning is the best way to help prevent the spread of RSV. Synagis is a medication that can be administered to help prevent RSV. Depending on the severity of certain underlying illnesses and the presence of risk factors, the baby may benefit from a series of monthly injections during RSV season.

Feeding

The AAP recommends exclusive breastfeeding for the first 6 months, followed by continued breastfeeding as complementary foods are introduced, with continuation of breastfeeding for 1 year or longer, as determined by



mother and infant. According to the AAP, “The risk of hospitalization for lower respiratory tract infections in the first year is reduced 72% if infants are breastfed exclusively for more than 4 months” (AAP, 2012). The severity of RSV infections and gastrointestinal infections also are greatly reduced in breastfed babies. See Breastfeeding Overview and Breastfeeding at Home for more information.

The AAP guidelines for storing breast milk are as follows:

- Wash hands before expressing or handling milk.
- Use only clean containers to store expressed milk. Use collection containers specific for the purpose of storing human milk. Do not use ordinary plastic bags or formula bottle bags for storing milk.
- Freshly expressed milk can remain at room temperature for up to 4 hours.
- Use refrigerated and not previously frozen milk within 48 hours.

Instruct the mother to label, date, and time the bottle of breast milk when it is expressed. Preferably, human milk should be refrigerated or chilled right after it is expressed. Acceptable guidelines for storing human milk are as follows:

- at room temperature for 4 hours (ideal) and up to 6 hours (acceptable)
- in a refrigerator for 48 hours (ideal)
- in a deep freezer for 6 months (ideal) and up to 12 months (acceptable).

Seal and chill breast milk for 4 hours, if possible, and discard breast milk that has been refrigerated for more than 72 hours. Milk can be kept in a freezer attached to a refrigerator for 1 month and for 3–6 months if kept in a zero-degree deep freezer. Milk can be thawed in the refrigerator or by swirling in a bowl of warm water (not shaken). Once thawed, milk must be used within 24 hours. Thawed milk should not be refrozen.

Be sure that the parents understand that heating milk in microwave ovens is not safe. Excess heat can destroy the important proteins and vitamins in the milk. If parents heat the milk in the storage container, they should

avoid rigid plastic bottles that have recycling plastic identification code 7 in the triangle to prevent exposure to bisphenol A (BPA), a potential hormone disrupter. For more information, visit www.niehs.nih.gov/health/topics/agents/sya-bpa.

If the parents will be using formula or supplementing, safe preparation is essential. Water used for mixing infant formula must be from a safe source. The local health department can help parents determine if tap water is safe to use for their baby’s bottles.

According to the U.S. Food and Drug Administration, “In most cases, it’s safe to mix formula using ordinary cold tap water that’s brought to a boil and then boiled for one minute and cooled” (U.S. Food and Drug Administration, 2013). Prior to discharge, teach parents how to follow mixing directions exactly, preparing the smallest quantity needed for a day. Allow parents to perform this skill and observe their technique well in advance of discharge. This is an important safety requirement, because underdiluted formula can lead to digestive problems, including dehydration. Overdiluted formula will not provide adequate nutrition or calories and can be dangerous. Too much water can disturb electrolyte balance and slow growth and development.

As with all food preparation, the area must be clean. Feedings should not be prepared near where parents change the baby’s diaper. Instruct parents to wash their hands before and after preparing milk or formula. There are several methods for cleaning nipples and bottles. Home sterilization kits are available or parents can wash bottles in the dishwasher.

The AAP recommends that once formula has been prepared and mixed, it must be consumed or stored in the refrigerator within 1 hour to prevent the growth of bacteria. Formula that has not been given to an infant can be stored in the refrigerator for up to 24 hours.

Prevention of Diaper Rash

The first sign of diaper rash is usually redness or small bumps on the lower abdomen, buttocks, genitals, and



thigh folds—surfaces that have been in direct contact with the wet or soiled diaper. This type of diaper rash is rarely serious and usually clears up in 3 or 4 days with appropriate care. Diaper rash can be prevented by changing wet diapers, especially stool-soiled diapers, every 2–3 hours. The stool-soiled diaper can irritate the skin. The baby’s bottom can be cleansed with plain water and a soft cloth. Allow the area to air dry before applying an ointment barrier and a clean diaper. Because yeast thrives in wet places, yeast infections are common. If the baby is not responding to routine diaper care or the parent suspects he or she has a yeast infection, they should contact the baby’s provider for advice on over-the-counter or prescription medications that may help.

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Preventing Infections: Information for Parents

Babies born early have more risk of needing to return to the hospital due to problems with feeding, weight gain, or respiratory infections. There are things you can do to lower these risks. The most important thing to remember is to wash your hands. Teach everyone who touches your baby about good handwashing. Be sure to have soap or hand gel by all bathroom sinks. It's a good idea to have hand gel in any room in which you will take the baby. Keep hand gel in purses and diaper bags, too.

Cleaning

Give the baby's room a good cleaning. Remove dust and dirt, but avoid the use of strong-smelling cleaners. Preterm babies don't like strong smells and because their lungs are still growing, those smells may be irritating. This is especially true for secondhand smoke.

Sleeping

Your baby should always be placed on his or her back for sleep. Sleeping on the back lowers the risk of sudden infant death syndrome as well as fever, stuffy nose, and ear infection.

Friends and Family

Do not let anyone who is sick or smokes near your baby. Ask anyone who is "coming down with something" to wait to visit. Limit the number of visitors and the length of time that guests stay. Secondhand smoke can harm your baby's lungs and increase your baby's chances of having respiratory infection, ear infection, and hearing problems. Don't take your baby to crowded areas (malls or church) until they have been home for several weeks. This is especially important during the winter months of respiratory syncytial virus (RSV) season (October through March).

RSV Prevention

There are ways to protect your baby. RSV is a respiratory virus that spreads easily from coughing and sneezing. The virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours. During RSV season, wash your hands frequently and avoid crowded places and school-age children. Speak with your pediatric provider about your day care plans, too.

There also is a medicine (Synagis) that can help lower your baby's risk of getting sick with RSV. Follow the appointment schedule given by your baby's provider.

Other Notes

Breast milk is the best food for your baby for the first 6 months of life. Breast milk helps your baby's immune system fight respiratory and stomach infections.

You may see redness or small bumps on the parts of your baby's bottom that have been near the wet or dirty part of the diaper. A poopy diaper can bother the skin. Diaper rash isn't serious and usually heals in 3 or 4 days with care. You can prevent diaper rash by changing wet and dirty diapers every 2–3 hours.

Clean your baby's bottom with plain water and a soft cloth. Let the area air dry before putting on an ointment and a clean diaper. If the diaper rash doesn't get better in 3–4 days, call your baby's provider. Ask about diaper care ointments you can buy at the store. They may want to give your baby medications that can help clear up diaper rash.

Step

8



Preparing to Take Your Baby Home

The American Academy of Pediatrics (AAP) has published discharge guidelines for high-risk newborn babies. Generally, babies may be ready for discharge when they

- are steadily gaining weight
- have a stable temperature in a regular/open crib
- can feed from a bottle or the breast without difficulty breathing or other problems
- have mature and stable heart and breathing ability.

The baby will undergo some or all of the following before discharge: hearing test, eye exam for retinopathy of prematurity, metabolic screening blood test, a car seat study, immunizations/respiratory syncytial virus prevention, and assessment for special home equipment and home care.

Preparing for discharge begins the day the baby is admitted to the neonatal intensive care unit. It is important for parents to actively participate in direct care of their baby as early as possible during the baby's hospital stay. Parents should be considered part of the healthcare team because their active involvement in daily care improves outcomes and may decrease length of hospital stay. Before discharge, parents and other primary caregivers will need instructions on

- feeding (for mothers planning to breastfeed, it is best to provide a written feeding plan with instructions on transitioning to full breastfeeding)
- basic infant care (bathing, skin care, temperature)
- infant cardiopulmonary resuscitation (recommended prior to discharge)
- symptoms of illness
- safe sleep positioning
- car seat safety
- use and care of special medical devices and equipment
- how to give medications and vitamins
- any special procedures for care (suctioning, special dressing changes, etc.)
- basic home safety.

Preparing the Home, Friends, and Family for Baby's Homecoming

As the family prepares their home for their new baby, they should look for sturdy furnishings and equipment. Be sure that all products meet current safety standards. This is especially important when borrowing or buying second-hand items.

Exposing pets to a piece of baby's clothing or blanket before the baby comes home may help the pet become familiar with the baby's scent. Any direct contact the baby has with the family pet should be limited until the baby is older and the pet has become comfortable with the newest member of the family.

Anyone caring for a baby should know the importance of safe sleep positioning. The National Safe Sleep campaign recommends that all babies be positioned on their backs when put down for sleep (see Safe Sleep in Step 6). Studies demonstrate that the *back-to-sleep* position significantly reduces the incidence of SIDS. A baby should only have tummy time when he or she is awake and a caregiver is there to observe.

The AAP Committee on Environmental Health has identified the following problems with secondhand smoke exposure:

- decreased lung growth
- decreased lung function
- increased frequency of lower respiratory tract infections and respiratory symptoms.

Secondhand smoke is bad for babies. Research clearly indicates that exposure to smoke may increase an infant's risk for ear infections and related hearing problems. In addition, exposure to secondhand smoke may increase incidence of hospitalization related to bronchitis and pneumonia and risk for sudden infant death syndrome (SIDS).



Preparing for When the Baby Cries

Caregivers should have a plan in place for times when the baby is crying or fretful. It is smart for new parents to ask for help from a trusted family member or friend when they are feeling overwhelmed or exhausted while caring for their baby. Many babies have an increase in crying episodes starting at 2 weeks and peaking at 8 weeks and often getting better by 3–4 months. Some of these crying episodes can be resistant to soothing. It is important to make sure the baby is not sick. When a baby is sick, the crying usually is associated with poor feeding, fever, vomiting, or diarrhea. If a baby has long bouts of crying, the parent should make an appointment to see the baby's doctor. The baby's doctor will check to see if the crying is due to an illness. If the doctor says the baby is healthy, it usually means that the crying pattern is a normal part of infant development. It is very frustrating for the parent when a baby continues to cry without being able to soothe the baby. It is important not to get angry or lose control. It is best to put the baby down and walk away if you are feeling frustrated.

Any family member or friend caring for the baby should be told about the episodes of crying and be prepared to gently care for the infant without losing their temper. This type of crying often is called the Period of PURPLE Crying. Please visit <http://purplecrying.info/what-is-the-period-of-purple-crying.php> to receive more information on this topic and have all caregivers listen to the video.

Shaken Baby Syndrome

Shaken baby syndrome (SBS) is a form of abusive head trauma and is the term used to describe the constellation of signs and symptoms resulting from violent shaking or impacting of the head of an infant or small child. Although shaking an infant can cause neurologic injury, blunt impact or a combination of shaking and blunt impact also can cause injury. In recognition of the need for broad medical terminology that includes all mechanisms of injury, the American Academy of Pediatrics (AAP) 2009 policy statement, "Abusive Head Trauma in Infants and Children," recommends use of the term *abusive head trauma* (AHT) by medical professionals to describe an inflicted injury to the head and its contents. The AAP

supports prevention efforts that reduce the frequency of AHT and recognizes the utility of maintaining the use of the term shaken baby syndrome for prevention efforts.

Because there is no central reporting registry for cases and a lack of standardized data, statistics on SBS/AHT are not available on a national level. However, it is recognized as the most common cause of mortality and accounts for the most long-term disability in infants and young children. Based on a North Carolina research project published in the *Journal of the American Medical Association* in 2003, approximately 1,300 U.S. children experience severe or fatal head trauma from child abuse every year (Keenan et al., 2003). The same study revealed that approximately 30 per 100,000 children younger than 1 year suffered inflicted traumatic brain injuries.

What Can Happen to a Shaken Baby?

Shaking an infant can cause bleeding within the brain or the eyes. The degree of brain damage depends on the amount and duration of the shaking and the forces involved in impact of the head.

There are various signs and symptoms of SBS/AHT that range on a spectrum of neurological alterations from minor (irritability, lethargy, tremors, vomiting) to major (seizures, coma, stupor, death). These neurological changes are due to destruction of brain cells secondary to trauma, lack of oxygen to the brain cells, and swelling of the brain. Extensive retinal hemorrhages in one or both eyes are found in the vast majority of these cases. Subdural hematoma, brain swelling, and retinal hemorrhages are accompanied in some, but not all, cases by bruising of the part of the body used as a "handle" for shaking. Fractures of the long bones and ribs also may be seen in some cases. In many cases, however, there is no external evidence of trauma either to the head or the body.

The consequences of less severe cases may not be brought to the attention of medical professionals and may never be diagnosed. In most severe cases, which usually result in death or severe neurological consequences, the child usually becomes immediately unconscious and



suffers rapidly escalating, life-threatening central nervous system dysfunction.

Any of these injuries can lead to severe disability or death. If you suspect a child has been shaken, seek medical attention immediately. This could be the difference between life and death.

Common symptoms of SBS include lethargy, extreme irritability, decreased appetite, vomiting for no apparent reason, grab-type bruises on arms or chest (rare), no smiling or vocalization, poor sucking or swallowing, rigidity or posturing, difficulty breathing, seizures, head or forehead appears larger than usual, inability to lift head, and inability of eyes to focus or track movement or unequal size of pupils.

A significant proportion of cases of SBS/AHT (about 25%) die during the initial phase of hospitalization. The survivors do very poorly as shown in a number of studies. In a study done in Canada, only 7% of the survivors were reported as “normal,” 12% were in a coma or vegetative state in the hospital, 60% had a moderate or greater degree of disability, 55% had lasting neurologic deficits, 65% had visual impairments, and 85% would require ongoing multidisciplinary care for the rest of their lives (Ornstein & Dipenta, 2011). The negative effects following hospital discharge are likely to be underestimated because it often takes several months or even years before neurologic and developmental difficulties become apparent.

Activities involving an infant or a child such as tossing in the air, bouncing on the knee, placing a child in an infant swing or jogging with them in a back pack do not cause the brain, bone, and eye injuries characteristic of shaken baby syndrome.

What Population Is at Highest Risk?

Babies younger than 1 year (with the highest risk period at 2–4 months) are at greatest risk for SBS/AHT, because they cry longer and more frequently and are easier to shake than older and larger children. Male infants are at a slightly greater risk than females.

How Can SBS/AHT Be Prevented?

It is important to note that SBS/AHT is preventable. Parents should share the message of the dangers of shaking with all who care for their infant or child, including spouses, their own parents, siblings, day care providers, and others. Parents need to let those caring for the infant know that it is OK to call for help when needed.

Most cases involving shaking injuries occur when a frustrated care giver loses control with an inconsolable crying baby. It is important to realize just saying “don’t shake a baby” is not enough; a plan of action or suggestions to deal with the situation need to be offered. Parents and other care providers need assurance that allowing a baby to cry is OK if all of their needs have been met.

There is evidence that infant crying is the most important stimulus for SBS/AHT. The Period of PURPLE Crying program approaches SBS prevention by educating parents about normal infant development and, specifically, about crying patterns to be expected in normal infants based on scientific evidence about infant crying. Information about the Period of PURPLE Crying is available at <http://PURPLEcrying.info/nann>.

For an overview of various prevention programs addressing SBS/AHT, please see <https://www.cdc.gov/violenceprevention/childmaltreatment/Abusive-Head-Trauma.html>

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Preparing to Take Your Baby Home: Information for Parents

Babies are ready to go home when they

- are gaining weight regularly
- keep a normal temperature in a regular crib
- can feed from a bottle or the breast without breathing or other problems
- have regular heart beat and breathing (no periods of stopped breathing [known as *apnea*] or slow heart rate [known as *bradycardia*]).

To get ready for your baby to come home, help care for your baby as soon as possible during your baby's hospital stay. Before going home, you and others who will take care of the baby will need to learn about

- feeding
- voiding and stooling patterns
- basic care (baths, skin care, taking temperature)
- safety at home
- infant cardiopulmonary resuscitation (CPR)
- signs of illness and protecting your baby from infection
- sleep positioning
- car seat safety
- use and care of special equipment
- giving medicine
- other special care that your baby might need.

Before leaving the hospital, your baby may have some or all of the following

- eye exam
- hearing test
- car seat study
- critical congenital heart disease and jaundice screening and eye examinations
- immunizations and respiratory syncytial virus prevention
- assessment for special home equipment and home care.

Your Home

To prepare for your baby to come home, give your baby's room a thorough cleaning. Remove dust and dirt, but avoid the use of strong-smelling cleaning products. Premature babies don't like strong smells, and their lungs

are still growing. Don't let anyone who is sick or smoking around your baby. If you have a pet, keep the pet away from the baby until the baby is older and the pet has become used to this newest family member.

The room should be comfortable—not too hot or stuffy. Look for sturdy furniture and baby care items. Be sure that they meet today's safety rules. This is especially important if you are borrowing or buying used items.

The baby always should be placed on his or her back for sleep. This position is safest and decreases the chance of sudden infant death syndrome (SIDS). When you are with the baby and he or she is awake, you can place your baby on his or her tummy to help make his or her back and neck muscles strong.

Have a plan for times when the baby is crying or fretful. Your baby may cry more at times, such as at 8–12 weeks. This kind of crying is not because the baby is sick or you are not a good parent. It is easy to become angry when the baby won't calm down when you try to comfort him or her. Reach out to trusted family and friends who can help when you are tired or need a break.

About Shaken Baby Syndrome

What is shaken baby syndrome?

Shaken baby syndrome happens from violent shaking of the head of an infant or small child.

What can happen to a baby that is shaken?

Shaking an infant can cause bleeding in the brain or the eyes. The degree of brain damage varies. Any of these injuries can lead to severe disability or death. If you suspect a child has been shaken, get medical help right away. This could be the difference between life and death.

What are the symptoms of shaken baby syndrome?

- Decreased muscle tone
- Crying all of the time
- Poor feeding or vomiting for no reason



- No smiling or baby talk
- Poor sucking or swallowing
- Stiffness or posturing
- Difficulty breathing
- Seizures
- Head or forehead appears larger than usual or soft spot on head appears to be bulging
- Not able to lift head

What population is at the highest risk?

Babies who are younger than 1 year (with the highest risk period at 2–4 months) are at greatest risk. Babies can cry longer and more often at this age. Male infants are at a slightly greater risk than females.

How can shaken baby syndrome be prevented?

It is important to know this is preventable. Parents should share the message of the dangers of shaking with all who care for their infant or child. This includes husbands, grandparents, older children, day care providers, and others who care for your baby. Parents need to let those

caring for the infant know that it is OK to call for help when needed.

Most cases involving shaking injuries occur when a frustrated caregiver loses control with a crying baby. It is important to realize that just saying “don’t shake a baby” is not enough; a plan of action or suggestions to deal with the situation need to be offered. Parents and other care providers need assurance that allowing a baby to cry is OK if all of their needs have been met.

Information about the Period of PURPLE Crying is available in the list of resources at <http://PURPLEcrying.info/nann> and <http://purplecrying.info/what-is-the-period-of-purple-crying.php>



Breastfeeding at Home: Information for the Healthcare Team

Prior to discharge from the neonatal intensive care unit, an individualized feeding plan should be discussed and written out for the family. The infant's gestational age, feeding endurance, and the mother's milk supply should be considered. A breastfeeding assessment, which includes a pre- and postweight, will allow the practitioner to provide guidelines for supplementation after breastfeeding (Meier, Johnson, Patel, & Rossman, 2017; Spatz & Edwards, 2016).

Parents benefit from receiving realistic expectations related to breastfeeding after discharge and need a clear understanding of the process for transitioning their infant from bottle feeding with expressed breast milk (EBM) to full feedings at the breast (Callen & Pinelli, 2005; Spatz & Edwards, 2016). The nurse should explain to parents that many preterm infants are discharged home with a feeding plan that includes alternating breastfeeding with bottle feeding while offering a supplement of fortified EBM to the infant after each breastfeeding session. Long-term fortification of EBM often is necessary to promote adequate growth and development of the preterm infant who has increased nutritional demands compared with the full-term infant (Mangili & Garzoli, 2017).

The length of time needed to fortify EBM varies from infant to infant and must be done on an individual basis with close monitoring of the infant by the pediatrician. Readiness to decrease fortification is done by evaluating the infant for sustained adequate growth, the ability to take in adequate milk volume, and having lab values within normal limits. Depending on the infant's gestational age at birth, fortification may be indicated for 2–3 months or, in extreme cases, up to a year following discharge. For the infant who is nursing well but has a continued need for fortification, the healthcare provider may suggest a concentration of EBM to 24, 26, or 30 calories to maximize nutrition in a limited number of bottles.

A revised individual feeding plan should be assessed within 1–2 weeks of discharge by the pediatrician or a board-certified lactation consultant. The mother should be informed that with close follow-up, most preterm infants will gradually transition to full breastfeeding shortly after their due date.

The healthcare team and parents should discuss options for providing supplementation. Options include supplementing at the breast with a supplemental nursing system (SNS) or a feeding tube, or supplementing by bottle. If supplementation is provided by bottle, the nurse, lactation consultant, or feeding specialist should discuss bottle feeding system options. Wide-based nipples, which often are recommended for the breastfed full-term infant, may not be appropriate for the preterm infant after discharge. In general, if it takes longer than 30 minutes to complete the bottle feeding, the infant may need a different bottle system. A standard or narrow-based nipple may be more appropriate during the early weeks following discharge. The mother may decide to transition to a wide-based nipple at a later date when the infant has gained additional weight and endurance.

Alternative options, such as use of a nipple shield during breastfeeding or supplementation with an SNS, should be considered on an individual basis with close outpatient follow-up to monitor weight gain. A nipple shield, which is frequently discouraged for the full-term infant, has been shown to allow the preterm infant to maintain better attachment to the breast and increase milk transfer while decreasing infant fatigue. The parents should demonstrate all skills related to infant feedings and use of alternative devices prior to their infant's discharge home.

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Breastfeeding at Home: Information for Parents

Many mothers of premature and special care babies feel a little nervous about how they will manage breastfeeding once their baby is discharged home. To help with this transition, we encourage you to spend as much time in the neonatal intensive care unit as you are able during the final weeks of your baby's hospital stay. The healthcare team will help you create a feeding plan and determine whether you need to add any supplements to your milk to help your baby grow. The team also will discuss ways to tell if your baby is drinking enough milk while feeding at the breast. Your NICU's lactation consultant is a wonderful resource to use when breastfeeding or pumping. Ask your nurse to schedule an appointment as soon as your baby is ready to start breastfeeding, several days prior to his or her discharge, and any time in between when you need additional support.

Breastfeeding begins with lots of skin-to-skin (STS) time and some nuzzling. Nuzzling is the suckling by a baby at the breast without taking more than a few drops of milk. When your baby is ready to begin nuzzling, the nurse will ask you to pump immediately before STS to empty your breasts. Once your baby is placed STS, if he or she shows signs of interest in suckling, you can allow your baby to attach to the breast. When your baby is ready to feed from a fuller breast and drink milk, your doctor or nurse should schedule an appointment with the lactation consultant to assist you in starting to breastfeed. In some situations, if your baby is able to feed by mouth, he or she can begin breastfeeding. This may happen at 34 weeks gestational age. It may take some time because your baby has to learn how to coordinate their suck and swallow in a rhythmic pattern to move milk out of the breast. As your baby gets closer to his or her due date, your baby will have more endurance and coordination and drink more milk when feeding at the breast.

Breastfeeding is an important developmental task for your baby. Because your baby is relaxed when in your arms, he or she may fall asleep before taking a full feeding. Don't give up! Over time your baby will drink as much milk

when feeding from the breast as he or she does when feeding from the bottle.

Your baby's healthcare provider may recommend that you fortify your breast milk with a powdered formula when you bottle feed. Discuss the types of fortification that are available and be sure to ask about the risks and benefits of fortification with your baby's healthcare provider. The growth of your preterm infant in his or her first year of life requires extra nutrients such as protein, calcium, and phosphorus for bone and brain development. Your pediatric providers can help you monitor your baby's growth and feeding requirements. Do not stop any additives to your baby's feeding without first discussing with your healthcare provider.

The journey toward full breastfeeding takes time. Be patient with yourself and your baby. Most babies who are born premature are not ready to fully breastfeed until they are 1–2 weeks past their due date. Term babies who have been very ill or have had surgery may need extra help to learn to breastfeed. This means your baby may be 41–42 weeks gestation before he or she is breastfeeding without the need for additional supplements by bottle.

Pumping and Breastfeeding

It is natural to think that once your baby starts to feed at the breast, you can stop pumping. In fact, most mothers cannot wait to stop pumping. Remember, your baby may not be strong enough to empty your breast, and you have worked so hard to get your milk supply where it is. It is important to continue to pump your breasts after your baby has nursed to make sure that your breasts are empty. This will make sure you continue to make enough milk. Stopping too quickly may cause your milk to dry up.

Before you stop pumping, make sure your baby is getting enough milk when nursing and gaining weight. During the first week at home you may be pumping six to seven times per day in addition to breastfeeding. If your baby gains weight that first week, talk to your lactation consultant or your baby's provider to help you taper off pumping



in a manner that will work for you and your baby and talk about any concerns you have with breastfeeding.

Some mothers choose to continue to pump and bottle feed their expressed milk instead of breastfeeding. When bottle feeding breast milk there is some loss of nutrients due to the storing and warming of the milk. Discuss this option with a lactation consultant to learn how to preserve as many nutrients as possible. If you choose to pump only, you may want to schedule your pumping session 30 minutes before your baby's feeding time. This will allow you to feed fresh breastmilk several times per day while at the other feedings you will want to feed your baby your oldest frozen milk.

Your nurse will provide you with outpatient resources and support groups to help you with breastfeeding after discharge. Remember to ask for the name and contact information of a board certified lactation consultant who can answer questions or provide one-on-one assistance.

How to Tell If Your Baby Is Getting Enough Milk

The following signs indicate that your baby is getting enough milk when breastfeeding:

- Your baby wakes up on his or her own every 2–3 hours.
- Your baby latches and stays on the breast sucking and swallowing for more than 10 minutes before falling asleep.
- Your baby sucks and swallows in a nice rhythmic pattern, taking 8–10 bursts of sucking and swallowing before pausing for 5–10 seconds.
- You can hear swallowing.
- Your breast softens during and after breastfeeding.
- When you pump after breastfeeding, you remove less milk than you do if you did not breastfeed.
- Your baby is having 6–8 wet diapers and several dirty diapers every day.
- Your baby is gaining weight—6–8 ounces per week—and growing well.

If your baby does not wake up on his or her own to feed, has a weak suck, or falls asleep after only 5 minutes at the breast, it is likely that he or she is not drinking enough milk during the breastfeeding and will need a supplemental bottle after nursing. Be sure to discuss your concerns with your baby's healthcare provider if your baby is not feeding well.

Diet and Breastfeeding

It takes energy to make breast milk. You will need to get at least 1,500–1,800 calories per day while breastfeeding. Eating a healthy balanced diet, similar to what was recommended when you were pregnant, is important. Continue to take your prenatal vitamins and drink plenty of fluids. Do not plan on dieting for at least 2 months after having the baby. There are many resources on dieting while breastfeeding. One resource can be found at <http://kellymom.com/nutrition/mothers-diet/mom-weightloss>.

Many women have questions related to eating fish while pregnant or breastfeeding due to concerns about mercury exposure. In January 2017, the U.S. Food and Drug Administration and U.S. Environmental Protection Agency issued advice on eating fish with an easy-to-use reference chart. They list three categories: best choices, good choices, and fish to avoid. The advice recommends 2–3 servings of low-mercury fish per week or 8–12 ounces per week. Lower-mercury fish are the most commonly eaten fish and include shrimp, pollock, salmon, canned light tuna, tilapia, catfish, and cod. Higher-mercury fish include tilefish from the Gulf of Mexico, shark, swordfish, orange roughy, bigeye tuna, marlin, and king mackerel.

Resources

Eating Fish: What Pregnant Women and Parents Should Know www.fda.gov/Food/FoodborneIllnessContaminants/Metals/ucm393070.htm

Advice about Eating Fish: From the Environmental Protection Agency (EPA) and the Food and Drug Administration (FDA); Revised Fish Advice. www.federalregister.gov/documents/2017/01/19/2017-01073/advice-about-eating-fish

Step

9



Home Medical Equipment: Apnea Monitor (Cardiorespiratory Monitor)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?

Your baby is at risk to stop breathing, take too long to take the next breath, or have a heartbeat that is too fast or too slow. You will hear an alarm if your baby's breathing or heartbeat is not safe.

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

Other Emergency Numbers: _____

Important Things to Remember

- Apnea monitors *do not* prevent sudden infant death syndrome (SIDS). Always use safe sleep practices (Put your baby on his or her back to sleep and keep your baby alone on a firm crib mattress with his or her face uncovered; do not overdress your baby for sleep and keep toys and stuffed animals out of the crib).
- Always use the apnea monitor when your baby is asleep, takes a nap, while he or she is riding in the car, or when you are busy. Don't leave the monitor at home.
- Always check on your baby when you hear the monitor alarm. Tap your baby's foot or rub your baby's chest to help remind your baby to breathe or help to raise the heartbeat. If your baby is not breathing, shout for help, start cardiopulmonary resuscitation (CPR), and call emergency medical services (EMS) or 911 right away.
- False alarms may sound if the monitor belt around your baby's chest is too loose.
- Call your EMS, telephone, and electric companies to let them know that your baby uses an apnea monitor. This is important so if there is a power outage or emergency, you will be on a priority list for help.
- The equipment company may visit your home to get (download) information from the apnea monitor about your baby's breathing and heartbeat.
- Do not stop using the apnea monitor until your baby's provider tells you it is safe to do so.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It's always OK to ask for help! Make sure you ask your baby's healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Home Medical Equipment: Feeding Pump

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?

- Some babies who need extra nutrition or cannot swallow require special feeding tubes. A nasogastric tube (NG tube) is inserted into the nose and goes directly down into the stomach. A gastrostomy tube (G-tube) goes directly into the stomach. A jejunostomy tube (J-tube) goes past the stomach and directly into the top part of the small intestine (called the *jejunum*). Proper nutrition helps your baby to have the best health and healing abilities.
- A *feeding pump* is a small electric or battery-powered machine that sends formula or breast milk (liquid food) through a tube that connects to your baby's feeding tube.
- The feeding pump controls how much of the food is given, how fast, and for how long.

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

Other Emergency Numbers: _____

Important Things to Remember

- Always follow the directions for mixing your baby's formula or breast milk.
- Always follow the directions given by the vendor of the feeding pump.
- Always follow the schedule for your baby's feedings. A *bolus feeding* is a large amount of feeding given at regular meal times over a set amount of time (usually 20–30 minutes). A *continuous feeding* is given slowly (usually overnight); small amounts of food go through the feeding pump each hour.
- Some babies who need a feeding pump are also able to eat by mouth. Be sure to talk with your baby's provider to check if it is safe for your baby to take any food or liquid by mouth.
- Do not stop using the special formula or feeding pump until your baby's provider says it is safe to do so.
- Check with your insurance company to see if they can arrange to have the formula sent directly to your house. Make sure you have extra supplies and formula on hand so you don't run out.
- Call your emergency medical services, telephone, and electric companies to let them know that your baby uses a feeding pump. This is important because if there is a power outage or emergency, you will be on a priority list for help.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It's always OK to ask for help! Make sure you ask your baby's healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Home Medical Equipment: Nebulizer (Aerosol or Inhalation Treatment)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?

- Nebulizer treatments help prevent or treat breathing problems.
- A *nebulizer* is a small electric or battery-powered machine that turns liquid medicine into a mist that will help your baby breathe more easily.
- A face mask or mouthpiece sends the misted medicine to your baby so he or she can breathe the medicine right into the lungs.

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

Other Emergency Numbers: _____

Important Things to Remember

- Wash your hands before giving your baby a nebulizer treatment.
- Get together all needed supplies (a face mask works best for children younger than 3 years old).
- Always follow the directions given by the vendor of the nebulizer.
- Hold your baby upright and support his or her head and neck, or place your baby in an infant seat.
- Always give your baby his or her breathing medicine(s) using the directions on the bottle or container given to you by the pharmacy. Never mix medicines unless specifically told to do so by your baby's providers.
- Stay with your baby during the nebulizer treatment and try to keep your baby calm so that he or she can breathe in most of the medicine.
- When the treatment is finished, take off your baby's face mask and turn off the nebulizer. Your baby's breathing should be easier. Call your baby's provider if you're worried.
- Wash your hands and clean the equipment following the vendor's instructions.
- Do **not** stop using the nebulizer or change the times when you give the treatments unless your baby's provider tells you it is safe to do so.
- Call your emergency medical services, telephone, and electric companies to let them know that your baby uses a nebulizer. This is important so that if there is a power outage or emergency, you will be on a priority list for help.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It's always OK to ask for help! Make sure you ask your baby's healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Healthy Children
www.healthychildren.org

Kids Health
www.kidshealth.org



Home Medical Equipment: Ostomy Supplies

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?

- Your baby has a stoma (also called *ileostomy* or *colostomy opening*) on his or her belly that lets fecal waste (poop/stool) leave the intestine.
- An *ostomy bag* (also called a *pouch*) covers the stoma and collects the waste.

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

Other Emergency Numbers: _____

Important Things to Remember

- Get together all needed supplies before starting ostomy care (emptying or changing pouch).
- Wash your hands.
- Follow the package directions to ready the pouch and skin barrier to put on your baby.
- Wear gloves during ostomy care.
- Place your baby on his or her back.
- Warm the skin barrier by placing it under your baby while you prepare his or her skin.
- Gently take off the old ostomy bag. (If needed, use a warm, damp cloth to loosen stickiness.)
- Clean the skin around the stoma with warm water only. Your baby's skin is delicate, so avoid use of products that contain powder or alcohol.
- Dry skin well with a clean, soft towel.
- Check your baby's skin for color, breakdown, and signs of infection. (Is it swollen, firm, or tender to touch? Is there any redness or a rash?) Check the stoma to see if it is getting larger or smaller. Call your baby's care provider if you're worried.
- Follow the package directions to put on the new stoma bag and close the clamp.
- Empty the old bag into the toilet or diaper pail.
- Take off gloves and wash your hands.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It's always OK to ask for help! Make sure you ask your baby's healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Healthy Children
www.healthychildren.org

Kids Health
www.kidshealth.org



Home Medical Equipment: Oxygen

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?

- Oxygen is a gas that provides energy for every organ in the body. Room air is 21% oxygen.
- Oxygen is also a drug and must be ordered by a doctor or nurse practitioner.
- Extra oxygen from the nasal cannula will help your baby breathe easier, feed better, and grow.
- You will be going home with a pulse oximeter (pulse or oxygen saturation monitor).

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

Other Emergency Numbers: _____

Important Things to Remember

- Complete cardiopulmonary resuscitation (CPR) teaching, as well as monitor and equipment training.
- Stay overnight with your baby—use the equipment you will be going home with and care for your baby for at least 24 to 48 hours before going home.
- Prepare for a smoke-free home, so that your baby can breathe easy.
- Do not let anyone smoke in the house, the car, or anywhere around your baby or the oxygen tanks.
- Oxygen burns easily. It cannot be around an open flame. Keep the oxygen tanks and tubing at least 6 to 10 feet away from candles, fire or burners, radiators, fireplaces, or heaters.
- Do not use grease, oil, rubbing alcohol, powders, petroleum jelly, or spray cans near your baby on oxygen or the equipment.
- Keep the door to the baby's room open.
- Use stands to keep the oxygen tanks on a flat surface. Be careful that the tanks don't tip over on anyone.
- Call your emergency medical services, telephone, and electric companies to let them know that your baby uses a pulse oximeter (pulse ox or oxygen saturation monitor). This is important so that if there is a power outage or emergency, you will be on a priority list for help.
- Always check your baby when you hear the pulse monitor alarm. If your baby is blue or having breathing problems, be sure the oxygen tank is on, that oxygen is flowing out of the cannula, and that prongs are in your baby's nose. If your baby is not breathing, shout for help, start CPR, and call emergency medical services (EMS) or 911 right away.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org



Home Medical Equipment: Pulse Oximeter (Pulse Ox, Oxygen Saturation Monitor)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

Why does my baby need this equipment?

- Your baby needs a pulse oximeter to monitor the amount of oxygen in his or her blood (oxygen saturation).
- A small, lighted probe attached to your baby's foot or hand will measure the amount of oxygen in his or her blood.
- You will hear an alarm if the amount of oxygen in your baby's blood becomes too low.

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

Other Emergency Numbers: _____

Important Things to Remember

- Always use safe sleep practices. (Put your baby on his or her back to sleep in crib and keep him or her alone in the crib on a firm mattress with his or her face uncovered; do not overdress your baby for sleep, and keep toys and stuffed animals out of the crib.)
- Always use the pulse oximeter when your baby is asleep, takes a nap, while he or she is riding in the car, or when you are busy. Don't leave the monitor at home.
- False alarms may sound if your baby is moving or the lighted probe becomes loose. Make sure the monitor is hooked up the right way to decrease false alarms.
- Always check on your baby when you hear the pulse oximeter alarm. If needed, tap your baby's foot or rub your baby's chest to help remind your baby to breathe or help raise the heartbeat. Check to make sure their nasal cannula oxygen is still in their nose if the alarm goes off. If your baby is not breathing, shout for help, start cardiopulmonary resuscitation (CPR), and call emergency medical services (EMS) or 911 right away.
- Call your EMS, telephone, and electric companies if your baby also uses oxygen. This is important so that if there is a power outage or emergency, you will be on a priority list for help.
- Do **not** stop using the pulse oximeter until your baby's provider tells you it is safe to do so.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It's always OK to ask for help! Make sure you ask your baby's healthcare provider who you can call for help, questions, and concerns.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Home Medical Equipment: Tracheostomy

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need special home medical equipment (also called durable medical equipment) to help keep him or her well.

What is a tracheostomy?

A tracheostomy is surgically created so air enters the windpipe and lungs directly through the neck instead of going through the nose and mouth. This causes some changes in how the body works.

Vendor Information

A company, also called a vendor, will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

Other Emergency Numbers: _____

Important Things to Remember

- Air now bypasses the voice box, or vocal cords, so your baby may or may not be able to make voice noises.
- Breathing through the mouth and nose filters, warms, and moistens air. Your baby will need extra moisture to keep the airway from drying out and to keep mucus thin.
- You can give moisture through a “trach collar.” This is a humidifier with flexible tubing and a mask that fits loosely over the tracheostomy.
- You can also use an “artificial nose” that collects the moisture and heat that your baby breathes out. The “nose” puts the heat and moisture back in with every breath.

Stoma Care

The stoma is the opening in the neck. It is very important to keep the skin around the tracheostomy clean and dry.

- Look at the skin for any red or irritated areas.
- Clean this area at least twice a day; more frequent cleaning may be needed.
- Wash hands with soap and water before performing any cares.
- Use cotton-tip applicators or lint-free gauze to clean around the stoma.
- Use a mild, fragrance-free soap and water.
- Use a rolling motion, starting at the stoma and working outward. This will prevent you from pushing dried secretions or soap into the tracheostomy.
- Rinse with water and then dry the area completely.

Suctioning

Suctioning is a way to keep the airway clear. Suction the tracheostomy if you notice that your baby is

- breathing faster or harder
- tugging or pulling the skin around and under the ribs with each breath
- pale, gray, or blue color especially around the mouth or has a decreased oxygen saturation
- frightened or anxious looking
- bubbling mucus out of the tracheostomy tube
- making rattling or whistling sounds
- refusing to eat or drink.



In children with no evidence of secretions, a minimum of suctioning, at morning and bedtime, to check for patency of the tube is recommended.

Suction Technique

To suction your baby you need to

1. Wash hands with soap and water before performing any cares.
2. Remove the catheter from the package, taking care not to touch the tip of the catheter.
3. Turn on the suction machine and attach the catheter to the tubing.
4. Insert the catheter into the trach tube to the premeasured depth.
5. Place your thumb over the suction port.
6. Withdraw the catheter using a rotating motion.
7. Limit suction time to less than 5 seconds.
8. Suction catheter size.
9. Suction catheter insertion depth.

Changing the Tracheostomy Tube

If the tube is plugged it may need to be changed. Your team recommends a routine change every day. Have all of your supplies ready before you begin to change the tube.

1. Wash hands with soap and water before performing any care.
2. Put the obturator into the clean tube.
3. Attach a tracheostomy tie to one side of the neck plate.
4. Lightly coat the tip of the tube with a water-soluble lubricant.
5. Use a roll under your baby's shoulders to extend the neck.
6. Keep the head straight.
7. Hold the old tube in place while the trach tie is loosened.
8. Remove the old tube.
9. Put the clean tube in using a downward curving motion.
10. Remove the obturator and secure the trach tie to the other side of the tube.

Cleaning the Reuseable Supplies

- Use warm, soapy water to clean supplies. Rinse well and air dry thoroughly.

Keeping Your Baby Safe and Healthy

- Make sure all who come in contact with your baby washes their hands and do not have any symptoms of illness.
- Your baby should not be around anyone who smokes. Smoke will irritate the airway and lungs and make it hard to breathe.
- Keep your home free from lint, dust, and fine pet hair.
- Do not use powders, strong cleaning products, or aerosol sprays in the same room with your baby.
- Choose clothes that do not block the tracheostomy. Avoid high necklines and clothes that shed fibers or lint.
- Do not have toys with small parts that could fit inside the tracheostomy.
- Bath water must be shallow to avoid splashing. Water will go directly to the lungs if it gets in the tracheostomy. When your baby is sitting up, make sure the tracheostomy isn't blocked.

Signs of Illness

Call your health care provider if your baby has

- a fever above 101 °F
- mucus that is yellow or green or smells bad



- blood in secretions
- breathing problems that do not improve after suctioning.

Signs of an Emergency

- Make sure all local emergency responders (e.g., fire, police, ambulance), and electric, gas, water, phone companies know of your baby's condition.
- Keep a list of emergency phone numbers including the local emergency room and your pediatrician.
- Ensure any family members or friends that take care of your baby know who to call and what to do in an emergency.
- An emergency can happen at any time. If the tracheostomy is not working your baby will not be able to get enough air in and out of the lungs. In an emergency call out for help, begin CPR, and call 911. Some common emergencies are:
 - inability to clear the tube with suctioning (it is probably plugged)
 - inability to replace the tracheostomy tube

Keep the following equipment with you at all times, including leaving your home:

- suctioning equipment (suction machine, catheters, saline)
- tube change supplies (extra trach tubes with obturators) (same size and one size smaller), lubricant, tracheostomy ties
- self-inflating resuscitation bag and mask.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and ask questions if you have concerns about your baby.



Medications at Home: Albuterol (Proventil, Ventolin)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Albuterol is used to prevent and treat shortness of breath, wheezing, and chest tightening caused by obstructive lung disease (chronic lung disease).
- This fast-acting, emergency drug (rescue medicine) acts to relax and open the airways of the lungs.

How, how much, and when is this medication given to my baby?

- Albuterol is given with a special machine called a *nebulizer* that turns liquid medication into a mist. Your baby will breathe in the mist from a face mask. Be careful not to get the mist in your baby's eyes. Nebulizer treatments take about 10–20 minutes to complete. The NICU team will teach you how to use the nebulizer.
- Some babies may use an inhaler. Always follow the directions given to you by your baby's team about how to administer the medication, including the use of a spacer if it is provided. Shake well before use.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____

What are the possible side effects?

- Increased heartbeat
- Tremor
- Restlessness (fussiness)
- Dry nose and throat
- Nosebleed

Call your baby's provider right away if your baby has

- fast, pounding, irregular heartbeat
- rash or hives
- problems swallowing
- swelling of face, throat, tongue, lips, eyes, hands, feet, ankles, or lower legs
- hoarse voice
- increased shortness of breath, wheezing, and increased work of breathing.

What if my baby misses a dose?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses.

Important Medication Safety Tips

- Only give your baby medicine prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give albuterol exactly as directed by your baby's provider.



- Never stop albuterol or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services (EMS) or 911 right away.
- Optionally, you may store albuterol in the refrigerator.
- If your baby also uses an inhaled steroid, such as budesonide (Pulmicort), give albuterol first to open the airways.
 - If your baby is receiving more than one inhaled medication, do not mix them together for the nebulizer unless specifically instructed to do so by your baby’s provider.
- If your baby has severe difficulty breathing or stops breathing, start CPR and call your local EMS or 911 right away.
- Always use the five *rights* when giving medicines to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby. Clean your nebulizer regularly. Follow the manufacturer’s directions carefully and ask your doctor or pharmacist if you have any questions about cleaning your nebulizer. Albuterol inhalation sometimes causes wheezing and difficulty breathing immediately after it is inhaled. If this happens, call your doctor right away. Do not use albuterol inhalation again unless your doctor instructs you to do so.

Online Resources

American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.consumermedsafety.org

Kids Health
www.kidshealth.org

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration
www.fda.gov



Medications at Home: Budesonide (Pulmicort)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Budesonide is used to prevent or control wheezing and shortness of breath caused by lung disease.
- This medication is a corticosteroid used to prevent or treat inflammation (swelling) in the airways.
- Budesonide does *not* give fast relief of wheezing and shortness of breath.

How, how much, and when is this medication given to my baby?

- This medicine is given with a special machine called a *nebulizer* that turns liquid medication into a mist. Your baby will breathe in the mist from a face mask. Be careful not to get the mist in your baby's eyes. Nebulizer treatments take about 10–20 minutes to complete. Rinse mouth following treatment to avoid infection. The NICU team will teach you how to use the nebulizer.
- Some babies may use an inhaler. Always follow the directions given to you by your baby's team about how to administer the medication, including the use of a spacer if it is provided.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____

What are possible side effects?

- Dry mouth or sore throat
- Cough or runny nose
- Dizziness
- Problems sleeping
- Neck or stomach pain

Call your baby's provider right away if your baby has

- white spots or sores in the mouth
- chest pain
- swollen face, tongue, lips, lower legs, or ankles
- common cold or eye, ear, or other infection
- headache, weakness, or fatigue
- increased difficulty with breathing
- skin rash
- bleeding or bruising
- fever
- vomiting or diarrhea
- pain with urination.

What if my baby misses a dose?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's provider. Do not share prescription medications with other children or adults.



- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give budesonide exactly as directed by your baby's provider.
 - Never stop giving the budesonide or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - If your baby is taking more than one inhaled medication, do not mix them together for the nebulizer unless specifically instructed to do so by your baby's provider.
 - Store budesonide at room temperature and away from excess heat and damp areas like the bathroom.
 - If you are using the nebulizer solution, you must dispose of unused ampules 2 weeks after opening the foil pouch.
- Clean your baby's mouth with a soft cloth moistened with water after treatment is finished.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby. Clean your nebulizer regularly. Follow the manufacturer's directions carefully and ask your doctor or pharmacist if you have any questions about cleaning your nebulizer.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org

HealthFinder.gov
www.healthfinder.gov

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

Institute for Safe Medication Practices
www.consumermedsafety.org

U.S. Food and Drug Administration
www.fda.gov



Medications at Home: Caffeine Citrate

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Caffeine citrate is used to prevent and treat apnea (long pauses between breaths or irregular breathing during sleep).
- This medication stimulates the brain to “remind” your baby to breathe.

How, how much, and when is this medication given to my baby?

- Caffeine citrate is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. You may need a small syringe to accurately measure the dose. Do not change the dosage without talking to your baby’s provider.
- The caffeine citrate oral solution does not contain any preservatives. Do not open the vial until it is time for your baby to receive the dose of medicine. Use each vial only once. After you remove your baby’s dose, throw away the vial and all medicine left in the opened vial.
- Dose Instructions: _____

What are possible side effects?

- Restlessness (fussiness)
- Vomiting
- Fast heartbeat
- Increased urination, diaper wetting

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby’s healthcare provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medications with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give caffeine citrate exactly as directed by your baby’s provider.
 - Never stop caffeine citrate or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222.
 - If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Store caffeine citrate at room temperature and away from light, heat, and damp areas like the bathroom.
 - Do not give your baby food or drinks that contain caffeine (e.g., soda, energy drinks, coffee, tea, chocolate).
 - Your baby may need blood tests while on this medication.
- Contact your provider if
 - your baby begins to have more monitor alarms or blood in his or her stools



- your baby’s heart rate is higher than 180 beats per minute, talk to your baby’s provider before giving caffeine citrate
- your baby has a bloated abdomen or vomiting.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.consumermedsafety.org

Kids Health
www.kidshealth.org

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration
www.fda.gov



Medications at Home: Chlorothiazide (Diuril)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Chlorothiazide helps babies with chronic lung disease breathe easier by decreasing extra fluid in the lungs.
- It also is used to treat high blood pressure and diabetes insipidus.
- Commonly called a *water pill* (diuretic), this medication helps the kidneys get rid of extra water and salt that the body does not need.
- You may have to give other medicines with this one, such as other electrolytes (potassium).

How, how much, and when is this medication given to my baby?

- This medication is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____
 - Measure the oral medicine with a marked measuring spoon, oral syringe, or medicine cup.

What are possible side effects?

- Muscle weakness
- Cramps
- Dizziness
- Restlessness
- Dry mouth or increased thirst
- Decreased appetite
- Upset stomach or stomach pain
- Vomiting
- Diarrhea (watery stools) or constipation
- Changes in the amount of urine passed
- Hair loss
- High blood sugar
- Yellow eyes or skin tone

Call your baby's provider right away if your baby has

- fever, chills, or body aches
- bleeding or bruising
- skin rash with peeling skin
- problems breathing or swallowing.

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's healthcare provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's provider. Do not share prescription medications with other children or adults.



- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottle or container it came in, and with the label of directions given by the pharmacy.
- Give chlorothiazide exactly as directed by your baby's provider.
 - Never stop chlorothiazide or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or if he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Store chlorothiazide at room temperature away from extreme heat or cold.
- Your baby may need blood tests while on this medication.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

Online Resources

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U.S. Food and Drug Administration
www.fda.gov



Medications at Home: Clonidine

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Clonidine is sometimes used to help with withdrawal symptoms in babies exposed to illegal drugs before birth.
- Clonidine helps relieve some of the symptoms of a fast heart rate, high blood pressure, sweating, restlessness, and diarrhea.

How, how much, and when is this medication given to my baby?

- Clonidine is a liquid and will be given in your baby's mouth.
- Wash and dry your hands before giving your baby the medicine.
- Using a children's measuring device, available at the pharmacy, give the exact dose the doctor ordered for your baby.
- Give the medicine using a syringe and slowly drip it into the inside of the baby's cheek or mix it in 5–10 mL of milk and have the baby suck it out of the bottle.
- Make sure your baby swallows/takes the entire dose.
- The amount of medicine your baby will receive has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____

What are possible side effects?

- Dry mouth
- Constipation
- Tired, lack of energy
- Irritability
- Decreased appetite—not feeding well
- Nausea/vomiting
- Low blood pressure

Call your baby's provider right away if your baby has

- skin rash/itching—don't give the medicine if this develops
- slow, fast, or abnormal heart rate
- skin discoloration—redness
- difficult, slow, or shallow breathing.

Call 911 if your baby has

- trouble breathing—wheezing, bad cough
- swelling of the face, lips, tongue, or throat
- blue skin
- seizures.

What if my baby misses a dose?

- If it is within an hour of the missed dose, give the missed dose as soon as you remember and stick to the regular medication schedule.
- If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses.



Important Medication Safety Tips

- Only give your baby medicine prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
 - Light and moisture can make the medicine not work properly.
 - Keep the bottle tightly sealed in a dark, dry place at room temperature.
- Give clonidine exactly as directed by your baby's provider.
 - Never stop clonidine or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services (EMS) or 911 right away.
- If your baby has severe difficulty breathing or stops breathing, start CPR and call your local EMS or 911 right away.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).
- When the baby no longer needs the medicine, mix any leftover medicine with an unwanted material like cat litter or coffee grounds. Place the mixture into a container or bag that will not leak and throw it in the trash where children and pets cannot reach it.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

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Medication at Home: Compounding Pharmacy

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Some prescription medications must be made using a special process called *compounding*. Your baby is taking the drug _____, which is made by compounding. For help finding a compounding pharmacy in your neighborhood, please call the hospital pharmacy at _____. Another resource for locating a compounding pharmacy is the Professional Compounding Centers of America (www.pccarx.com).

Compounding Pharmacy

Name: _____

Address: _____

Phone Number: _____



Medications at Home: Digoxin (Lanoxin)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Digoxin is used to treat heart failure and heart arrhythmias (supraventricular tachycardia, atrial fibrillation, and atrial flutter).
- This medication controls the heartbeat so that the heart works better.

How, how much, and when is this medication given to my baby?

- Digoxin is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____
 - Give at the same time every day.
 - You may need a small syringe to accurately measure the dose.

What are possible side effects?

- Itching or rash
- Irregular heartbeat
- Headache or dizziness

Call your baby's provider right away if your baby has

- upset stomach or vomiting
- diarrhea (watery stools)
- loss of appetite
- swelling of feet or hands
- problems breathing
- numbness or tingling in the lips, hands, or feet.

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medication prescribed by your baby's provider. Do not share prescription medications with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottle or container it came in, and with the label of directions given by the pharmacy.
- Give digoxin exactly as directed by your baby's provider.
 - Never stop digoxin or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222.
 - If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Call your baby's provider right away if there is a sudden increase or decrease in your baby's heart rate.
 - Store digoxin at room temperature and away from light, heat, and damp areas like the bathroom.
 - Your baby may need to have blood tests and heart monitoring while on this medication.



- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.consumermedsafety.org

Kids Health
www.kidshealth.org

Medline Plus: Drug Information
www.nlm.nih.gov/medlineplus/druginfo/meds

U.S. Food and Drug Administration
www.fda.gov



Medications at Home: Ferrous Sulfate (Fer-In-Sol)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Ferrous sulfate is used to prevent and treat anemia (also called low blood count).
- This medication helps your baby's body make red blood cells and carry oxygen to his or her important organs like the brain and heart.

How, how much, and when is this medication given to my baby?

- Ferrous sulfate is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. You may need a small syringe or dropper to accurately measure the dose. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____
 - Mix ferrous sulfate with a small amount of breast milk or water to help make it easier on your baby's stomach.

What are possible side effects?

- Upset stomach
- Stomach pain
- Constipation
- Black stools (causes no harm to baby)
- Decreased appetite

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's healthcare provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottle or container it came in, and with the label of directions given by the pharmacy.
- Give ferrous sulfate exactly as directed by your baby's provider.
 - Never stop ferrous sulfate or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Store ferrous sulfate at room temperature and away from excess light, heat, and damp areas like the bathroom.
 - Your baby may need to have blood tests while on this medication.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication



- Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
- Right time
- Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

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U.S. Food and Drug Administration
www.fda.gov



Medications at Home: Fluticasone (Flovent)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Fluticasone is used to prevent or control wheezing or reactive airway episodes caused by lung disease. Fluticasone is a corticosteroid used to prevent or treat inflammation (swelling) in the airways. It does *not* give fast relief of wheezing and shortness of breath.

How, how much, and when is this medication given to my baby?

- Fluticasone is given in “puffs” with an inhaler and a spacer. You will have to fit a mask over your baby’s nose and mouth to give this medicine. Be careful not to get the mist in your baby’s eyes. Clean your baby’s mouth with a soft cloth moistened with water after treatment is finished.
- Follow the directions given by your baby’s team about how to administer the medication.
- The amount of medicine to give has been carefully calculated based on your baby’s weight and needed response from the medicine. Do not change the dose without talking to your baby’s provider.
- Dose Instructions: _____

What are possible side effects?

- Nausea (upset stomach)
- Eye irritation (redness, watery eyes)
- Runny nose
- Headache
- Hoarse voice or throat irritation

Call your baby’s provider right away if your baby has

- white spots or sores in the mouth
- swollen face, lower legs, or ankles
- common cold or other infection
- weakness or fatigue
- increased difficulty with breathing or swallowing
- skin rash or itching
- fever.

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby’s provider if your baby misses two or more doses.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby’s provider. Do not share prescription medicines with other children or adults.
- Check with your baby’s provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give fluticasone exactly as directed by your baby’s provider.



- Never stop fluticasone or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
- Store fluticasone at room temperature and away from excess heat and damp areas like the bathroom.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby’s provider).

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s health-care provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
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Kids Health
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U.S. Food and Drug Administration
www.fda.gov



Medications at Home: Keppra

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Keppra helps to decrease or prevent seizures in your baby.

How, how much, and when is this medication given to my baby?

- Keppra is a liquid and will be given in your baby's mouth.
- Wash and dry your hands before giving your baby this medicine.
- Using a children's measuring device, available at the pharmacy, give the exact dose the doctor ordered for your baby.
- Administer the medicine using a syringe and slowly drip the medicine into the inside of your baby's cheek or mix it in 5–10 ml of milk and have your baby suck it out of the bottle.
- Make sure your baby swallows/takes the entire dose.
- The amount of medicine has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Your baby's provider will be working with you to wean from the medication. Follow the exact dose to be successful at getting the baby weaned off as quickly and as comfortably as possible.
- Dose Instructions: _____

What are possible side effects?

- Sleepiness
- Weakness
- Dizziness
- Shakiness
- Decreased appetite or nausea
- Skin rash

Call your baby's provider right away if your baby has

- a skin rash—don't give the medicine if a rash develops.

Call 911 if your baby has

- difficulty breathing, trouble being awakened, or swelling of the hands, feet, ankles, or tongue.

What if my baby misses a dose?

- Give the missed dose as soon as you remember if it is within an hour of the missed dose and stick to the regular medication schedule.
- If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses.

Important Medication Safety Tips

- Only give your baby medicine prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
 - Light and moisture can make the medicine not work properly.
 - Keep the bottle tightly sealed in a dark, dry place at room temperature.



- Kepra is a controlled substance, which means it has dangerous side effects if used improperly.
- Give Kepra exactly as directed by your baby's provider.
 - Never stop Kepra or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services (EMS) or 911 right away.
- If your baby has severe difficulty breathing or stops breathing, start CPR and call your local EMS or 911 right away.
- Always use the five *rights* when giving medications to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).
- When the baby no longer needs the medicine, mix any leftover medicine with an unwanted material like cat litter or coffee grounds. Place the mixture into a container or bag that will not leak and throw into the trash where children and pets cannot reach it.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

Online Resources

About Kids Health
www.aboutkidshealth.ca/En/HealthAZ/Drugs/Pages/Levetiracetam.aspx

Kids Health
www.kidshealth.org

UpToDate
www.uptodate.com/contents/treatment-of-neonatal-seizures

Medline Plus: Drug Information
<https://medlineplus.gov/druginfo/meds/a699059.html>



Medications at Home: Lansoprazole (Prevacid)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

Lansoprazole is used to treat gastroesophageal reflux disease (GERD), sometimes called *acid reflux*. In GERD, stomach acid flows upward into the throat and may cause pain and harm to the throat. Lansoprazole decreases the amount of stomach acid.

How, how much, and when is this medication given to my baby?

- Lansoprazole is given by mouth. It also can be given through a feeding tube.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dose without talking to your baby's provider.
- For best results, give your baby lansoprazole no more than 30 minutes before meals.
- Dose Instructions: _____

What are possible side effects?

- Nausea (upset stomach) or vomiting
- Abdominal pain or constipation
- Headache or dizziness
- Diarrhea (watery stool)

Call your baby's provider right away if your baby has

- rash, hives
- itching skin
- swelling of eyes, face, lips, mouth, tongue, or throat
- hoarse voice
- fast, pounding, or irregular heartbeat
- unusual tiredness, muscle cramps, or weakness
- uncontrollable shaking of a body part or seizures.

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give lansoprazole exactly as directed by your baby's provider.
 - Never stop lansoprazole or give more or less than prescribed without first talking with your baby's healthcare provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or they have stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Store lansoprazole at room temperature and away from excess heat and damp areas like the bathroom.



- Your baby may need to have blood tests while on this medicine.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

Online Resources

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Kids Health
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Medications at Home: Methadone (Methadone Intensol™, Methadose®)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Methadone is used to help with withdrawal symptoms in babies exposed to illegal or prescription drugs before birth.
- Methadone works like the narcotic medication the mother took while she was pregnant. By giving the same type of drug and slowly weaning from it over time, the baby will no longer need the medicine.
- Methadone helps to decrease the symptoms of fussiness, tremors, inconsolable crying, and stiffness.

How, how much, and when is this medication given to my baby?

- Methadone is a liquid and will be given in the baby's mouth.
- Wash and dry your hands before giving your baby the medicine.
- Using a children's measuring device, available at a pharmacy, give the exact dose the doctor ordered for your baby.
- Administer methadone using a syringe and slowly drip it into the inside of the baby's cheek or mix it in 5–10 ml of milk and have the baby suck it out of a bottle.
- Make sure the baby swallows/takes the entire dose.
- The amount of medicine has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Your baby's provider will be working with you to wean your baby from the medication. Follow the exact dose to be successful at getting your baby weaned off as quickly and as comfortably as possible.
- Dose Instructions: _____

What are possible side effects?

- Constipation
- Sleepiness
- Slow breathing, slow heart rate, and low blood pressure
- Nausea and vomiting
- Itchy skin
- Small pupils in the eyes

Call your baby's provider right away if your baby has

- a new skin rash—do not give the medicine if this develops
- become sleepy and is not feeding well
- a fast heartbeat
- become overly tired or weak
- severe constipation
- severe nausea and vomiting.

Call 911 if your baby has

- trouble breathing—wheezing, coughing
- fever
- itching
- blue skin



- swelling of lips, tongue, or throat
- signs of an overdose:
 - hard to wake up
 - not breathing
 - slow heart rate
 - blue skin

What if my baby misses a dose?

- Give the missed dose as soon as you remember, if it is within an hour of the missed dose, and stick to the regular medication schedule.
- If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- **Never** give a double dose.
- Call your baby's provider if your baby misses two or more doses.

Important Medication Safety Tips

- Only give your baby medicine prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, in the tightly closed bottles or containers they came in, and with the labels of directions given by the pharmacy.
 - Light can make the medicine not work properly.
 - Keep the bottle tightly sealed in a dark, dry place at room temperature.
- Methadone is a controlled substance, which means it has dangerous side effects if used improperly.
 - Dangerously slow breathing and nervous system depression can occur in newborns and babies younger than 3 months, so give medication only as ordered.
- Give methadone exactly as directed by your baby's provider.
 - Never stop methadone or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services (EMS) or 911 right away.
- If your baby has severe difficulty breathing or stops breathing, start CPR and call your local EMS or 911 right away.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).
- When your baby no longer needs the medicine, mix any leftover medicine with an unwanted material like cat litter or coffee grounds. Place the mixture into a container or bag that will not leak and throw it in the trash where children and pets cannot reach it.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.



Online Resources

American Academy of Pediatrics
www.aap.org

HealthFinder.gov
www.healthfinder.gov

Institute for Safe Medication Practices
www.consumermedsafety.org

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U.S. Food and Drug Administration
www.fda.gov



Medications at Home: Morphine Sulfate

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Morphine is used to help with withdrawal symptoms in babies exposed to illegal or prescription drugs before birth.
- Morphine works like the narcotic medication the mother took while she was pregnant. By giving the same type of drug and slowly weaning it over time, the baby will no longer need the medicine.
- Morphine helps to decrease the symptoms of fussiness, tremors, inconsolable crying, and stiffness.

How, how much, and when is this medication given to my baby?

- Morphine is a liquid and will be given in the baby's mouth.
- Wash and dry your hands before giving your baby this medicine.
- Using a children's measuring device, available at a pharmacy, give the exact dose the doctor ordered for your baby.
- Administer the medicine using a syringe and slowly drip it into the inside of the baby's cheek or mix it in 5–10 ml of milk and have the baby suck it out of a bottle.
- Make sure the baby swallows/takes the entire dose.
- The amount of medicine has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Your baby's provider will be working with you to wean your baby from the medication. Follow the exact dose to be successful at getting your baby weaned off as quickly and as comfortably as possible.
- Dose Instructions: _____

What are the possible side effects?

- Sleepiness
- Constipation
- Vomiting
- Sleepiness
- Slow breathing, slow heart rate, and low blood pressure
- Nausea and vomiting
- Decreased urination or wet diapers

Call your baby's provider right away if your baby has

- a new skin rash—do not give the medicine if a rash develops
- become sleepy and is not feeding well
- become overly tired or weak
- severe constipation
- severe nausea and vomiting.

Call 911 if your baby has

- trouble breathing—wheezing, coughing
- blue skin



- swelling of lips, tongue, or throat
- signs of an overdose:
 - hard to wake up
 - not breathing
 - slow heart rate
 - blue skin.

What if my baby misses a dose?

- Give the missed dose as soon as you remember it, if it is within an hour of the missed dose, and stick to the regular medication schedule.
- If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- **Never** give a double dose.
- Call your baby's provider if your baby misses two or more doses.

Important Medication Safety Tips

- Only give your baby medicine prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, in the tightly closed bottles or containers they came in, and with the labels of directions given by the pharmacy.
 - Light and moisture can make the medicine not work properly.
 - Keep the bottle tightly sealed in a dark, dry place at room temperature.
- Morphine is a controlled substance, which means it has dangerous side effects if used improperly.
 - Dangerously slow breathing and nervous system depression can occur in newborns and babies younger than 3 months, so give medication only as ordered.
- Give morphine exactly as directed by your baby's provider.
 - Never stop morphine or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services (EMS) or 911 right away.
- If your baby has severe difficulty breathing or stops breathing, start CPR and call your local EMS or 911 right away.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).
- When the baby no longer needs the medicine, mix any leftover medicine with an unwanted material like cat litter or coffee grounds. Place the mixture into a container or bag that will not leak and throw into the trash where children and pets cannot reach it.

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.



Online Resources

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Medications at Home: Multivitamins (Poly Vi Sol)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

Multivitamins are nutritional supplements that promote healthy growth and development.

How, how much, and when is this medication given to my baby?

- Multivitamins are given by mouth.
- Dose Instructions: _____

What are possible side effects?

- Upset stomach

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule. Never give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give multivitamins exactly as directed by your baby's provider.
 - Never stop multivitamins or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Store multivitamins at room temperature and away from excess heat and damp areas like the bathroom.
 - Be aware that multivitamins that contain iron may stain clothing if spilled or if the infant spits up.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

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Medications at Home: Omeprazole (Prilosec)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

Omeprazole is used to treat *gastroesophageal reflux disease* (GERD), sometimes called *acid reflux*. In GERD, stomach acid flows upward into the throat and may cause pain and harm to the throat. Omeprazole decreases the amount of stomach acid.

How, how much, and when is this medication given to my baby?

- Omeprazole is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____

What are possible side effects?

- Nausea (upset stomach)
- Vomiting
- Stomach pain
- Constipation
- Gas
- Fever
- Rash, itching, or swelling of the face, lips, or tongue may be signs of allergic reaction. Contact your doctor immediately.

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and continue to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give omeprazole exactly as directed by your baby's provider.
 - Never stop omeprazole or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Store omeprazole at room temperature, away from excess heat and damp areas like the bathroom.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)



- Right time
- Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

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Medications at Home: Phenobarbital (NAS)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Phenobarbital is sometimes used to help with withdrawal symptoms in babies exposed to illegal drugs while in utero.
- Phenobarbital helps to relieve some of the symptoms of stiffness, tremors, and agitation.

How, how much, and when is this medication given to my baby?

- Phenobarbital is a liquid and will be given in the baby's mouth.
- Wash and dry your hands before giving your baby this medicine.
- Using a children's measuring device, available at a pharmacy, give the exact dose the doctor ordered for your baby.
- Administer the medicine using a syringe and slowly drip it into the inside of the baby's cheek or mix it in 5–10 ml of milk and have the baby suck it out of a bottle.
- Make sure the baby has swallowed/taken the entire dose.
- The amount of medicine has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____

What are possible side effects?

- Sleepiness
- Slow breathing
- Trouble sleeping
- Skin rash

Call your baby's provider right away if your baby has

- skin rash—do not give the medicine if a rash develops.

Call 911 if your baby has

- trouble breathing or swelling of the hands, feet, ankles, or tongue.

What if my baby misses a dose?

- Give the missed dose as soon as you remember it, if it is within an hour of the missed dose, and stick to the regular medication schedule.
- If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- **Never** give a double dose.
- Call your baby's provider if your baby misses two or more doses.

Important Medication Safety Tips

- Only give your baby medicine prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
 - Light and moisture can make the medicine not work properly.
 - Keep bottle tightly sealed in a dark, dry place at room temperature.
- Phenobarbital is a controlled substance, which means it has dangerous side effects if used improperly.
- Give phenobarbital exactly as directed by your baby's provider.



- Never stop phenobarbital or give more or less than prescribed without first talking with your baby’s provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services (EMS) or 911 right away.
- If your baby has severe difficulty breathing or stops breathing, start CPR and call your local EMS or 911 right away.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby’s provider).
- When the baby no longer needs the medicine, mix any leftover medicine with an unwanted material like cat litter or coffee grounds. Place the mixture into a container or bag that will not leak and throw it in the trash where children and pets cannot reach it.

The above information is to help you better understand your baby’s care. Always follow the instructions given by your baby’s provider and pharmacist. It’s always OK to ask questions if you have concerns about your baby.

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Medications at Home: Phenobarbital (Seizures)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Phenobarbital is used to prevent or treat seizures (convulsions).
- This medication also is used to treat sluggish gallbladder (direct hyperbilirubinemia).

How, how much, and when is this medication given to my baby?

- Phenobarbital is given by mouth.
- The amount of medicine has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage or stop this medication without talking to your baby's provider.
- Dose Instructions: Measure the oral liquid medicine with a marked measuring spoon, oral syringe, or medicine cup. Administer with water, milk, or juice.

What are possible side effects?

- Sleepiness
- Constipation, nausea, or vomiting
- Nervousness
- Skin flushing (redness)

Call your baby's healthcare provider right away if your baby has

- rapid or slow heartbeat
- skin rash, peeling, or itching
- decreased number of wet diapers/problems urinating
- lack of sweating (in older child)
- shortness of breath or wheezing
- excitement or increased activity
- fever.

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- **Never** give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's healthcare provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottle or container it came in, and with the label of directions given by the pharmacy.
- Give phenobarbital exactly as directed by your baby's provider.
 - Never stop phenobarbital or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.



- Store phenobarbital at room temperature and away from excess heat and damp areas like the bathroom.
- Your baby may need to have blood tests while on this medicine.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

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Medications at Home: Ranitidine (Zantac)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Ranitidine is used to prevent and treat stress ulcers.
- This medication prevents and treats gastrointestinal bleeding caused by stomach acid.
- Ranitidine also treats gastroesophageal reflux disease (GERD), sometimes called *acid reflux*, by decreasing the amount of stomach acid. In GERD, stomach acid flows upward into the throat and may cause pain and harm to the throat.

How, how much, and when is this medication given to my baby?

- Ranitidine is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____

What are possible side effects?

- Irritability (due to headache)
- Constipation
- Diarrhea (watery stool)
- Nausea and vomiting
- Stomach pain

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's healthcare provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give ranitidine exactly as directed by your baby's healthcare provider.
 - Never stop the ranitidine or give too much or too little without first talking with your baby's healthcare provider. Too little may not be enough to help, and too much may cause harm. In the case of an overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or he or she has stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Store ranitidine at room temperature and away from excess heat and damp areas like the bathroom.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)



- Right time
- Right way (exactly as prescribed and directed by your baby's provider).

The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's health-care provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

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Medications at Home: Vitamin D (Ergocalciferol, Cholecalciferol)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! After graduation from the NICU, your baby will need medication to stay well.

Why does my baby need this medication?

- Vitamin D helps to prevent and treat low levels of vitamin D in the blood.
- This medication prevents and treats bone diseases like rickets (bone softening).
- This medication helps the body absorb calcium and phosphorus so that bones grow strong.
- This medication helps keep your baby's nerves, muscles, and immune system healthy.

How, how much, and when is this medication given to my baby?

- Vitamin D is given by mouth.
- The amount of medicine to give has been carefully calculated based on your baby's weight and needed response from the medicine. Do not change the dosage without talking to your baby's provider.
- Dose Instructions: _____

What are possible side effects?

- None (at the proper dose)

What if my baby misses a dose or spits up the medication?

- Give the missed dose as soon as you remember it. If it is almost time for the next dose, skip the missed dose and stick to the regular medication schedule.
- Never give a double dose.
- Call your baby's provider if your baby misses two or more doses or spits up the medication.
- Do not give with a multivitamin unless specifically recommended by your baby's provider. Many multivitamins also have vitamin D in them. In some instances, giving both is needed, but always ask before giving both.

Important Medication Safety Tips

- Only give your baby medicines prescribed by your baby's provider. Do not share prescription medicines with other children or adults.
- Check with your baby's provider before giving your baby any over-the-counter medicines.
- Keep all medicines out of reach of children, closed tightly in the bottles or containers they came in, and with the labels of directions given by the pharmacy.
- Give vitamin D exactly as directed by your baby's provider.
 - Never stop vitamin D or give more or less than prescribed without first talking with your baby's provider. Too little may not be enough to help, and too much may cause harm. In case of overdose, immediately call the Poison Control Center at 800.222.1222. If you cannot wake your baby or they have stopped breathing, start cardiopulmonary resuscitation (CPR) and call your local emergency medical services or 911 right away.
 - Store vitamin D at room temperature, away from excess heat and damp areas like the bathroom.
- Always use the five *rights* when giving medication to your baby:
 - Right baby (if other children are in the home)
 - Right medication
 - Right amount (always measure the dose with the syringe or dropper provided by the pharmacy, not a common household teaspoon)
 - Right time
 - Right way (exactly as prescribed and directed by your baby's provider).



The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and pharmacist. It's always OK to ask questions if you have concerns about your baby.

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Follow-Up Appointment: Cardiology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric cardiologist* is a children's doctor who is also an expert in the diagnosis and treatment of nonsurgical heart problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric cardiology office to schedule your baby's appointment.

The pediatric cardiology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric cardiology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future heart examinations as directed by the pediatric cardiologist.
- Bring a list of your baby's current medicines, dose, and time you gave the last dose with you to the appointment. Make sure you tell the staff if you need refills.
- If your baby takes special medications to help the heart pump better, always follow the directions on the bottle or container that came from the pharmacy.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Cardiothoracic Surgery

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric cardiothoracic surgeon* is a children's doctor who also is an expert in the diagnosis and surgical treatment of heart problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric cardiothoracic surgery office to schedule your baby's appointment.

The pediatric cardiothoracic surgery office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric cardiothoracic surgery is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future surgical examinations as directed by the pediatric cardiothoracic surgeon.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

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Kids Health
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Follow-Up Appointment: Community Resources

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____

You will need to call the office to schedule your baby's appointment.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____

You will need to call the office to schedule your baby's appointment.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____

You will need to call the office to schedule your baby's appointment.



Follow-Up Appointment: Dermatology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric dermatologist* is a children's doctor who is also an expert in the diagnosis and treatment of skin problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You need to call the pediatric dermatology office to schedule your baby's appointment.

The pediatric dermatology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric dermatology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future skin examinations as directed by the pediatric dermatologist.
- Bring a list of your baby's current medicines, dose, and time you gave the last dose or any ointments for their skin with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's healthcare provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Early Intervention or Early Childhood Intervention

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- Babies born premature, with low birth weight, or with other complications around birth are at higher risk for delays in development or problems with movement and speech.
- *Early intervention/early childhood intervention (EI/ECI)* is a program to promote your baby's best development by helping you be your baby's first and most important teacher.
- EI/ECI experts include teachers and rehabilitation therapists such as occupational therapists, physical therapists, and speech language pathologists.
- EI/ECI experts help prevent and also diagnosis and treat problems with movement, feeding, and language.
- Because a baby's job is to play, EI/ECI experts use play activities to help your baby learn how best to move, feed, talk, and play.

Where is the appointment?

(Many EI programs make home visits to teach you how to help your baby's development.)

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You need to call the EI/ECI office to schedule your baby's appointment.

The EI/ECI office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with EI/ECI is important and is in addition to well-child check-ups with your baby's primary care provider and any high-risk infant follow-up appointments.
- If you are unable to keep this important follow-up appointment, please call to reschedule.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

High-Risk Infant Follow-Up Quality of Care Initiative
www.ccsrif.org

American Occupational Therapy Association, Inc.
www.aota.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Endocrinology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- A *pediatric endocrinologist* is a children's doctor who is also an expert in the diagnosis and treatment of problems of the endocrine system.
- The endocrine system is also called the hormone and gland system and affects almost every cell and organ in your baby's body.
- Growth disorders and low thyroid are just a few types of endocrine problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric endocrinology office to schedule your baby's appointment.

The pediatric endocrinology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric endocrinology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future endocrinology examinations as directed by the pediatric endocrinologist.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Gastroenterology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric gastroenterologist* is a children's doctor who is also an expert in the diagnosis and treatment of stomach and intestinal problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

- Date: _____ Time: _____
- You need to call the pediatric gastroenterology office to schedule your baby's appointment.
- The pediatric gastroenterology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric gastroenterology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future follow-up examinations as directed by the pediatric gastroenterologist.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

This information is provided to help you better understand your baby's care. Always follow the directions given by your baby's provider. Always share your questions or concerns about your baby with the healthcare provider.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Genetics

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric geneticist* is a children's doctor who is also an expert in the diagnosis and cause(s) of birth defects and genetics problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You need to call the pediatrics genetics office to schedule your baby's appointment.

The pediatrics genetics office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric genetics is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future genetics examinations as directed by the pediatric geneticist.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Hematology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric hematologist* is a children's doctor who is also an expert in the diagnosis and treatment of blood problems.

Where is the appointment?

Name: _____

Street Address _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric hematology office to schedule your baby's appointment.

The pediatric hematology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric hematology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future hematology examinations as directed by the pediatric hematologist.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: High-Risk Infant Follow-Up (Neuro Brain Developmental Follow-Up)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because of your baby's complications at birth, he or she is at higher risk for certain delays after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- Babies born premature, with low birth weight, or with other complications around birth are at higher risk for growth and development delays.
- During your child's first 3 years of life, he or she will have several in-depth neurodevelopmental examinations at high-risk infant follow-up (HRIF).
- The HRIF team uses play to check on the quality of your child's
 - thinking and learning (cognitive skills)
 - movement (gross motor or large muscle and fine motor or small muscle skills, strength, and coordination)
 - play with toys (adaptive skills)
 - smiling and eye contact (social skills)
 - talking and gestures (communication skills).

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the HRIF office to schedule your baby's appointment.

The HRIF office will call you to schedule your baby's appointment.

Important Things to Remember

- Each HRIF appointment is important and is in addition to well-child check-ups with your baby's primary care provider and early intervention appointments.
- When problems are identified early, children receive help from experts and community services so they can reach their best growth and development.
- If you are unable to keep this important follow-up appointment, please call to reschedule.

This information is provided to help you better understand your baby's care. Always follow the directions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org

High-Risk Infant Follow-Up Quality of Care Initiative
[www.cpqcc.org/perinatal-programs/
high-risk-infant-follow-quality-care-initiative](http://www.cpqcc.org/perinatal-programs/high-risk-infant-follow-quality-care-initiative)



Follow-Up Appointment: Nephrology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric nephrologist* is a children's doctor who is also an expert in the diagnosis and treatment of kidney problems.

Where is the appointment?

Name: _____

Street Address _____

Phone Number _____

When is the appointment?

Date: _____ Time: _____

You need to call the pediatric nephrology office to schedule your baby's appointment.

The pediatric nephrology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric nephrology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future nephrology examinations as directed by the pediatric nephrologist.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Neurology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric neurologist* is a children's doctor who is also an expert in the diagnosis and treatment of nonsurgical nervous system (brain and spinal cord) problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric neurology office to schedule your baby's appointment.

The pediatric neurology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric neurology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future neurology examinations as directed by the pediatric neurologist.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Neurosurgery

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric neurosurgeon* is a children's doctor who is also an expert in the diagnosis and surgical treatment of nervous system (brain and spinal cord) problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric neurosurgery office to schedule your baby's appointment.

The pediatric neurosurgery office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric neurosurgery is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future neurosurgery examinations as directed by the pediatric neurosurgeon.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Nutrition Clinic

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- Babies born premature who have low birth weight or other complications around birth are at higher risk for poor growth.
- A registered dietitian, a nutrition expert in infants and children, will teach you how to safely help your baby eat healthy and grow.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric nutrition clinic to schedule your baby's appointment.

The pediatric nutrition clinic will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with the pediatric nutrition clinic is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future nutrition or dietitian examinations as directed by the pediatric nutrition clinic.
- Bring a list of your baby's current medicines with you to the appointment.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org

California Department of Health Care Services
www.dhcs.ca.gov/services



Follow-Up Appointment: Ophthalmology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- A *pediatric ophthalmologist* is a children's doctor who is also an expert in the diagnosis and treatment of eye problems.
- Babies born premature or with certain complications around birth are at higher risk for eye and vision problems.
- If your baby has retinopathy of prematurity, he or she is at even higher risk for vision problems that may lead to severe loss of sight if not treated by a pediatric ophthalmologist.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You need to call the pediatric ophthalmology office to schedule your baby's appointment.

The pediatric ophthalmology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric ophthalmology is very important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future eye examinations as directed by the pediatric ophthalmologist.
- Bring a list of your baby's current medicines with you to the appointment.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Otolaryngology (ENT)

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric otolaryngologist* is a children's doctor who is also an expert in the diagnosis and treatment of ear, nose, and throat problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric otolaryngology office to schedule your baby's appointment.

The pediatric otolaryngology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric otolaryngology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future ear, nose, and throat examinations as directed by the pediatric otolaryngologist.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Primary Care Provider

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric primary care provider* (PCP) is a physician or nurse practitioner who is an expert in caring for babies, infants, and children as they grow and develop.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call your pediatric PCP office to schedule your baby's appointment.

The pediatric PCP office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric PCP is important and is part of your baby's well-child check-ups.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future examinations as directed by the pediatric PCP.
- Bring a list of your baby's current medicines with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Pulmonology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

- A *pediatric pulmonologist* is a children's doctor who is also an expert in the diagnosis and treatment of lung problems.
- Babies born premature, with chronic lung disease (also known as *bronchopulmonary dysplasia*, or BPD), or with other complications are at higher risk for ongoing lung problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You will need to call the pediatric pulmonology office to schedule your baby's appointment.

The pediatric pulmonology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric pulmonology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future lung examinations as directed by the pediatric pulmonologist
- Bring a list of your baby's current medicines, dose, and the time you gave the last dose with you to the appointment. Make sure you tell the staff if you need refills.
- If your baby takes special medicines to help breathe easier, always follow the directions on the bottle or container that came from the pharmacy.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Surgery

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric surgeon* is a children's doctor who is also an expert in the diagnosis and surgical treatment of a variety of problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You need to call the pediatric surgery office to schedule your baby's appointment.

The pediatric surgery office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric surgery is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future surgery examinations as directed by the pediatric surgeon.
- Bring a list of your baby's current medicines, dose, and the time you gave the last dose with you to the appointment.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org



Follow-Up Appointment: Urology

The neonatal intensive care unit (NICU) team celebrates with you as your baby goes home! Because your baby is a NICU graduate, he or she is at higher risk for certain problems after discharge. That's why your baby needs important follow-up appointments to ensure his or her best health.

Why does my baby need this appointment?

A *pediatric urologist* is a children's doctor who is also an expert in the diagnosis and treatment of urinary problems.

Where is the appointment?

Name: _____

Street Address: _____

Phone Number: _____

When is the appointment?

Date: _____ Time: _____

You need to call the pediatric urology office to schedule your baby's appointment.

The pediatric urology office will call you to schedule your baby's appointment.

Important Things to Remember

- Each follow-up appointment with pediatric urology is important and is in addition to well-child check-ups with your baby's primary care provider.
- If you are unable to keep this important follow-up appointment, please call to reschedule.
- Always take your baby for future urinary examinations as directed by the pediatric urologist.
- Bring a list of your baby's current medicines, dose, and the time you gave the last dose with you to the appointment. Make sure you tell the staff if you need refills.

The above information is provided to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.

Online Resources

American Academy of Pediatrics
www.aap.org

Kids Health
www.kidshealth.org

Step **10**



Rooming-In

For many infants, the NICU experience is lengthy and complex. As families prepare for their infants to come home, they may exhibit varying degrees of anxiety and stress. A thorough assessment of the family's needs, environmental issues, and knowledge of their infant's care before discharge is an important part of the transition to home. Providing an opportunity to care for their infant with professional caregivers nearby for assistance has been shown to increase parental competence and provide confirmation of their readiness to provide independent care at home.

Rooming-in is a practice where parents and other caregivers provide total care for their baby in a home-like environment while in the hospital. This process provides the caregiver with the opportunity to care for their infant with the availability of assistance from healthcare professionals. Studies indicate that mothers found rooming-in experiences to be beneficial in preparing them for the discharge of their infant. Other mothers stated that it was an extremely positive experience, aided them in breastfeeding, increased their confidence, and helped them feel like a family. Rooming-in facilitates the transition of the patient from hospital to home prior to discharge.

While rooming-in, the parents or caregivers provide all of the physical care and supervision for their infant, including giving medications, changing diapers, and feeding.

Additional equipment, such as monitors, oxygen therapy, or feeding pumps, also is used during the rooming-in period. All discharge education, including equipment training from the identified home health agency or durable medical equipment company, should be completed prior to rooming-in.

The rooming-in process can start any time during the hospital stay. Rooming-in early and throughout the hospitalization allows for additional teaching time and demonstration of competence by the caregivers (Bowles, 2016).

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Rooming-In: Information for Parents

“Rooming-in” at the hospital allows you to stay with your baby for a long period of time (such as 24 hours) and provide all the care for your baby. This experience is like a practice session for taking care of your baby on your own before you go home. It gives you a chance to try all you have learned with a nurse close by for help and advice. Rooming-in can make the change from hospital to home much smoother for you and your baby. Speak to your baby’s nurse about opportunities throughout your baby’s stay when you could have the opportunity to room-in. Some hospitals may not be able to provide a 24-hour time frame or individual room for you to stay, but even for you to stay 12–16 hours at your baby’s bedside to provide your baby’s care is helpful for the transition home.

Before Rooming-In

- Hospital staff will give you instruction, and you will be able to demonstrate all care for your baby.
- You may receive training on equipment to be used at home.
- Your baby’s nurse will review the rooming-in process and make suggestions about what to bring for rooming-in, such as your personal grooming supplies and comfortable clothes.
- You may bring clothes you want your baby to wear during rooming-in time.
- All the supplies you need to care for your baby (such as diapers, bottles, nipples, formula, and blankets) will be in the room with you.

During Rooming-In

- You provide all care for your baby, including giving medications, changing diapers, and feedings.
- You use any monitoring or other equipment you will need to use at home.
- Take notes on what your baby is doing, what you did and when you did it, and how your baby responded. Things you should note include the time of feedings, number of wet or dirty diapers, times when your baby is fussy, or other things you may have questions about.
- Nurses are available by phone to answer questions and offer assistance.
- One parent or caregiver is expected to stay with the baby at all times.
- Rooming-in is a time for you and your baby; visitation by family and friends who are not primary caregivers is not recommended.

You are almost home. Rooming-in helps you learn more about your baby’s habits, behaviors, and routines *before* going home. It gives you the time to ask questions and gain confidence in caring for your baby.



Going Home

The goal of the discharge plan is to ensure a successful transition to home. Essential discharge criteria are a physiologically stable infant, a family who can provide the necessary care with appropriate support services in the community, and a primary care provider who is prepared to assume the responsibility with appropriate backup from specialists and other professionals as needed. The American Academy of Pediatrics (AAP) has provided recommendations for the discharge of the high-risk neonate to guide us (AAP, 2008).

Infant Readiness for Hospital Discharge

The infant is considered ready for discharge if, in the judgment of the responsible provider, the following have been accomplished:

- a sustained pattern of weight gain of sufficient duration has been demonstrated
- the infant has demonstrated adequate maintenance of normal body temperature while fully clothed in an open bed with normal ambient temperature (20 °C–25 °C)
- the infant has established competent feeding by breast or bottle without cardiorespiratory compromise
- physiologically mature and stable cardiorespiratory function has been documented for a sufficient duration
- appropriate immunizations have been administered
- appropriate metabolic screening has been performed
- hematologic status has been assessed and appropriate therapy has been instituted, if indicated
- nutritional risks have been assessed and therapy and dietary modification has been instituted, if indicated
- hearing evaluation has been completed
- critical congenital heart disease screening has been completed, as indicated
- eye (retina of prematurity) examinations have been completed, as indicated
- neurodevelopmental and neurobehavioral status has been assessed and demonstrated to the parents
- car seat evaluation has been completed
- review of the hospital course has been completed, unresolved medical problems have been identified,

and plans for follow-up monitoring and treatment have been instituted

- an individualized home-care plan has been developed with input from all appropriate disciplines and family.

Assessment of the family's caregiving capabilities, resource availability, and home physical facilities is essential prior to discharge. This includes identification of at least two family caregivers and assessment of their ability, availability, and commitment to caring for the infant. The case manager or care coordinator can assist in review of financial resources and support.

In preparation for home care of the technology-dependent infant, parents should complete an assessment documenting availability of 24-hour telephone access, electricity, safe in-house water supply, and adequate heating/cooling. Parents and caregivers should have demonstrated the necessary capabilities to provide all components of care, including completing cardiopulmonary resuscitation (CPR) training. A rooming-in period of 24–48 hours is recommended so parents and caregivers have time to care independently for their baby while still having the support of neonatal intensive care unit staff.

Nurses are instrumental in bridging the gap between the hospital and home. You have partnered with the family in caring for the infant and now are ready to reinforce education and preparation for discharge to home. You assess discharge readiness, completion of fundamental and specialized education, and transition points in care from hospital to primary care. Parental education includes basic infant care and safety, car seat safety, medication administration, nutrition support, reinforcing instructions for any home equipment or special care procedures, reinforcing importance of follow-up appointments, home safety, and CPR. Nurses also assist in connecting parents with community resources and follow-up agencies. Communicating the importance of timely follow-up regarding unresolved



medical conditions such as retinopathy of prematurity, hearing screening referrals, and other individualized care is essential. Additional follow-up of the infant's neurodevelopmental progress also is recommended to identify and promote optimal development through infancy and childhood.

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Going Home: Information for Parents

Congratulations, you are going home!

Going home with your baby is an exciting time. You and your healthcare team have worked together throughout your time in the neonatal intensive care unit (NICU) to prepare for this wonderful moment. It is normal to feel anxious about bringing your baby home. Your baby's healthcare team will help you learn about your baby's condition, medications, and care so that you are confident in taking your baby home. Your baby needs to meet three milestones before going home:

- maintain normal body temperature in an open crib
- take all feedings by breast or bottle
- have steady weight gain.

There are a few important things to review and complete before you go home:

- **Selecting a Primary Care Provider (PCP).** It is important to choose your pediatric PCP before it is time for your baby to be discharged. Let your baby's nurse know your provider's name and phone number. The NICU will send important information about your baby to your baby's provider.
- **Infant CPR Classes.** Preparing for emergencies at home is very important. Classes are held in the hospital and at community sites. Ask your baby's nurse about times and places for classes.
- **Car Seat.** Every baby must have a car seat in place at time of discharge. If you have a premature or very small baby, your baby will have a car seat test before going home.
- **Hearing Screening.** All infants are given a hearing screening prior to discharge. A baby who does not pass the screening does not necessarily have hearing loss. A retest to confirm the results should be done within the first 3 months of life. You will receive any needed information prior to discharge of your infant.
- **Circumcision.** If your baby is a boy, you will need to decide whether to have him circumcised. Full-term baby boys usually can be circumcised before they leave

the hospital. Usually the same applies to a healthy premature baby.

- **Medications.** Your baby's provider may prescribe medications to give to your baby at home. Before your infant is discharged, your baby's healthcare team will ask you to get the prescriptions filled and bring them to the hospital. They will teach you what the medicine is, why your baby needs the medicine, and how to give it to your infant. They also will help you with a home schedule for the medicines.
- **Special Equipment.** Some babies require home oxygen, a home apnea monitor, or other special equipment. The healthcare team will arrange for all the needed equipment for discharge. The company that supplies the equipment will train you to use it.

Discharge Follow-Up

- **Developmental Follow-Up.** Babies who were very small at birth or who had other difficulties that may affect their development are referred to follow-up clinics or early intervention services. Providers, occupational therapists, and physical therapists who specialize in infant development examine the babies. If any problems are found, early treatment is recommended to improve your baby's development.
- **Other Specialists.** At discharge, your baby may need to be seen by other specialists such as a pulmonary (lung), urology (urinary tract), cardiology (heart), or ophthalmology (eye) specialist. It is very important for the health of your baby to get follow-up care. Please be sure to follow the recommended appointments as scheduled.

When to Call Your Baby's Provider

If you are concerned about your baby and wonder whether you should call your primary care provider's office, call them. If you see something unexpected or different that concerns you, call them. Here are some important reasons for calling your pediatric provider:

- temperature 100.4 °F (38 °C) or higher (in babies younger than 3 months) or when fever rises above 104 °F (40 °C) repeatedly for a child of any age



- symptoms of dehydration (crying without tears, sunken eyes, a depression in the soft spot on baby's head, no wet diapers in 6–8 hours)
- a soft spot that bulges when your baby is quiet and upright
- a baby who is difficult to wake up
- rapid or labored breathing (Call 911 if your baby has breathing difficulty and begins turning bluish around the lips or mouth.)
- repeated forceful vomiting and an inability to keep fluids down
- bloody vomit or stool
- more than eight diarrhea stools in 8 hours.

If your concern is urgent, call your provider or take your baby to the emergency room.

Visits from Family and Friends

Don't be afraid to tell friends and family not to visit right away so you can spend precious time with your baby and settle in to home life together.

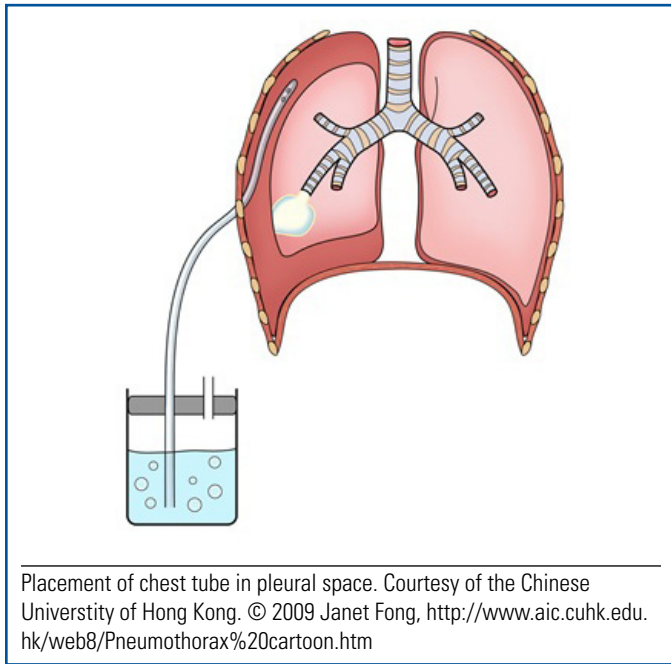
Once friends and family do start to visit, remember that premature infants and babies who have had a long NICU stay are more likely to catch an infection, so if someone is even a little sick, they should not visit. Visitors should be limited and should always wash their hands before touching the baby. Visitors should not be around the baby if they are smoking or have been smoking. Trips outside the home should be limited to appointments for the first several weeks. This is especially important if your baby is discharged during the winter months. Try scheduling follow-up appointments as the first of the day or request to wait in an examining room instead of the main waiting area.

Procedures



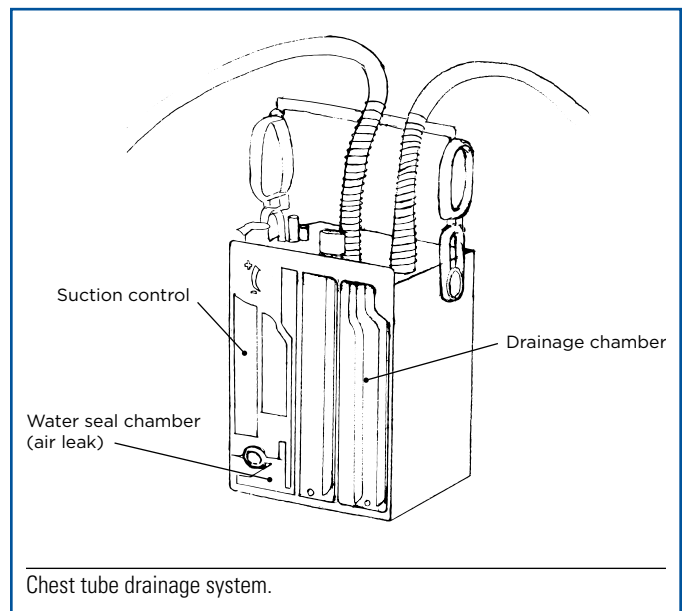
Chest Tubes

A chest tube may be placed to aid in the drainage of air, in the case of a pneumothorax, or to drain fluid, such as with a pleural effusion, hemothorax, or chylothorax. A chest tube is placed between the lung and the chest wall (see figure below). The chest tube will be placed anterior (above the lung) for removal of air or posterior (below the lung) for the removal of fluid.



There are many different types and brands of chest tubes. The type of chest tube will depend on the type of drainage needed. Chest tubes may be placed using a needle introducer or by making a small incision in the chest wall. All chest tubes have potential complications, including pain, infections, hemorrhage, lung trauma or perforation, scarring, damage to breast tissue, nerve damage, and injury to the diaphragm. A chest X ray should be obtained after chest tube placement to ensure that the chest tube is appropriately positioned and achieving the desired drainage. The infant may require special positioning to help this tube drain properly. Generally, infants must remain on their back or tipped slightly to one side; infants should not be placed on their abdomen with a chest tube in place.

Immediately after the chest tube is placed, it should be connected to a collection device that prevents air or fluid from being pulled back into the chest. This can be accomplished temporarily with a Heimlich device, or a chest tube drainage system can be used (see figure below). A chest tube drainage system will have a water seal to prevent air from entering the chest, a chamber to collect any drainage, and a method for applying suction. This device must be positioned below the infant and remain upright at all times.



An infant receiving a chest tube will be given medication to control pain and should have routine monitoring for pain and the adequacy of pain medication.

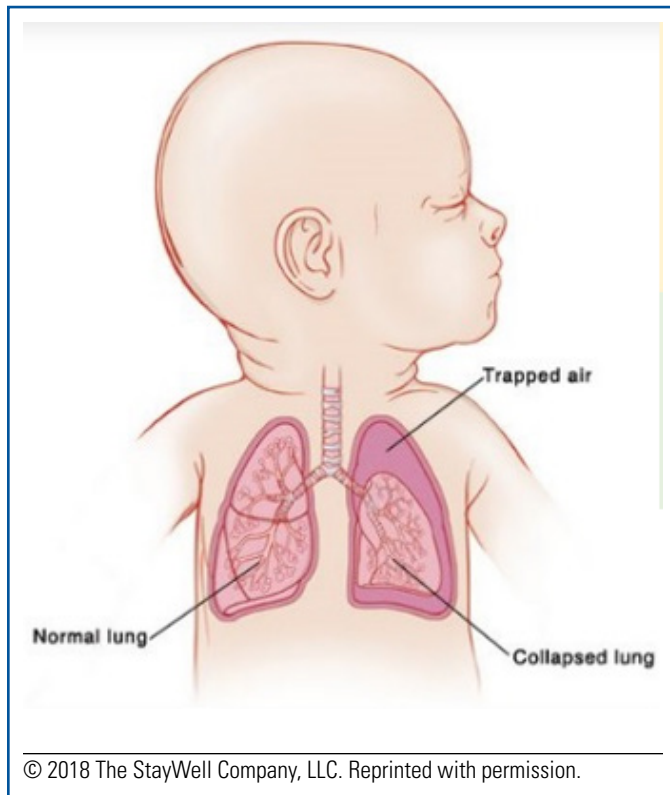
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Chest Tubes: Information for Parents

Your baby has developed a collection of air or fluid in his or her chest that will require a chest tube to allow for drainage. This is a sterile procedure, and you may be asked to step away from the bedside so that a germ-free area can be maintained. Your baby will be given medication to control any pain during this procedure and will be monitored at all times. A tube will be placed between the lung and the chest wall. The chest tube may be introduced using a needle or by making a very small incision in the chest (see figure below).



After the chest tube is in place, an X ray will be taken to make sure that the tube is in the right place and working well. A bandage will be placed over the chest tube site to protect it and keep the tube securely in place. A drainage system will be attached to the chest tube to allow the medical team to monitor drainage and function of the tube. The attached tubing will be secured to the bed so that no pressure is placed on the tube. Please do not try to pick up or move your baby without assistance to stabilize this chest tube. Your baby will benefit from your touch, comfort, and presence at the bedside while this tube is in place.

Some problems associated with chest tube placement are bleeding and infection. Occasionally, the tube will need to be replaced due to plugging by fluid or blood. Other problems, including injury to the lung, breast tissue, and other structures in the chest, are very rare.

The length of time the chest tube will be in place is determined by how long it is needed for drainage. Once drainage appears to be decreasing, the medical team will make a plan for when they can safely remove this tube.

While the tube is in place, your baby will be given pain medication as needed to ensure that he or she is comfortable. Your baby might need to be positioned in a certain way to assist with proper drainage. Most babies heal quickly after the tube is removed, but they may have a small scar where it was placed.



Circumcision

Male circumcision is one of the most common procedures in the world. Derived from the Latin word *circumcido*, circumcision means “cutting around.” It consists of the surgical removal of all or part of the foreskin (or prepuce) that typically covers the head of the penis. The foreskin is freed from the head of the penis (or glans) and surgically removed.

Benefits

The benefits of male circumcision include prevention of urinary tract infections, penile cancer, and transmission of some sexually transmitted infections, including HIV. According to the American Academy of Pediatrics, current evidence indicates that the health benefits of newborn male circumcision outweigh the risks and justify access to this procedure for families who choose it (American Academy of Pediatrics [AAP], 2012a). Although the health benefits are not great enough to recommend routine circumcision for all male newborns, they are sufficient to warrant third-party payment for the procedure.

Risks

Acute complications are rare and usually minor. They most commonly involve bleeding, infection, or an imperfect amount of tissue removed. Two large hospital-based studies estimated the risk of acute circumcision complications in the United States to be between 0.19% and 0.22% (AAP, 2012b). Bleeding was the most common complication (0.08% to 0.18%), followed by infection (0.06%) and penile injury (0.04%). There is no significant difference in the risk of complications between different methods of circumcision.

Late complications include excessive residual skin, excessive skin removal, adhesions, meatal stenosis, phimosis, and, rarely, epithelial inclusion cysts. Circumcision of a premature infant is associated with an increased risk for late complications (poor cosmesis, increased risk of trapped penis, adhesions).

Contraindications

Contraindications include extreme prematurity, penile length less than 1 cm, blood dyscrasias, family history of bleeding disorders, and congenital abnormalities such as

hypospadias, congenital chordee, or deficient shaft skin (penoscrotal fusion or congenital buried penis).

Decision Making

Parents should receive factually correct, nonbiased information about circumcision, preferably before conception or early in pregnancy. Providers should explain in a nonbiased manner the potential benefits and risks and ensure parents understand the elective nature of the procedure. Parents should take into consideration their own religious, cultural, and personal preferences when making this decision.

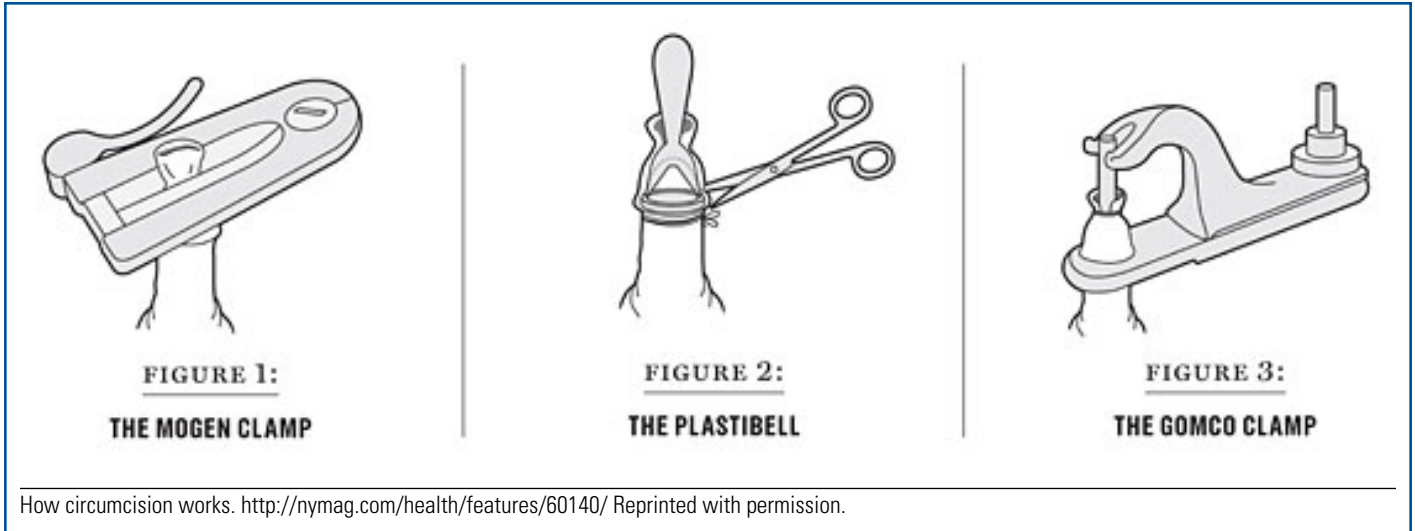
Methods

The three most commonly used techniques for male circumcision in the United States are the Gomco clamp, the Plastibell device, and the Mogen clamp.

With the Gomco clamp method, the foreskin is cut lengthwise to allow space to insert the device. The bell of the Gomco clamp is placed over the glans, and the foreskin is pulled over the bell. The base of the clamp is placed over the bell, and the Gomco clamp’s arm is fitted. After confirming correct fitting and placement, the nut on the Gomco clamp is tightened and left in place for 3 to 5 minutes to allow hemostasis to occur, then the foreskin is removed using a scalpel. The Gomco’s base and bell are then removed.

With the Plastibell method, a plastic ring is inserted under the foreskin, and a tie is placed over the ring to provide hemostasis. The ring remains on the penis for several days until the tissue necroses and the ring falls off spontaneously.

The Mogen clamp is a device consisting of two flat blades that have a slit-like space between them and a mechanism that draws the blades together and locks them in place. The slit is limited to 3 mm to allow the foreskin, but not the glans, to cross the opening. The foreskin distal to the glans is drawn into the slit between the blades and positioned. The blades are locked together, crushing the skin and creating hemostasis. The skin is excised from above the



clamp, the Mogen clamp is removed, and the skin pushed into proper position.

Pain Management

Adequate analgesia should be provided whenever newborn circumcision is performed. Positioning and oral sucrose should be used as adjuncts to improve comfort during the procedure. Positioning the infant in a padded environment and swaddling of the upper part of the body may decrease stress during the procedure.

There is no evidence that it is necessary to hold feedings before the procedure. Holding feedings may add to the infant's discomfort during the circumcision.

Analgesia should be provided with topical lidocaine-prilocaine (EMLA), subcutaneous ring block, or dorsal penile nerve block. In a comparison of the three types of anesthetics for neonatal circumcision, the most effective was the subcutaneous ring block and the least effective was EMLA (Lander, Brady-Freyer, Metcalfe, Nazerali, & Muttit, 1997). No evidence-based recommendations state that there is persistent pain that should be treated after the local anesthetic wears off.

Post-Circumcision Care

After circumcision, the site should be inspected for bleeding. If continued bleeding occurs, apply direct pressure for 5 minutes. If bleeding is local and minor, reapply the dressing accompanied by 10 minutes of direct

pressure. If bleeding persists, notify the provider who performed the procedure.

Apply a lubricant (petroleum jelly, Vaseline®, or petrolatum) gauze dressing to the wound with each diaper change, unless otherwise indicated by the provider. The period of superficial wound healing after male circumcision is generally 5 to 7 days, and most wounds heal completely within 14 days.

Parents should be instructed about the care of the penis at the time of discharge, regardless of whether the newborn was circumcised or not.

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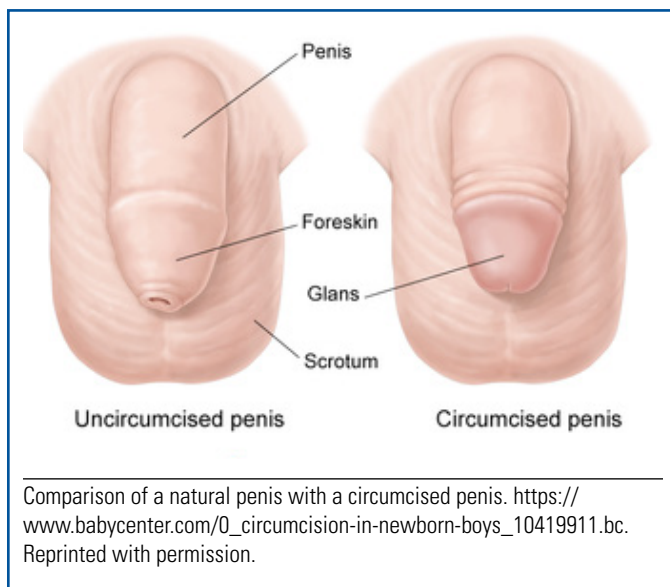
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Circumcision: Information for Parents

Boys are born with a hood of skin, called the *foreskin*, covering the head of the penis. In circumcision, the foreskin is removed, leaving the end of the penis exposed.

The decision to have your baby circumcised is very personal. It should be made after careful consideration of the risks and benefits as well as your cultural, religious, and personal preferences. Your healthcare provider should explain the risks and benefits and answer any questions.



Benefits

Baby boys who are circumcised are less likely to develop urinary tract infections. They may have a lower risk of penile cancer, although the disease is rare. Circumcision can help prevent the spread of sexually transmitted diseases, including HIV.

Risks

Most of the complications are minor and rare. They include bleeding, infection, injury to the penis, and poor cosmetic outcome.



Methods

The method of the circumcision will be decided by your healthcare provider. Your baby should receive local anesthesia and pain management during the procedure. You may ask which method will be used and what will be given for pain management. The three methods are Gomco clamp, Plastibell clamp, and Mogen clamp.

Care of the Circumcision

Your baby's nurse will show you how to care for your baby after circumcision. Wash the area gently with soap and water without pulling back on the skin. Apply a lubricant (petroleum jelly, Vaseline®, or petrolatum) to the circumcised area with each diaper change for at least 24 hours or until the area is healed. Lubricants help protect the wound and keep the wound from sticking to the diaper.

The healing area will have some swelling and redness but should start to look better after 24 to 48 hours. During the healing process a shiny white or yellowish film may cover part of the penis. This coating is part of the normal healing process. Do not try to remove the coating.



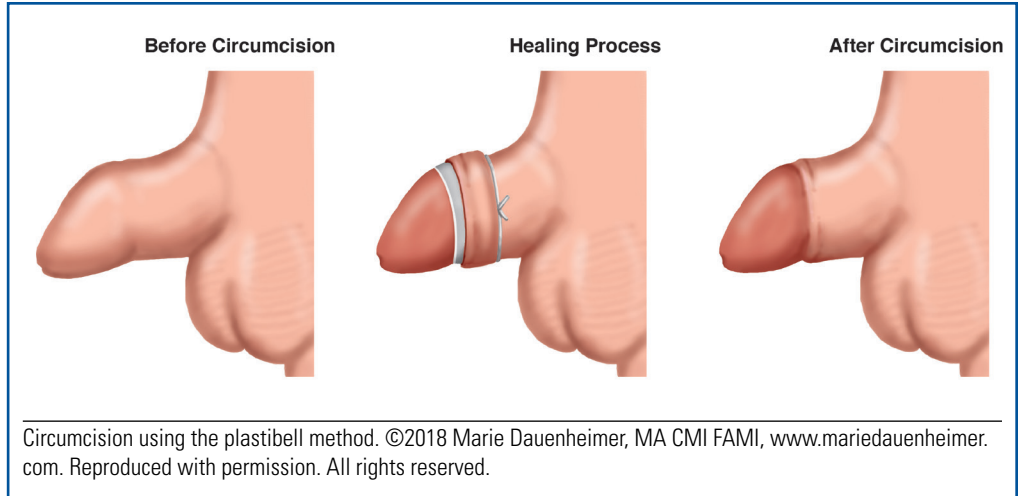
If the Plastibell method was used, the plastic ring should drop off within 5 to 8 days.

Call your baby's provider or take him to the emergency room if

- the healing area starts to look worse
- your baby develops a fever
- your baby stops having wet diapers
- your baby stops eating or becomes inconsolable
- the area forms a yellowish discharge that can be easily wiped away and has a foul odor
- bleeding doesn't stop after you apply pressure for 5 minutes
- the plastic ring doesn't fall off within 5 to 8 days.

Care of the Uncircumcised Penis

Wash around the penis with soap and water. Do not forcibly pull back on the foreskin. The foreskin will start



to retract (pull back) on its own by 2 to 4 months of age. When the foreskin can easily be pulled back, wash the penis with soap and water.

The foreskin fully retracts around 3 years of age. At that time boys should be taught to wash underneath the foreskin every day.



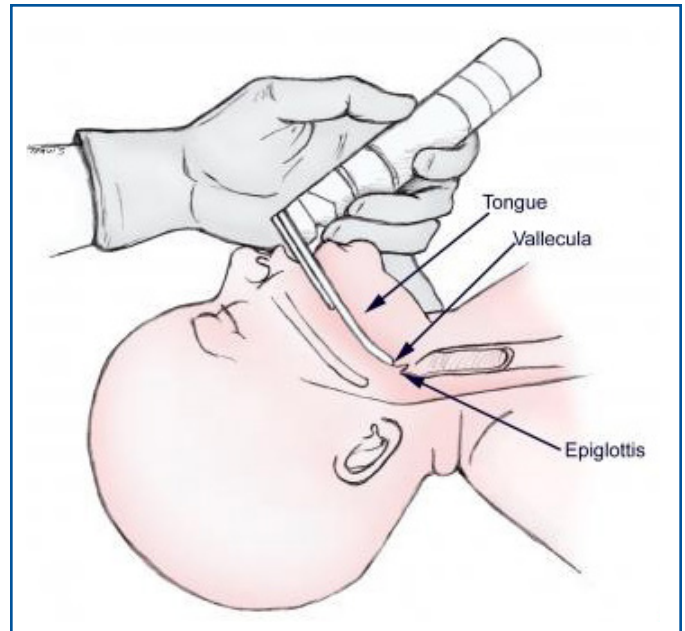
Intubation

Intubation is the passage of a tube into the infant's trachea. It may be emergent or elective, based on the neonate's condition. Neonatal nurse practitioners (NNPs), neonatologists, and other skilled healthcare providers are trained in this procedure. Indications for intubation are airway protection, control of the airway, perinatal resuscitation, mechanical ventilation, medication administration into the lungs such as surfactant, respiratory distress, suctioning the trachea/lungs, general surgery, and providing aid in the event of an airway obstruction.

The procedure involves the infant positioned supine on a radiant warmer and on cardiorespiratory monitors. Medication is given for sedation and pain management prior to the procedure if it is a controlled, nonemergent situation. The person performing the procedure will wear gloves, suction the infant's mouth and throat, and insert a laryngoscope into the infant's mouth to lift the tongue and visualize the vocal cords. The endotracheal tube (ETT) will be passed through the vocal cords, into the trachea. The ETT will be connected to a ventilator or to bag-and-mask ventilation. After the ETT is inserted, confirmation of correct ETT placement is done by auscultation of breath sounds equally bilaterally, a disposable CO₂ sensor, and an X ray. The ETT is secured with tape or an ETT stabilization device.

Endotracheal tubes come in many different brands and sizes; a stylet may be used to aid in intubation. Intubation has potential complications of acute or chronic trauma. Acute trauma includes tracheal perforation, hemorrhage, laryngeal edema, and injury to vocal cords. Chronic trauma includes cricoid ulceration and fibrosis, stenosis of glottis, hoarseness, stridor, wheezing, and tracheomegaly.

Potential systemic side effects of intubation are infection, aspiration, increased intracranial pressure, hypoxemia, hypertension, apnea, bradycardia, and cardiac arrest. Potential prolonged intubation side effects are alveolar/



Baby with endotracheal tube. Image reproduced with permission from Medscape Drugs & Diseases (<https://emedicine.medscape.com/>), Intubation and Tracheal Suctioning for Meconium Aspiration, 2015, available at: <https://emedicine.medscape.com/article/1413467-overview>.

palatal grooving, dentition interference, and feeding/oral issues.

Duration of intubation is based on clinical condition of the infant and may last minutes for medication administration only (surfactant) or for hours to days for respiratory support. Extubation is removal of the ETT.

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Intubation: Information for Parents

Your baby was born with or has developed breathing problems. There are many different types of breathing problems, many related to a baby being born too early, that require intubation. Intubation is the passage of a flexible plastic tube into the baby's trachea (airway or windpipe). The trachea goes from the baby's mouth and nose to the lungs to help them breathe. The tube in the baby's windpipe is then connected to oxygen or a ventilator (a machine that breathes for your baby).

Intubation = Tube In

Intubation may happen as an emergency, meaning your baby needs help breathing immediately, or it can be elective, meaning when the health team decides it is time to help your baby breathe better. Neonatal nurse practitioners (NNPs), neonatologists, and other skilled healthcare providers are trained to do this procedure. Intubation may be done to help the baby breathe, to give special medicine into the lungs such as surfactant, to suction the airways/lungs, for surgery, or to aid when there is an obstruction (airway blockage).

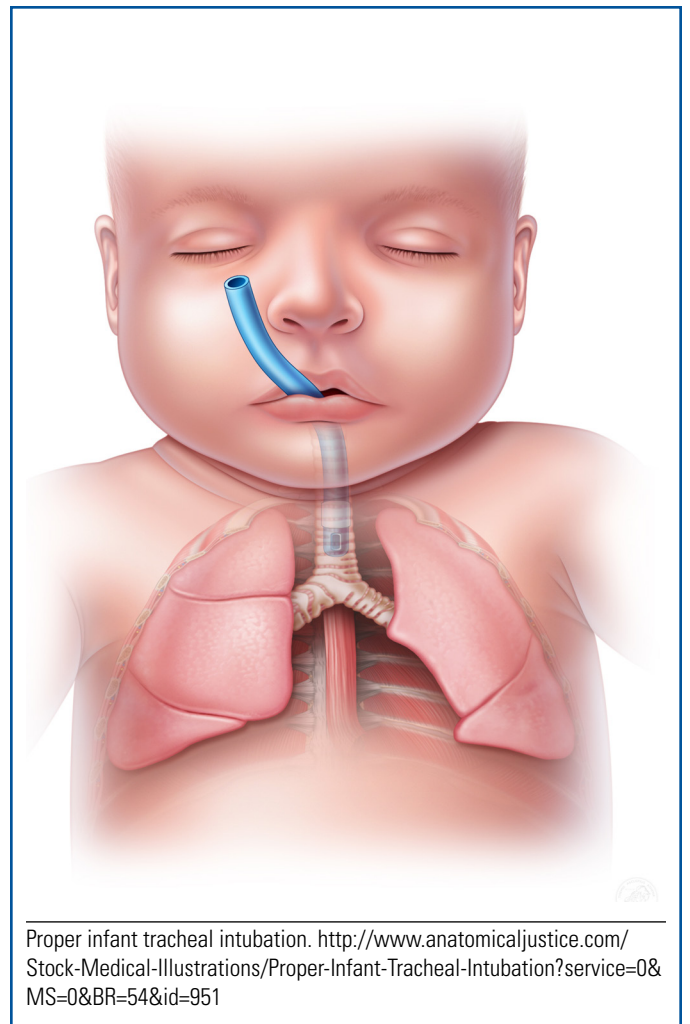
The procedure involves having your baby lying face up on a flat surface, usually a warming bed, and monitored at all times. Medication may be given to control any discomfort and help quiet your baby for the procedure. The person performing the procedure will wear gloves, suction your baby's mouth and throat, and look into your baby's mouth with a special flashlight called a laryngoscope. The plastic tube inserted into the trachea is called an endotracheal tube (ETT). The ETT will be put through your baby's vocal cords, into the opening of the trachea. The ETT will be connected to a ventilator (breathing machine) or to a bag-and-mask device to breathe for the baby. After the ETT is inserted, an X ray will be taken to make sure the tube is in the right place and working well. Tape around the baby's lips will hold the ETT in place.

The ETT may stay in for a few minutes—only long enough to give medicine—or for days depending on your baby and his or her needs. Occasionally, the ETT may come out by accidentally bumping it or moving your baby and must be

replaced. The ETT in babies is very small and only goes into the trachea a tiny bit so any movement can easily displace this fragile tube. For this reason, it is really important that you speak to the nurse before trying to move or pick up your baby.

Babies who are intubated cannot eat by bottle and must be fed by the IV or by a feeding tube. But, parents can assist the nurse or respiratory therapist when they are doing oral (mouth) care.

Once the decision is made to remove the ETT, it can be easily untaped and pulled out. Your baby may have a somewhat sore and swollen throat afterward and may sound hoarse when crying for a while after the tube is out. This usually gets better after a day or two.





Lumbar Puncture

The indications of a lumbar puncture may fall into several different categories. These indications include

- to aid in the diagnosis of central nervous system (CNS) infections, such as meningitis or encephalitis, or to aid in the diagnosis of congenital infections, such as herpes simplex, rubella, and cytomegalovirus as well as other bacterial and fungal infections
- to monitor the efficacy of antimicrobial therapy in the presence of CNS infections
- to aid in the diagnosis of metabolic diseases
- to provide a route for the administration of medications
- to decrease volume of cerebral spinal fluid (CSF) inside the ventricles.

Contraindications for the procedure include increased intracranial pressure due to the risk of CNS herniation, presence of known bleeding abnormalities or low platelet counts, current infection near the site of the injection for the procedure, and lumbosacral abnormalities.

Precautions

- The infant should have ongoing cardiorespiratory monitoring, including oxygen saturations, during the procedure. Airway compromise can be an issue because of the positioning of the infant for the procedure. This can be reduced by avoiding fully flexed lateral position and direct flexion of the neck. Supplemental oxygen administration may assist in avoiding hypoxia. Lastly, flexing the hips only to a 90-degree angle may avoid abdominal compression and the potential for aspiration.
- Strict aseptic technique should be employed.
- Always use a needle with a stylet to avoid development of intraspinal epidermoid tumor. Do *not* use a butterfly needle for the procedure.
- Never aspirate the spinal fluid with a syringe. Allow the specimen collection to occur by gravity to avoid the increased risk for a subdural hemorrhage or herniation.

Procedure Considerations

Consider offering the infant preprocedural pain measures such as 24% sucrose solution, swaddling that doesn't

interfere with procedure site or sterile field, and use of a pacifier if appropriate to the infant's condition. EMLA cream also is a consideration for older infants or premature infants with mature skin.

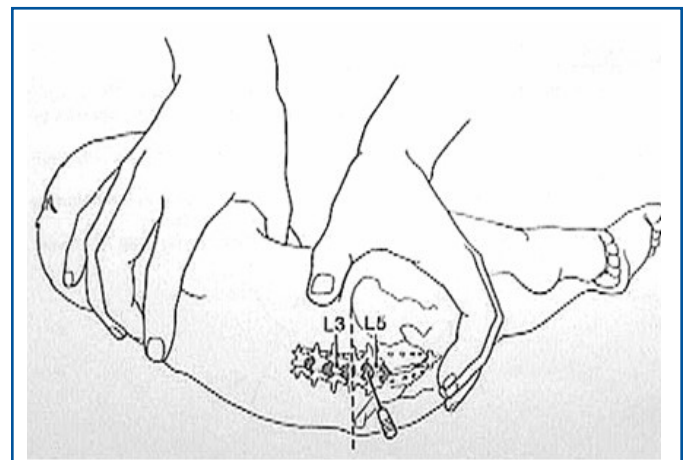
The lateral decubitus or sitting position is appropriate as long as there is good spine flexion. The assistant should avoid flexion of the neck to avoid the chance of airway compromise.

The CSF is generally collected in the tubes in the following order to be sent for testing:

- Tube 1. Gram stain, bacterial culture and sensitivity.
- Tube 2. Glucose and protein levels.
- Tube 3. Cell count and differential
- Tube 4 (optional). Rapid antigen testing for specific pathogen or polymerase chain reaction (PCR).

Complications

In neonates, a common complication is transient hypoxemia from positioning during the procedure as mentioned above. Other potential complications include contamination of CSF specimen with blood, infection (bacteremia, vertebral body osteomyelitis, spinal cord, or epidural abscess), intraspinal epidermoid tumor from lack of use of stylet, spinal cord or nerve damage if performed



Positioning and landmark used for lumbar puncture. The iliac crest (dotted line) marks the approximate level of L4. Reproduced with permission from Pediatrics, Vol. 128, Copyright ©2018 by the AAP.



above L4, bleeding or hematoma at site, CSF leakage into epidural space, and pain.

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Lumbar Puncture: Information for Parents

A lumbar puncture, also known as a “spinal tap,” is a procedure your baby needs in which cerebral spinal fluid (CSF) will be collected. CSF is the colorless liquid that is contained in your infant’s back (spine) and around their brain and acts as a “cushion” to the brain and spinal cord. In a lumbar puncture, this fluid is carefully collected with a needle inserted into your baby’s back (much like an epidural for moms in labor) and will be sent for testing.

Common reasons that a lumbar puncture may be indicated for your child

- to help determine if your baby has an infection in the spinal fluid (meningitis)
- to remove excessive spinal fluid buildup when certain conditions are present.

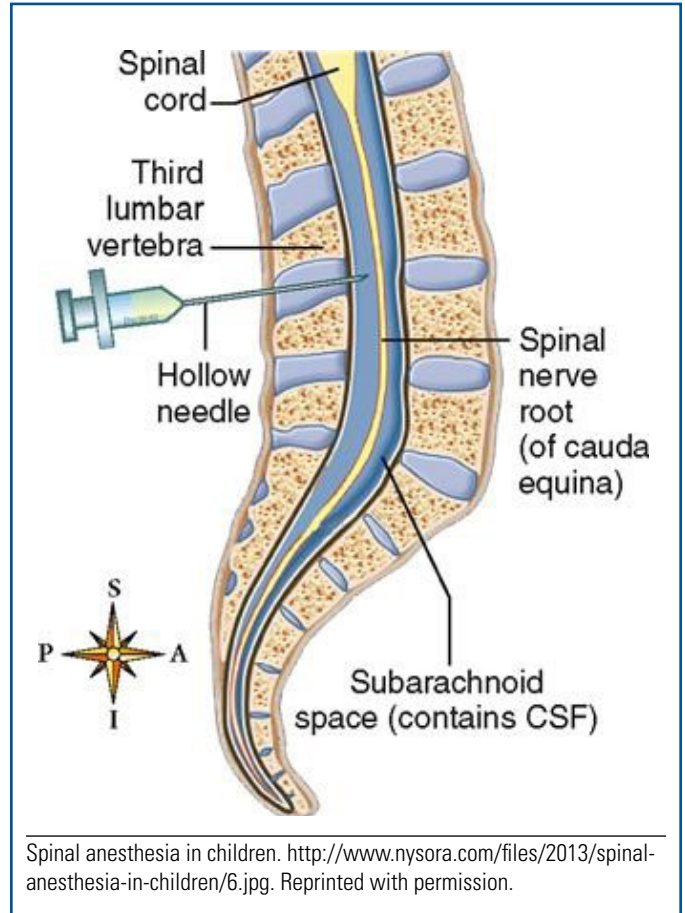
Procedure

In most instances, after your provider has discussed the need for the procedure and has explained the risks and benefits, you will need to complete a consent form. Before doing a lumbar puncture, a numbing cream may be applied to the area of the spine where the lumbar puncture will take place. Sometimes, the provider may use a local anesthetic to numb the site on your baby’s back. Other comfort measures can be done for your baby during the procedure, such as offering a sucrose pacifier. A hollow needle is then inserted between the bones (called the vertebrae) of your baby’s back. A sample of the CSF is collected through the needle and sent for testing. A small dressing will be used to cover the site where the needle was inserted.

Risks and Benefits

The information obtained from the fluid testing can give life-saving and diagnostic information to your healthcare team. There are a few risks, which include

- infection where the needle was inserted in to the back
- bleeding into the spinal canal or leakage of fluid from the spinal canal
- injury to the spinal cord itself (very rare).



If your baby requires a lumbar puncture, don’t be afraid to ask questions. Try to remind yourself that the procedure is necessary to make an accurate diagnosis and provide the best possible treatment for your baby. In some cases, a lumbar puncture is the only way to gain information on the nature of your baby’s illness.



Peripherally Inserted Central Catheters

Most babies admitted to intensive care nurseries require vascular access for prolonged intravenous (IV) therapy. Extremely-low-birth-weight and critically ill neonates usually have umbilical lines placed for access right after birth. A peripherally inserted central catheter (PICC) may be considered in place of or before removing the umbilical venous line (UVC) to reduce stress and pain at repeated attempts to place a peripheral IV.

PICC insertion is considered an expanded practice role for nurses, and therefore is intended for nurses who are experienced in intravenous therapy and in the care of central lines. Some intensive care units use nurse practitioners or physicians to insert PICCs while other insertion teams consist of both staff nurses and advanced practice nurses.

Informed Consent

The infant's parents may be asked to sign an additional consent form prior to PICC insertion. You or a member of the healthcare team will review with the parents the procedure and risks/benefits for their infant.

Pain Management

The infant may be given medications to manage any procedural pain and provide sedation during the PICC line placement. This is to ensure that the baby is comfortable during the procedure. You may notice that the infant is sleepy after the procedure is completed. This is a common side effect of the medications and not concerning.

Care and Maintenance of the PICC

Each nurse caring for a patient with a PICC is able to identify potential complications and knowledge of care and maintenance strategies. The PICC will be assessed by the nurse at least once each shift.

Post-Insertion Complications

Although there are many benefits to the use of PICCs in neonatal patients, there are some risks and potential complications, including

- cellulitis (localized site infection that may present as pain, tenderness, and redness at the entrance site of the catheter)
- edema (swelling) of the extremity (may be due to many factors such as the size of the catheter relative to the size of the vein, a restrictive dressing, a bend in the extremity, dependent positioning, or decreased movement)
- thrombus-thrombosis (may be caused by endothelial injury from local trauma or inflammation of the vessel wall). Catheter occlusion and thrombosis can result in significant problems and inability to use the device.
- phlebitis (defined as an inflammation of the vein and seen as edema or erythema surrounding the vein, a visible red streak along the vein and/or a palpable cord of vein). Phlebitis is the result of vessel wall irritation due to a mechanical irritant (i.e., the catheter), a chemical irritation due to medication or hyperosmolar solution, or a poorly secured catheter with movement in and out of the vessel.

Catheter Tip Migration

Malposition occurs because of misdirection on catheter insertion, perforation, curling, knotting, or spontaneous migration after initial placement.

Blood Sampling and Administration

Once placement is verified, the PICC line may be used for blood sampling and blood product administration based on the facility's policies and practice guidelines.

Dressing Changes

PICC dressings provide a protective environment for the catheter entrance site and help prevent catheter migration. Transparent dressings should be changed when the catheter is replaced; when the dressing becomes damp, loosened, or soiled; or when inspection of the site is necessary.

All facilities involved with insertion of PICCs have formal organizational policies and procedures in place that provide clear lines of responsibility for insertion, care



and maintenance, and outcomes monitoring. While PICCs have become a common practice in neonatal intensive care units, continued education and research are crucial to ensure the best outcomes for neonatal patients.

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Peripherally Inserted Central Catheter Lines: Information for Parents

A peripherally inserted central catheter (PICC) is a very thin intravenous (IV) catheter that is inserted in a vein in the arm, leg, or scalp of an infant. A PICC line is used in infants who will need total IV nutrition or medication for more than 7 days. It is usually placed within the first week after birth. A PICC can remain in place for weeks or for as long as the baby needs it.

When your baby is having a PICC inserted, the procedure consists of placing a very slim, soft catheter into an arm, leg, or scalp vein, and then advancing the catheter into a larger vein close to the heart. Once the line is in place, an X ray is done to make sure the position is correct before it is used. Having a PICC line alleviates the need for frequent IV insertions, reducing the number of sticks your baby will receive. Insertion of a PICC line is usually based on the needs of your baby. It is not an emergent procedure and parental consent is necessary.

Procedure

Most neonatal intensive care units (NICUs) have a neonatal PICC team who will insert the PICC lines. A physician, nurse practitioner, or a nurse from the PICC team will explain the risks and benefits of the procedure as part of obtaining parental consent.

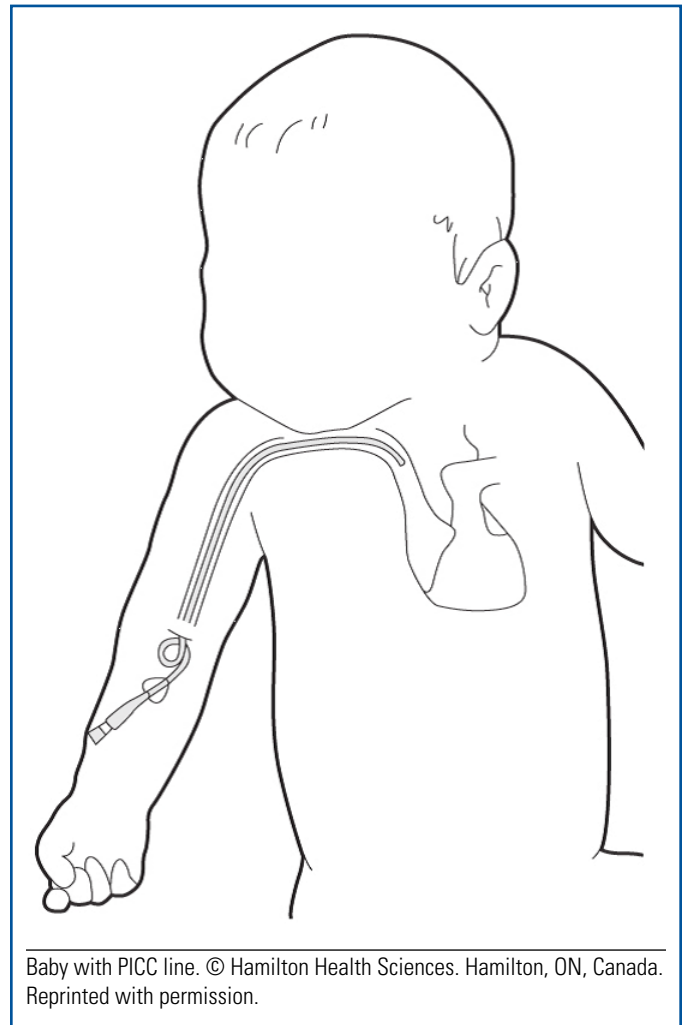
The entire process of inserting a PICC line may take 30 minutes to 1 hour, but it may take longer to make sure the catheter is in the correct position. The procedure is done under sterile (free from germs) technique and placement is usually done at your baby's bedside. Prior to the start of the procedure, your baby will be swaddled or wrapped snugly in a blanket and given sucrose (sweet water), a pacifier, and other pain medicines to keep your baby comfortable during the procedure. After the initial skin stick, your baby should not experience any pain. Your baby will be draped from head to toe with sterile towels/drapes with only the arm/leg/scalp site exposed. Your baby's skin will be washed with a solution to prevent infection. Once the catheter is in place, an X ray will be done to make sure the tip is in a good location. Then, a sterile dressing will cover the line on your baby's skin to help prevent infections.

Alternatives to PICC Lines

For babies who need total IV nutrition, the only alternative to a PICC line is having frequent or repeated IVs inserted. While the staff can make sure your baby has pain control with IV sticks, frequent sticks can increase your baby's risk of infection.

PICC Line Removal

Removal of a PICC line usually is a simple procedure and does not cause much pain to your baby. A PICC line will be removed as soon as your baby no longer needs it. Usually, this is when a baby no longer needs IV medications or when the infant is receiving full nutrition from either mom's breast milk or formula (by bottle or a feeding tube). Once the line is removed, pressure will be applied to the site and the site will be monitored for bleeding.

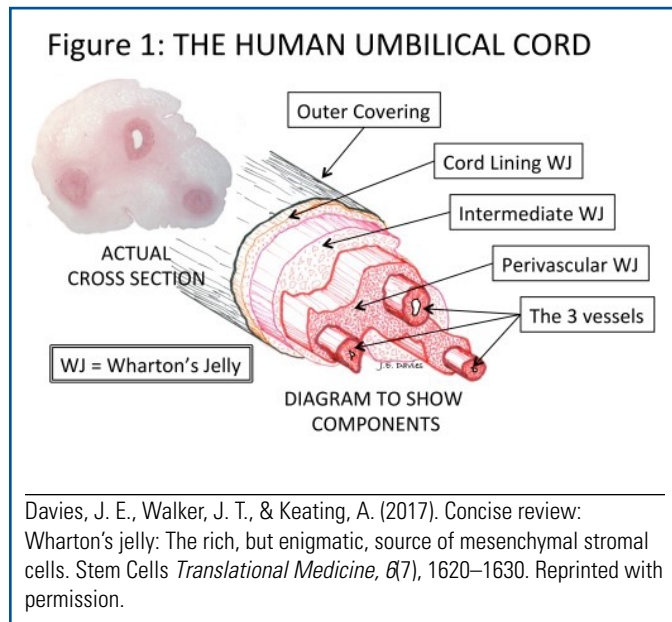




Umbilical Venous Catheter/Umbilical Artery Catheter

The umbilical cord is clamped just prior to separating an infant from his or her mother. This cord usually has three vessels consisting of two arteries and one vein. Because these vessels are easily accessible, if an infant is sick or premature and needs intravenous or arterial access, these vessels may be used first for quick access.

The umbilical venous catheter (UVC) is placed in the vein of the cord. This line is used to administer total parenteral nutrition, emergency or vasoactive medications (epinephrine, dopamine, etc.), and other fluids to infants who are sick and will need to receive nothing by mouth for some time. The line also may be used to administer blood products if needed. UVCs decrease the need for intravenous (IV) lines in the hands, arms, or feet and thereby decreases the number of times an infant is stuck to maintain a peripheral IV. The line is placed by a neonatal provider (medical doctor, neonatal nurse practitioner) or specially trained registered nurses. Line placement should be a sterile procedure with full barrier protection. The procedure usually takes place at the infant's bedside, and requires an X ray to validate line placement. Placement should be verified before any fluids are infused through the UVC. The UVC tip should be above the diaphragm but below the junction of the inferior vena cava and the superior vena cava on chest X ray. The only exception to this rule is when the UVC is placed in the delivery room during resuscitation. When the catheter tip is in a good position, a UVC can be left in place for several days but should be removed as soon as possible.



Umbilical Catheters

1. Remove and do not replace umbilical artery catheters if any signs of CRBSI, vascular insufficiency in the lower extremities, or thrombosis are present [145]. **Category II**
2. Remove and do not replace umbilical venous catheters if any signs of CRBSI or thrombosis are present [145]. **Category II**
3. No recommendation can be made regarding attempts to salvage an umbilical catheter by administering antibiotic treatment through the catheter.
Unresolved issue
4. Cleanse the umbilical insertion site with an antiseptic before catheter insertion. Avoid tincture of iodine because of the potential effect on the neonatal thyroid. Other iodine-containing products (e.g., povidone iodine) can be used [146–150]. **Category IB**
5. Do not use topical antibiotic ointment or creams on umbilical catheter insertion sites because of the potential to promote fungal infections and antimicrobial resistance [88, 89]. **Category IA**
6. Add low-doses of heparin (0.25–1.0 U/ml) to the fluid infused through umbilical arterial catheters [151–153]. **Category IB**
7. Remove umbilical catheters as soon as possible when no longer needed or when any sign of vascular insufficiency to the lower extremities is observed. Optimally, umbilical artery catheters should not be left in place >5 days [145, 154]. **Category II**
8. Umbilical venous catheters should be removed as soon as possible when no longer needed, but can be used up to 14 days if managed aseptically [155, 156]. **Category II**
9. An umbilical catheter may be replaced if it is malfunctioning, and there is no other indication for catheter removal, and the total duration of catheterization has not exceeded 5 days for an umbilical artery catheter or 14 days for an umbilical vein catheter. **Category II**

From the Centers for Disease Control and Prevention



CDC Guidelines for Umbilical Catheters

The umbilical artery catheter (UAC) is placed in one of the arteries in the cord. This line is used to continuously monitor an infant's blood pressure and also to collect frequent blood samples without sticking the infant. A UAC is usually placed at the same time a UVC is inserted. X-ray confirmation reveals the position of the UAC, and assuming the infant's abdomen is included in the film, the tip of the UAC should be between the sixth and eighth ribs. Some units still place the tip at the third to fourth lumbar intervertebral space, but a Cochrane systematic review (Barrington, 1999) found that high lines (T6-T8 tip position) had fewer complications than those placed low (L3-L4).

Lines should be secured according to the unit's policy. Securement is important as it reduces "play" in the lines and may reduce migration of the catheters to unsafe areas. The UAC will then require a pressure transducer to be connected to the line for pressure monitoring. It also is important to remember that all umbilical lines should always have luer connections and stopcocks, to decrease the risk of blood loss due to loose connections.

With both or either umbilical lines, care should be used when handling the infant to prevent dislodgement

of the line or stopcock (which can lead to bleeding). Dislodgment will require line replacement, repositioning, or removal. Meticulous care will help prevent inadvertent turning of the stopcock, which can lead to blood loss. When an infant is being held and wrapped in blankets, special attention should be paid to the integrity of the catheter and connections.

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Umbilical Vein Catheter and Umbilical Artery Catheter: Information for Parents

After delivery, a baby is separated from his or her mom by clamping, then cutting, the umbilical (navel) cord. The cord typically has two arteries and one vein that are easily accessible, providing quick access to the central circulation and are used frequently when infants are born early or sick. These lines will keep your baby from needing a regular intravenous (IV) line for several days and decrease the number of times they have their skin poked. Umbilical lines are inserted by a physician or neonatal nurse practitioner (NNP). The physician or NNP will explain the risks and benefits of the procedure.

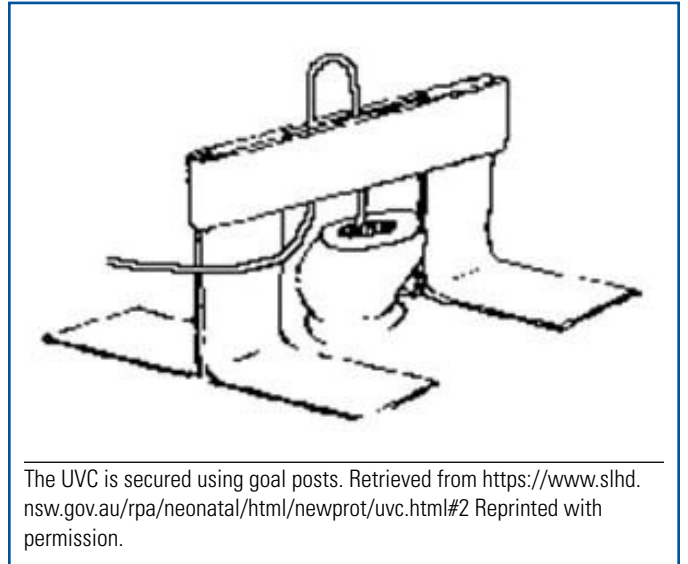
Umbilical Artery Catheter

An umbilical artery catheter (UAC) is placed in the artery of your baby's umbilical or navel cord. This catheter is used to obtain frequent blood samples and monitoring of your baby's blood pressure. Blood samples are necessary to help the medical team determine how well your baby's lungs and other body organs are functioning. Blood is drawn directly from this line, alleviating the need to do heel sticks on your baby. The UAC typically is in place for 7–10 days. If your baby still needs blood pressure monitoring or blood samples, an arterial line may be inserted in his or her ankle or wrist.

A UAC line usually is placed right after delivery or right after transport and admission to the referring hospital, and typically at the same time as an umbilical venous catheter (UVC) is placed. Once the lines are in place, an X ray is done to make sure the lines are in the correct position before they are used. The lines are then held in place with suture (like string) and secured to the infant's abdomen (see picture).

Umbilical Venous Catheters

An umbilical venous catheter (UVC) is placed in the vein of your baby's umbilical or navel cord. This catheter is used to give your baby IV nutrition (nutrition given in the vein) or medications. The line typically remains in place for 7–10 days. If your baby still needs IV nutrition, either a peripherally inserted central catheter (PICC) or regular IV



The UVC is secured using goal posts. Retrieved from <https://www.slhd.nsw.gov.au/rpa/neonatal/html/newprot/uvc.html#2> Reprinted with permission.

will be inserted. The UVC usually is inserted with a UAC right after delivery or transport. There are times when a UVC will be placed after the baby is a few days old when access to a big vein is needed. In this case, the provider caring for your baby will explain the reason for the line and get your approval.

When the proper position of both catheters is confirmed by the X ray, the lines will be sutured in place or secured to the infant's abdomen.

Possible Complications

Complications may include infection, formation of blood clot (thromboembolism) on the tip of the line, or the line moving in or out of position. Because of these possible complications, the nurse will watch your baby closely. The lines are placed with a sterile (without germs) technique to decrease the risk of infection. Fluids going in both UVC and UAC lines will contain a medicine called heparin, which prevents the formation of blood clots. Finally, the nursing staff will closely monitor the catheters for any potential issues. All umbilical lines will be discontinued as soon as they are no longer needed.

Diagnoses



Apnea of Prematurity

Apnea of prematurity (AOP) is the most common and recurring problem of respiratory control in the premature infant. AOP occurs in more than 85% of all infants born prior to 34 weeks gestational age. The incidence of AOP is inversely proportionate to gestational age at birth—as gestational age decreases, apnea becomes more prevalent.

In premature infants without respiratory distress syndrome (RDS), AOP may occur on the first day of life, but it may not present for several days in infants with RDS. Many perinatal and postnatal complications increase the infant's risk of developing AOP, including central nervous system insult or injury, respiratory insult or injury, metabolic disease, sepsis, congenital defects, inborn errors of metabolism, birth trauma, and maternal substance use (including smoking and alcohol consumption). Some evidence supports heredity as a risk factor.

Definition

AOP is most commonly defined as the cessation of breathing for more than 20 seconds, or 5–10 seconds in the presence of bradycardia (heart rate < 80 bpm or 30 bpm below baseline) or desaturations ($\text{SaO}_2 < 80\%$ –85%). Brief respiratory pauses that are less than 10 seconds in duration and not associated with bradycardia or desaturations can occur in conjunction with startles, movement, defecation, or asynchrony during feedings, and are usually self-limiting.

In the premature infant, apnea may be the presenting symptom accompanying altered homeostasis of nearly all organ systems. Temperature instability, asphyxia or hypoxemic events, sepsis, metabolic disturbances, respiratory compromise, patent ductus arteriosus or other heart defects, intracranial hemorrhage, feeding disruptions, hematologic disturbances, pain, and agitation are some examples. AOP is considered a diagnosis of exclusion because it often is the presenting symptom of other pathologic conditions and should be thoroughly investigated before being assigned this diagnosis.

Classification

AOP is distinguished by duration and hemodynamic dysfunction and is further classified into three categories based on the presence or absence of obstruction. *Central apnea* involves total cessation of respirations or the absence of respiratory muscle activity accompanied by the absence of airflow. *Obstructive apnea* is characterized by the presence of respiratory muscle activity in the absence of airflow that continues throughout the entire apnea episode. *Mixed apnea* consists of a combination of obstructed apnea and central apnea and is believed to represent the most common type of apnea in the newborn. Obstructive apnea may occur in the pharynx, the larynx, or in both areas of the upper airway. *Ideopathic apnea* is most commonly associated with prematurity.

Hypoxemic events resembling apnea have been detected in intubated, mechanically ventilated preterm infants. These episodes of hypoxemia are preceded by increased pulmonary resistance and decreased compliance similar to events occurring before apnea in unintubated infants. Subtle, spontaneous movements precede these episodes, and they are characterized by central respiratory depression and obstructed airflow. The events are a consequence of hypoventilation and are frequently associated with arousal.

Periodic Breathing

AOP should be distinguished from periodic breathing, in which the infant exhibits regular short cycles (10–20 seconds in length) of respiration that are interrupted by respiratory pauses of at least 3 seconds. The pattern recurs for at least 2 minutes followed by a stronger respiratory drive to restore normal ventilation and often is accompanied by mild hypoxemia. Periodic breathing is considered a benign developmental phenomenon, and medical treatment is not indicated. However, when preceded by significant hypoxemia or when associated with bradycardia or prolonged apnea with alveolar hypoventilation, it is abnormal and may be a precursor to pathologic apnea.



AOP and periodic breathing are disorders that tend to decline in frequency with advancing postconceptual age and are treated with administration of methylxanthines.

Pathophysiology

AOP is a common disorder of respiratory control in premature infants. Apnea presenting independent of other pathology is most likely a maturational feature representing a physiologic rather than pathologic immaturity of respiratory control. However, a clear mechanism responsible for apnea in premature infants has not been identified.

Normal rhythmic breathing requirements include a patent airway; a central respiratory drive originating from respiratory centers in the brainstem (modulated by input from peripheral neural and chemical receptors); and coordinated, effective functioning muscles of respiration. Changes in arterial PCO_2 , PO_2 , and pH act on neural and chemical receptors from these centers and are integrated by the respiratory center in the brainstem, which sends signals to the respiratory muscles responsible for maintaining airway patency and regulating the level of ventilation. The immature brainstem respiratory centers in preterm infants have an attenuated response to carbon dioxide and a paradoxical response to hypoxia, which results in apnea rather than the normal hyperventilation response. Anatomical characteristics such as decreased number of synaptic connections, decreased dendritic arborization, and poor myelination result in functional immaturity of the brainstem, which improves after treatment with methylxanthines.

Obstructive apnea can be the result of poor pharyngeal tone, which can cause the pharynx to collapse with negative airway pressures generated during inspiration. Structurally, the airways are more compliant and smaller, both in diameter and length, and are at increased risk for blockage by malpositioning, edema, and excess mucus.

Genetic factors associated with a higher risk of occurrence in premature infants include being born to first-degree consanguineous parents, being monozygotic twins, and having a sibling who presents with complications of apnea.

Significant ventilatory and cardiovascular consequences can be associated with AOP. Prolonged apnea results in hypoxemia and hypercarbia, which is directly related to the frequency, duration, and intensity of the episode.

Apnea and Gastroesophageal Reflux

Gastroesophageal reflux (GER) is a common problem in premature infants and often is suggested as a component of AOP. Reflux of gastric contents into the larynx may induce apnea as a result of stimulation of the laryngeal nerve or other afferent pathways; however, this mechanism is not proven to either cause or prolong apnea. The frequency with which the two conditions coexist is debated, and the cause-effect relationship is multifactorial. The majority of apnea occurring before GER is central in origin, but when apnea occurs during or after a GER episode, it is more frequently mixed apnea. In some instances, apnea occurs prior to reflux, decreasing lower esophageal tone and lower esophageal sphincter pressure resulting in reflux. In the overall premature infant population, GER does not induce apnea, prolong the duration of apnea, or exacerbate apnea-related bradycardia or desaturations. Further, there is no clear evidence that pharmacologic agents that decrease gastric acidity or enhance gastrointestinal motility impact the frequency or duration of apnea.

Management

Management begins by eliminating factors associated with increasing risk of apnea, by taking measures such as ensuring a stable thermal environment, maintaining airway patency, and using proper positioning. Ensuring proper placement of nasal and oral gastric tubes is important, as malposition of these tubes has been implicated in association with apnea. Cue-feeding, pacing with feedings, and left-side lying position are good measures for parents to facilitate better feeding patterns, which may reduce the incidence of choking and apnea. Prone positioning of the preterm infant assists to “splint” the chest wall and facilitate slight neck extension positioning and stabilization of the head; this positioning has been shown to improve breathing. Prone positioning in the preterm infant also is associated with improved gastric emptying time. Prone positioning is indicated only with



the use of cardiorespiratory monitoring, and the importance of transitioning to supine positioning for home care cannot be over emphasized.

Administering continuous airway pressure is associated with decreased apnea. Evidence suggests it may serve as a “splint” for upper airways and the chest wall, increase oxygenation, and help maintain functional residual capacity. Many times, the flow is enough to support the infant with apnea, but sometimes administration of oxygen along with flow is necessary. Continuous positive airway pressure reduces the frequency of only mixed and obstructive apnea, with little or no effect on central apnea in infants. Infants unresponsive to these therapies or methylxanthines will require intubation and ventilatory support.

Methylxanthines are the mainstay of treatment for apnea. These agents have multiple pharmacologic and physiologic mechanisms of action, including increased minute ventilation, improved CO₂ sensitivity, decreased hypoxic depression, enhanced diaphragmatic activity, and decreased periodic breathing episodes. Treatment usually is initiated with a loading dose followed by maintenance therapy in either oral or intravenous (IV) preparation. Common side effects include tachycardia, feeding intolerance, emesis, jitteriness, restlessness, and irritability. Toxic levels may produce cardiac dysrhythmias and seizures. Methylxanthines increase metabolic rate and oxygen consumption, have a mild diuretic effect, increase cerebral metabolic rate, and decrease cerebral blood flow.

Theophylline, aminophylline, and caffeine citrate have demonstrated effectiveness in the treatment of apnea of prematurity. Caffeine citrate is considered preferable because it is better tolerated and has fewer side effects, a larger margin of safety, a higher therapeutic index, and a longer half-life. The long half-life allows once-per-day dosing, and the larger margin of safety means monitoring levels at the recommended dosing is seldom necessary. Caffeine has been shown to reduce the rate of bronchopulmonary dysplasia and may have neuroprotective benefits as well.

Doxapram, another respiratory stimulant, has been used in infants with idiopathic apnea of prematurity refractory to methylxanthines. It acts through stimulation of a peripheral chemoreceptor and has been shown to increase minute ventilation, tidal volume, inspiratory flow, and airway pressure. Side effects include hypertension, irritability, hypoglycemia, gastric irritability, and in a small number of preterm infants, heart block. Doxapram is available as an oral drug, but it is poorly absorbed. Because of this, it is typically used as a continuous IV infusion. Benzyl alcohol is the preservative used in doxapram, although the concentration is considered low (0.9%/mL) and at recommended dosing, toxicity in the neonate is unlikely. Toxicity is associated with a potentially fatal side effect known as *gasping syndrome* in neonates. Due to the benzyl alcohol preservative and its potential side effects, use of doxapram is limited in the United States.

Anemia can lead to apnea of prematurity, desaturations, and bradycardia. The symptoms of anemia appear to be worse in more premature infants, and in infants with underlying disease processes. Red blood cell transfusion is a proposed mechanism to increase oxygen carrying capacity; however, blood transfusions also are associated with worsening bronchopulmonary dysplasia and necrotizing enterocolitis. Red blood cell transfusions should be reserved for infants with significant clinical signs and symptoms of anemia.

AOP often resolves and then resurges in response to other pathology. Retinopathy of prematurity exams, immunizations, and surgery are associated with recurrence of apnea.

Resolution

Apnea of prematurity resolves by around 36–40 weeks gestational age. However, in more premature infants it may last beyond 43–44 weeks gestational age and is a problem that frequently delays discharge.

Consequences

In premature infants, desaturations and bradycardia frequently occur along with apnea. Bradycardia most often



occurs after the onset of hypoxemia and may be accompanied by increased stroke volume. Prolonged apnea, bradycardia, and desaturations lead to decreased systemic blood pressure and cerebral hypoperfusion, which can contribute to hypoxic-ischemic injury of the immature brain. Untreated significant apnea often progresses and can lead to complications of the respiratory system, cardiac system, gastrointestinal system, central nervous system, and renal system.

Identifying the long-term consequences of apnea is difficult because of the numerous secondary causes of apnea. Neurodevelopmental outcome is less favorable in infants when apnea persists, when mechanical ventilation is required for longer periods of time, and when frequent apnea persists after discharge. Former premature infants with AOP may be at a higher risk to develop sleep-disordered breathing later in life.

Consistent and reliable evidence continues to support no relationship between persistent AOP and an increased risk of sudden infant death syndrome (SIDS). The use of

home monitoring for prevention of SIDS in infants with AOP is not indicated by the American Academy of Pediatrics. However, when apnea persists, the use of home monitoring may be an alternative to delayed hospital discharge. Because the monitors are subject to false alarms and “missing” some apnea and bradycardia, this practice remains controversial.

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Apnea of Prematurity: Information for Parents

Apnea of prematurity is when your baby's breathing pauses. It is very common for this to happen in premature babies. The more premature the baby is, the more common apnea is. The pauses in breathing may happen alone, but more commonly they happen with drops in heart rate (bradycardia) or oxygen saturations (desaturations).

Apnea can happen just because the baby is premature, or it can be a symptom of some other illness or problem. When the apnea happens alone and only once in a while, your baby's provider will watch your baby very closely. When the apnea happens with bradycardia or desaturations, your baby's provider will run blood tests and possibly do other tests such as X rays, head ultrasounds, and heart sonograms (known as an *echocardiogram* or *cardiac echo*) to make sure nothing else is causing the apnea.

Many times, premature babies need medications to help their bodies remember to breathe, and sometimes they need more help from a nasal cannula, continuous positive airway pressure, or a breathing machine. Apnea often is the first symptom seen when a baby has an infection, so antibiotics may be started even before the test results come back.

Premature babies often are placed on their tummies, which helps support the chest (so they breathe easier) and helps with digesting feedings. In the neonatal intensive care unit, your baby is on monitors that will sound an alarm if the baby stops breathing or has a drop in heart rate or oxygen saturations. As your baby grows and the apnea (and other conditions) improve, your baby will be

placed on his or her back because this is the safest way for your baby to sleep and rest as he or she gets closer to going home.

Apnea usually improves as your baby gets older, but it takes longer for it to improve in some premature babies. Sometimes even after the apnea seems to have stopped, it starts again. This can happen because the baby is still immature or because of necessary tests like an eye examination. Apnea may start again (briefly) after immunizations are given. The apnea that happens after immunizations is usually very mild. It is important that your baby has eye examinations and receives immunizations to protect him or her from serious problems later on.

Sometimes apnea continues as your baby is getting closer to going home. It is important to continue watching and caring for your baby in the hospital until it is safe for your baby to go home. Babies are sometimes sent home on the medications that help them remember to breathe.

Apnea of prematurity does not mean your baby is more at risk for sudden infant death syndrome (SIDS). Things that increase the baby's risk for SIDS are cigarette smoke; sleeping on their tummies; a lot of soft fluffy bedding (e.g., blankets, pillows, stuffed animals); keeping the room too warm; and sleeping with others.

It is important that you keep all of your follow-up appointments and that your baby receives immunizations at the scheduled times.



Bronchopulmonary Dysplasia

Introduction

Bronchopulmonary dysplasia (BPD) is a form of chronic lung disease (CLD) that is seen in preterm infants who had respiratory distress syndrome (RDS) at birth and continue to require supplemental oxygen and/or ventilator support beyond 36 weeks corrected gestational age (CGA). In addition to premature birth, risk factors include the need for supplemental oxygen and ventilator support. Factors such as intrauterine growth restriction, infection (acquired either in utero or postnatally), patent ductus arteriosus (PDA), and genetic predisposition may contribute to the pathogenesis of this disorder. For nurses who work in the NICU as well as those who are involved in the delivery, resuscitation, and stabilization of preterm infants, understanding the disease process, treatment, and outcomes will allow patient care to be based on a strong scientific foundation.

Definition

The definition of BPD has evolved over the years as viability thresholds for preterm infants have decreased; thus, it often is described as “old BPD” versus “new BPD.” This is a reflection on the distinct embryologic differences in pulmonary development at different gestational ages. It also is influenced by changes in treatment strategies and by technological and pharmacological options that exist today.

Etiology of BPD/CLD

Pulmonary disease of the newborn is multifactorial. Infants develop respiratory distress and possibly BPD/CLD in part because there is an interruption in the development of the lungs and inability to manufacture surfactant necessary to prevent alveolar collapse. Other factors that contribute to the pathogenesis of BPD include inflammation, genetic predisposition, clinical management techniques of respiratory failure, and response to infection or oxygen toxicity. These factors may increase the likelihood of chronic lung changes and support the need for continued support.

Old BPD

This form of CLD was first described in the 1960s by Northway, who observed radiographic changes in late preterm infants who had been exposed to aggressive mechanical ventilation and high concentrations of oxygen (Northway, 1990). This damage occurred in the late sacular stage of lung development with X-ray findings consistent with extensive inflammation and fibrotic and cystic changes in the lung parenchyma and airways. The diagnosis of BPD was assigned to the infant if he or she was oxygen dependent at 28 days of age.

As the practice of neonatology evolved and new technological and treatment modalities were developed, the gestational age at which infants were surviving became lower and lower. Exogenous surfactants improved lung compliance and reduced oxygen requirements. Ventilators designed for use in this patient population became increasingly more sophisticated. These innovations and others allowed for gentler methods of ventilation and, in some cases, reduced damage to airways and resultant fibrosis. However, as survival improved in extremely preterm infants, there was an inverse relationship seen in the severity of BPD with gestational age. Today, approximately two-thirds of infants who develop BPD are extremely low birth weight (< 1,000 g) and less than 28 weeks gestation at the time of their birth.

New BPD or CLD

As knowledge of factors that contribute to the development of BPD grew, neonatal centers worked to refine their management of respiratory diseases in preterm infants. Many centers have seen a reduction of the clinical presentation in the older preterm infant, but they have now noticed a different form of CLD that may not be associated solely with the absence of surfactant, high oxygen exposure, or lung damage related to ventilation. Although providers thought that reduction of volutrauma and surfactant replacement would significantly decrease BPD, chronic changes in respiratory function in full-term or near full-term infants experiencing antenatal infection,



pulmonary hypoplasia, and meconium aspiration have instead been noted. This new BPD results in impaired organogenesis of the lung (what historically was called pulmonary insufficiency), impaired distal lung growth, decreased microvascular development, and impaired pulmonary function in the first years of the infant's life. Rather than being able to assign the diagnosis of BPD solely based on the presence of oxygen at a specific gestational or chronologic age or on X-ray findings, the newer form of BPD is related more to the pulmonary outcomes of infants that are severely affected by respiratory disease. This is why some centers use the term *CLD* to describe this new form of respiratory disease.

A consensus conference in 2000 at the National Institutes of Health (NIH) suggested that the diagnosis of BPD/CLD be defined by a more clinical severity-based definition related to the level of respiratory support needed nearer to term gestation. The new definition uses oxygen dependency at 36 weeks postconceptual age (PCA), total duration of oxygen supplementation (> 28 days), positive pressure requirements, and gestational age of infant (< 32 weeks) to delineate the three degrees of severity: mild, moderate, and severe. Infants stratified by these diagnostic criteria rarely progress to severe BPD/CLD. Of those with the severest BPD, approximately 75% will be discharged on home oxygen therapy or require a tracheostomy for long-term ventilation.

Definitions

Mild BPD/CLD is assigned if there is a need for supplemental oxygen for more than 28 days but not by 36 weeks PCA.

Moderate BPD is defined as a need for supplemental oxygen for more than 28 days but the fraction of inspired oxygen (FiO_2) was less than 30% at 36 weeks PCA.

Severe BPD is defined as an oxygen requirement for more than 28 days and more than 30% FiO_2 and/or positive pressure ventilation (CPAP or ventilation) at 36 weeks PCA.

Genetics

As our knowledge of genetic expression and the ability to identify specific markers in the DNA of individuals have expanded, so too has the understanding of which of these markers may predispose or increase the likelihood of an individual developing different diseases, including BPD. For example, twin studies have shown that lacking the portion of the arm that expresses surfactant protein B (SP-B) may increase the risk of BPD. In addition, other gene pathways that regulate things such as DNA repair, mitochondrial energy metabolism, and control cell growth may be altered in the developing premature infant, resulting in their response to factors such as infection, exposure to oxygen, and growth. The continued study of the genome may lead to future opportunities to intervene earlier in the disease process by altering ventilation strategies or by tailoring therapies for those infants at highest risk.

Inflammation

Inflammation is a major factor in the development of BPD. The initiation of inflammation appears to cause impairment of the growth of alveoli and of the microvasculature. The ability of the infant to block inflammation by their own anti-inflammatory mediators is limited and may be easily overwhelmed. There is growing evidence that the persistent imbalance on the side of pro-inflammatory mediators and inadequate anti-inflammatory mediators is important in the pathogenesis of BPD.

Maternal chorioamnionitis is the single most important cause of preterm delivery, with severe chorioamnionitis seen frequently in infants who are born at less than 30 weeks gestation. Infants born in the presence of chorioamnionitis have a higher rate of BPD/CLD. The infant may present with mild to moderate RDS at the time of birth, rapidly improve with exogenous surfactant and ventilation, and wean to low ventilator support or continuous positive airway pressure (CPAP). Chest X-ray findings at that time may have been consistent with mild RDS. Sometime after the first week of life, the infant will exhibit symptoms of worsening respiratory distress and increased oxygen requirements without associated infection. Chest X rays may show progressive development of



atelectasis, scarring, and hyperinflation—all consistent with BPD.

The development of this atypical CLD is thought to be a systemic response by the infant following exposure to intrauterine infection. The fetus responds to this environment by increasing its inflammatory biomarkers, such as chemokine, pro- and anti-inflammatory cytokines, proteases and their inactivated inhibitors, and growth factors. Infants who were exposed to intrauterine infection and had histologic confirmation of chorioamnionitis were found with elevated interleukin 6 present in the cord blood and went on to develop BPD. The presence of these inflammatory biomarkers creates a complex interaction that alters subsequent lung maturation.

Disruption of Vasculogenesis

Inflammation in utero results in a cascade of events following delivery; one of these, decreased vascular endothelial growth factor (VEGF), has a major impact on the development of new pulmonary vessels, pulmonary capillary beds, and ultimately, alveoli. In the presence of inflammation, VEGF regulation is altered. Pathways that lead to VEGF production are inhibited, which leads to reduced production of growth factors. These are required for new healthy lung tissue to grow. Infants born at the threshold of viability are at highest risk because they have very few vessels and alveoli developed at birth. In addition, exposure to the higher levels of oxygen in extrauterine life also will contribute to the abnormal development of pulmonary circulation. Infants with severe BPD often will have comorbidities such as cor pulmonale or pulmonary hypertension caused in part by the interruption of pulmonary vascular growth.

Oxygen Toxicity

In the developing fetus, weeks 23–30 are a period of active development of the pulmonary system. Fetuses move from simple bronchial “tubes” to saccules, which are the precursors to alveoli. This growth occurs in utero in what would be considered hypoxic by extrauterine factors. Preterm birth interrupts this development and events such as chorioamnionitis or hyperoxia can result in changes to the growth and further branching of the

lung, specifically alveolar development. Although it was thought that high levels of oxygen (>40%) were toxic to the neonatal lung, there is strong evidence indicating that even room air (21%) may result in lung injury.

Ventilator-Induced Injury

Initiation of positive pressure ventilation during resuscitation often triggers a cascade of damage and changes to the airways and alveoli of the preterm infant. Volutrauma, the overdistension of the airway, causes stretching of the air sac on inspiration. At the end of the expiratory phase of the respiratory cycle, partial or total collapse potentially can alter the stretch responsive mediators in the preterm infant’s lung. Overventilation may induce an inflammatory response of the lungs, with large numbers of neutrophils being released. This can lead to scarring and alteration in existing lung tissue. The use of CPAP immediately after delivery and continued use in the NICU versus intubation after delivery was thought to reduce some of the mechanical injuries by mechanical ventilation. However, in a large randomized controlled study that evaluated CPAP versus mechanical ventilation, there was no difference found in BPD at 36 weeks (Geary, 2008).

Treatment

Despite increasing knowledge about factors that contribute directly to BPD/CLD, there is still uncertainty as to which treatment modalities are most successful in reducing the incidence of and treating the infant with BPD. Awareness of the importance of ventilation and nutritional and pharmacologic management will allow the team to apply best practices to improve both short- and long-term outcomes.

Ventilation/Oxygen

Reduction of volume and distending airway pressure will help reduce volutrauma and minimize alterations in the architecture of the developing airway. The use of positive pressure, even CPAP, has an impact on the ability of the neonate to continue to grow new saccules and alveoli, even after birth. Maintaining functional residual capacity and avoiding repeated bouts of atelectasis is an increasingly common strategy. Oxygen, though essential to avoid tissue damage and allow for anabolic growth, also can be damaging in concentrations that are higher



than necessary. Studies have evaluated what is considered a “safe range” for oxygen saturations and have recommended the range of 90%–95%. However, it is more important to avoid frequent swings in oxygen saturations from hypoxic to hyperoxic states, because this affects overall growth and neurodevelopmental outcomes.

Nutrition

Infants born prematurely miss an important window of intrauterine growth. Care providers are limited in their ability to deliver calories and nutrients, yet these infants have very high energy requirements to meet basic metabolic functions, even without their need to grow. Delay in establishing positive nitrogen balance with early introduction of protein and lipids is known to decrease alveolar number and delay extrauterine growth. Establishment of enteral feeds as early as possible with maternal breast milk provides the infant with growth factors found in maternal milk such as inositol, which has a role in cell membrane maintenance and maturation of pulmonary surfactant. Infants with BPD/CLD may need up to 130 kCal/kg/day to achieve positive growth. Some of these infants are fluid sensitive, and meeting high caloric needs with a restricted fluid intake can be a clinical challenge.

Medication Management

Although there is no “magic bullet” for BPD, the use of certain medications during the course of the disease may help to reduce severity and manage symptoms associated with long-term ventilation. Controversy remains surrounding the use of these medications. Antenatal steroids have been found to reduce mortality, RDS, and intraventricular hemorrhage (IVH) in preterm infants. Although antenatal steroids reduce risk factors for the development of BPD, they do not reduce the incidence of BPD. Antenatal steroids may reduce the severity of BPD, but there is conflicting evidence in this area.

Surfactant

The introduction of surfactant into the NICU has significantly changed outcomes of neonatal patients. Previously, infants as mature as 36 weeks gestation had prolonged and difficult RDS courses, with many ending with the cystic BPD described in early neonatal literature. The widespread use of surfactant has, in part, reduced the

threshold of survival so that NICUs are routinely resuscitating and later discharging preterm infants born at 24 weeks gestation. The debate of early versus late surfactant delivery after birth recognizes that surfactant should be given early in the clinical presentation of respiratory symptoms to reduce complications associated with RDS (e.g., pneumothorax, pulmonary interstitial emphysema, chronic lung disease, or death). Early use of surfactant also has been shown to reduce the risk for BPD or death at 28 days, even though surfactant use has not reduced the overall incidence of BPD.

Caffeine

Although caffeine is commonly used in infants to treat apnea of prematurity, it also has an impact on ventilation and has been shown to prevent BPD. Infants who received caffeine in the first week of life were shown to have a reduction in duration of positive pressure ventilation by 1 week when compared with the placebo group (Picone, Bedetta, & Paolillo, 2012). Caffeine may possess the ability to prevent respiratory failure in infants following extubation and may be related to adenosine receptors in the brain that affect capillary permeability, inflammation, and lung remodeling.

Vitamin A

Vitamin A is essential for immunity, growth, and the integrity of the epithelial cells that line the respiratory tract. Most preterm infants have low levels of vitamin A because of decreased intrauterine growth, which then increases the risk for BPD/CLD. In a large, multicenter, randomized, controlled study that compared giving 5000 IU of vitamin A intramuscularly three times a week for the first month of life versus placebo, results showed a significant decrease in either death or CLD in the treatment group (Beveja & Christou, 2006). Analysis of both groups at 18–24 months showed no change in mortality or neurodevelopmental outcomes, but the number of infants who required oxygen at 1 month or 36 weeks PCA was statistically significant. Vitamin A has been subjected to recurrent drug shortages over the past several years. The current status of this drug can be found on the U.S. Food and Drug Administration (FDA) website in the Current Drug Shortages Index.



Corticosteroids

The extremely preterm infant often has a reduced cortisol response that may increase the response to inflammation seen in the lungs. This can affect the preterm infant's lung that has been exposed to inflammation from maternal chorioamnionitis as well as mechanical ventilation and exposure to oxygen.

Systemic corticosteroids have strong anti-inflammatory properties. Systemic steroid use in infants with RDS allows for rapid weaning from both mechanical ventilation and high levels of oxygen. During the 1980s, steroid use was thought to have a major impact on the reduction of BPD and the improvement of neonatal outcomes. Dosing strategies were widely divergent in terms of initiation and duration of treatment and dosage. However, in the 1990s, as these infants were followed in high-risk clinics, there was a concerning increase in poor neurodevelopmental outcomes, reduced head circumference, and some potentially worse outcomes once the child reached school age with poor cognitive and motor skills.

In 2002, the American Academy of Pediatrics (AAP) released a policy statement regarding the use of postnatal corticosteroids for prevention or treatment of CLD in preterm infants. It called for limiting steroid use to exceptional clinical circumstances and counseling families about the risk of adverse neurodevelopmental outcomes.

In 2010, following an update of a systematic review of studies, the AAP released a revised policy statement on the use of postnatal corticosteroids to prevent or treat BPD. The academy continues to stress concerns about long-term neurodevelopmental outcomes in infants exposed early to steroids. However, following the review of the literature, the AAP now recommends judicious use of dexamethasone at a later time (after day 7) if the infant is unable to be weaned from the ventilator. The rationale is that, at this point, the risk of cerebral palsy from exposure to dexamethasone compared with the higher rate of mortality if not treated is equal.

The small studies that have been reported since then do not show an increase in adverse neurodevelopmental

outcomes when steroids are used after the first 7 days of life. There also was no difference in the response to high-versus low-dose dexamethasone, resulting in the conclusion that low doses and shorter duration of treatment can achieve the same effect as high dose or prolonged therapy.

In 2017, a large Cochrane review concluded that inhaled corticosteroids given to infants age 7 days or older who were at high risk for developing BPD/CLD did not reduce death or BPD rates and did not decrease ventilator days or oxygen requirement (Shah, Ohlsson, Halliday, & Dunn, 2017). The authors did not recommend inhaled corticosteroid use at that time.

Bronchodilators

Increased airway reactivity and decreased lung compliance are hallmarks of BPD/CLD. The use of beta-agonists such as albuterol to improve these clinical complications was a method to improve airway compliance and reduce incidence of bronchospasm. However, in a randomized, controlled study to evaluate use in the infant with BPD, there was no difference in mortality, incidence of BPD, duration of ventilation, or oxygen requirement when the treatment and control groups were compared. Although there may be a short-term response to bronchodilators, it does not appear that chronic use of this medication group improves outcomes.

Diuretics

Neonates with BPD/CLD have high caloric requirements, often resulting in high daily fluid intake. Alveolar edema, capillary leak from inflammation or lung injury, and volume overload because of left to right shunting across the PDA can result in pulmonary edema. This excess fluid can alter lung compliance and function.

The most common diuretic used is furosemide (Lasix), a loop diuretic. Furosemide works to increase interstitial fluid reabsorption and increase urine output. There is a transient improvement in both oxygen requirement and lung compliance, which is seen clinically but not always reflected by blood gases. A Cochrane meta-analysis reviewed the use of furosemide to treat infants with BPD/CLD and showed no benefit to duration of oxygen



requirement, ventilator support, CLD/BPD, or death. There are several risks involved with the use of furosemide. It may delay the closing of the ductus arteriosus, because furosemide stimulates renal production of prostaglandin. Ototoxicity, electrolyte disturbances, nephrocalcinosis (kidney stones), or bone demineralization also are potential complications of this therapy.

Another class of diuretics, thiazides, has less of an effect on diuresis but also less of an impact on the infant's electrolyte homeostasis. Thiazides have a short-term effect on pulmonary function but do nothing to improve or alter the outcomes or severity of BPD. Use of thiazides is thought to reduce the use of furosemide, thereby reducing the side effects.

Oxygen

Oxygen remains the most commonly used drug in the NICU. Tissue oxygenation is essential for life. Chronic hypoxia can contribute to the development of pulmonary hypertension, necrotizing enterocolitis, IVH, and adverse neurodevelopmental outcomes. In infants with BPD/CLD, episodes of acute hypoxia also may increase airway resistance. Oxygen toxicity has been associated with alterations in pulmonary development. Excessive oxygen levels may increase production of free oxygen radicals and cytokines that increase inflammation, which then inhibits the development of alveoli and the microvascular growth. These alterations affect critical organ blood vessel development in the lung and eyes, leading to increased rates of BPD and severe retinopathy of prematurity (ROP).

There is not a clear range of oxygen saturations that avoids both short- and long-term complications. Studies have examined preterm infants beyond the first 28 days of life. The STOP-ROP and Benefits of Oxygen Saturation Targeting (BOOST) trials evaluated using target saturation ranges in two groups—low (saturations 89%–94%) and high (saturations 95%–98%)—and the impact on growth, development, and changes in prethreshold ROP. In the BOOST study, there was no significant difference in the outcome measures (growth or development) between the two groups. In the high saturation group, a

longer duration of oxygen therapy, greater need for home oxygen, and increased rate of BPD/CLD was found. In the STOP-ROP study, there was no change in the progression of the ROP between the groups; however, the researchers also reported that the group with lower saturations had fewer incidences of pneumonia or BPD exacerbations. There is concern that targeted saturations (less than 90%) may be associated with increased risk of death based on the recent BOOST II trial. Several multicenter, randomized, controlled studies are underway to determine the most appropriate target saturations for preterm infants.

Once the diagnosis of BPD/CLD has been made and the infant is on oxygen (nasal cannula or positive pressure device), it is important to maintain saturations in the 90%–95% range. This promotes growth and avoids using more energy to breathe because of lower oxygen saturations. It also reduces the risk of developing pulmonary hypertension and vasoconstriction. Some infants with BPD will require oxygen for up to 2 years of life, either by cannula or by ventilator with a tracheostomy in the most severe of cases.

Nitric Oxide

The use of inhaled nitric oxide (iNO) is part of the NICU toolbox to manage full-term infants with persistent pulmonary hypertension of the newborn (PPHN). iNO decreases pulmonary vascular resistance, improves ventilation/perfusion mismatch, and provides bronchodilation. In addition, iNO has been found to have an anti-inflammatory effect and may assist in remodeling of the pulmonary vasculature following chronic hypoxic failure. Several randomized trials evaluating the use of iNO in low-birthweight infants have produced inconsistent results, with a limited number of patients experiencing a reduction in the incidence of BPD. In 2010, the NIH issued a consensus statement on the use of iNO in preterm infants. The recommendation was that iNO should not be used routinely in the care of infants younger than 34 weeks to prevent BPD or alter neurodevelopmental outcomes. However, they did not rule out the use of this treatment in extreme cases as a lifesaving measure. Studies are underway to evaluate timing, dose, and duration of iNO use and potential respiratory and long-term outcomes in the preterm infant. Currently, it does not



have widespread acceptance as a useful therapy for preventing BPD.

Other Possible Therapies

Attempts to target specific issues that surround BPD, such as inflammation and tissue growth, have led to small studies examining other interventions that may lead to a reduction of the incidence or the severity. One such intervention is the administration of stem cells to the neonate with the goal of targeting damaged lung tissue and providing healthy cells to generate new growth. Systemic treatment with erythromycin is given to reduce ureaplasma colonization, which may play a role in developing BPD/CLD, although the role ureaplasma plays in developing CLD remains controversial. Heliox, a mixture of helium and oxygen, has been found to aid ventilation in infants with BPD/CLD and to decrease work of breathing, improve gas exchange, and decrease respiratory support requirements. These findings have been noted anecdotally and require more rigorous study before efficacy can be determined.

Treatment of Severe BPD

Many infants who have severe BPD remain ventilator dependent despite maximal medical management; they can remain in the NICU for as long as 1 year. These infants have unique challenges and additional management strategies may need to be employed.

Ventilation

As with the infant who has RDS in the first days and weeks of life, the goal for older, more chronically affected infants remains the same: minimize oxygen requirements and mechanical ventilation support. However, in infants with severe BPD/CLD, these goals are more difficult to achieve. Infants with severe BPD/CLD need to maintain oxygen saturation levels in a range allowing for adequate oxygenation, yet avoiding extreme swings. Chronic hypoxia has been shown to diminish neurodevelopmental outcomes and can cause vascular remodeling in the pulmonary and cardiac vessels. This results in pulmonary hypertension (PH) or cor pulmonale. Infants with severe BPD may have reduced lung compliance and increased airway reactivity, much like that of a child with asthma. In some but not all cases, use of bronchodilators for acute

symptom management may improve bronchospasm. In addition, long-term endotracheal intubation or tracheotomy may result in tracheobronchomalacia, which presents as airway obstruction unresponsive to bronchodilators. These infants may require a higher amount of positive end expiratory pressure to reduce collapsing of the central airway on exhalation. To minimize these episodes, sedation, and in some cases, temporary pharmacologic paralysis may be required.

Weaning infants with severe BPD must include attempting to “normalize” blood gases that have previously been allowed to reflect a higher degree of carbon dioxide retention and compensatory metabolic alkalosis. The carbon dioxide set point of some chronic infants has been allowed to go as high as the mid 60s in an effort to wean the infant off of the ventilator. There is usually an accompanying metabolic alkalosis as the infant attempts to normalize his or her acid base balance. If the infant’s electrolytes are within normal limits, additional medications to reduce the alkalosis—such as Diamox, a carbonic anhydrase inhibitor, or arginine hydrochloride—may need to be added.

If multiple attempts to extubate the infant with severe BPD have not been successful, performing a tracheotomy should be considered. Placement of a tracheostomy (trach) in an older NICU patient may have some direct benefits. First, it may allow for easier ventilator weaning due to less dead space and decreased airway resistance. The trach allows for better clearance of secretions and is usually more comfortable for the infant, thus reducing the need for sedation. The risk associated with placement of a trach needs to be considered. Most infants who progress to requiring tracheostomies will require long-term ventilator support that may extend into the home setting. Trachs offers a more stable airway and may allow the older infant more freedom of movement. This permits more normal play and feeding options and promotes better neurodevelopmental outcomes.

Pulmonary Hypertension

Some infants with severe BPD will go on to develop PH, resulting in increased morbidity and mortality. The



mechanism of action is not known, but it has been suggested that this is a result of changes in the pulmonary vasculature related to hypoxia and exposure to inflammation and ventilator-induced injury. Alterations of growth factors and vascular tone may lead to thickening of the ventricles and septum and abnormal growth of capillaries throughout the cardiac structure. Infants also may have elevated pulmonary vascular resistance, precipitated by the presence of chronic hypoxia, hypercapnea, and acidosis.

Diagnosis of pulmonary hypertension can be difficult. Echocardiograms, which evaluate the velocity of regurgitation through the tricuspid valve, with pulmonary pressures being compared to systemic pressures, are more commonly used. The echocardiogram also can be helpful to assess the heart's response to initiation of a particular therapy.

Treatment of PH in the infant with BPD/CLD is determined by the severity. Often, in milder forms of PH, avoidance of hypoxia and optimizing overall growth is all that is required. In more severe forms of PH, additional support may include ventilation and medications such as iNO, sildenafil, and bosentan. There is a higher incidence of mortality in infants with this severity of BPD/CLD.

Although it has proven effective in acute PPHN, in this subgroup of NICU patients, iNO is not an ideal therapy due to its expense and unwieldy long-term use. Sildenafil has been used in long-term treatment of PH. Animal studies have been conducted to determine the efficacy of sildenafil's use earlier in the life of preterm infants to decrease the incidence or severity of BPD. There is little known about the long-term effects of sildenafil's use in this patient population. There is concern about the safety of this drug, and the FDA has issued an advisory about the use of sildenafil in children between the ages of 1 and 17 with PH. Bosentan also is being evaluated for use in treating BPD/CLD infants with PH. Bosentan, an antagonist of ET-1, which is a neurohormone released from the vascular endothelium and a potent vasoconstrictor, has been shown to reduce endothelial smooth muscle constriction, hypertrophy, and hyperplasia in adult

populations. It has a direct antifibrotic effect that makes it appealing for treating BPD. Much like sildenafil, bosentan is used with extreme caution in the NICU population because there is no data on patients younger than 9 months in currently published studies.

Complications and Long-Term Outcomes

Long-term morbidities in infants with BPD/CLD have included ROP, cerebral palsy, cognitive and behavioral difficulties, speech and feeding disorders, and long-term pulmonary disease. They often require physical, speech, and occupational therapy—to address issues such as feeding aversion, developmental milestone delays, speech delays, and dental problems related to long-term intubation with oral endotracheal tubes—as well as diligent monitoring of growth. These infants may require frequent rehospitalization during the first 2 years of life due to their lung disease.

Nursing Implications

The nurse at the bedside is the first line of defense for these vulnerable infants. It is through diligent assessment and monitoring that subtle changes are noted. Consistent and aggressive titration of oxygen delivery is very important. Prevention of oxygen toxicity is equally important for issues discussed earlier in this section. Assessment of comfort and pain with provisions of both nonpharmacologic as well as pharmacologic therapies will assist in maintaining a stable oxygen saturation range.

The hospital course of extremely preterm infants is defined by periods of ups and downs followed by long periods of feeling as though things will never change or get better. Many families are far away from their own social support network and experience isolation and loneliness due to the extended length of hospital stays. It is essential that the NICU staff refer parents to support venues in the hospital and nearby while their baby is hospitalized.

Maintaining breast milk supply over a long period of time is a difficult endeavor for the mother, but it is critical to the well-being of the infant. Ongoing support and management of this process is an integral part of the nurse's



role. Provision of skin-to-skin care is a major incentive for moms, who observe a noticeable increase in milk production after or during time with the baby. Later, as the infant is extubated and beginning to take oral feeds, close work with lactation specialists will help mom and baby transition successfully to breastfeeding if the baby is physiologically stable.

Parental inclusion in the daily care of their infant increases confidence in caring for their child as well as encourages engagement through the long days when things seem to be at a standstill. Inclusion of families as members of the multidisciplinary team conveys the message that they are very much a part of their baby's care. As the infant progresses to discharge, early teaching reduces the amount of overwhelming information provided at the last minute. Offering information and care activities early decreases anxiety and fear of not being able to care for their baby outside the hospital setting. Many parents will room-in with their child for a period of time as a transition to home. Follow-up by home health-care providers offers reassurance and resources following discharge from the NICU.

Postdischarge follow-up may be challenging due to the number of subspecialty services involved. Coordinating visits as much as possible is recommended. Infants with BPD/CLD are at high risk for developing upper respiratory infections, such as respiratory syncytial virus (RSV) in the first 2 years. It is important to provide education about limiting exposure to visitors and practicing good hand hygiene at home. Immunizations for care providers and siblings, including flu shots and a pertussis (whooping cough) vaccine booster shot, should be up to date. RSV immunoprophylaxis and appropriately timed immunizations should decrease the incidence of potentially lethal infections. Transfer of care to the community provider is accomplished through both verbal communication and by comprehensive discharge summaries. Providing the families with a copy of the discharge summary will help them convey vital information concerning their baby's hospital course should they need to seek emergency services for any reason.

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Bronchopulmonary Dysplasia: Information for Parents

What is bronchopulmonary dysplasia?

- *Bronchopulmonary dysplasia* (BPD), also called *chronic lung disease* (CLD), is a lung disease that can develop in babies who are born early and have breathing problems.
- *Broncho* means “airways or air tubes in the lungs.” *Pulmonary* means “air sacs in the lungs.”
- *Dysplasia* means “unusual changes in cells.”
- *Chronic* means “long term.”
- The lung tissue and airways of a premature baby are very soft and fragile. They are easily damaged and can become inflamed (swollen) and scarred.
- Once damaged, the growth of lung tissue and airways is abnormal and breathing becomes difficult.
- BPD is one of the most common lung diseases in children.

What causes BPD?

The exact cause of BPD is not known. The following are some things that make a baby more likely to develop BPD:

- BPD is most common in babies who have immature lungs. Babies born more than 10 weeks premature or weighing less than 2 pounds have the highest risk for developing BPD.
- Sometimes the very things that are needed to save the lives of preemie babies with respiratory distress syndrome (RDS) also can damage their lungs. Important treatments like oxygen and a breathing machine (ventilator) are very helpful. Sometimes a large amount of high pressure is needed to help breathing; however, high pressure also can be harmful to fragile lung tissue.
- Lung infections like pneumonia also can cause swelling in the airways and tissue of the lungs.

What are the signs of BPD?

BPD is usually suspected when a baby is between 1 and 2 months of age and has one or more of the following:

- A baby needs extra oxygen at 36 weeks corrected gestational age (about 1 month before the due date).
- A chest X ray shows lung damage.

- Ongoing breathing problems (breathes too fast or uses extra chest muscles to breathe) are present.



Chest X ray of baby with BPD/CLD. From “The Changing Face of Bronchopulmonary Dysplasia: Part 1,” by K. Gracey, D. Talbot, R. Lankford, and P. Dodge., 2002, *Advances in Neonatal Care*, 2(6).

How do babies with BPD act?

Babies with BPD may have some or all of the following:

- fast, shallow, or noisy (grunting) breathing
- frequent coughing, wheezing, shortness of breath, and flaring of nostrils
- pulling of chest muscles inward between the rib spaces (retractions)
- sometimes look blue or dusky in color because of low blood oxygen levels
- need extra oxygen to grow and develop
- tire easily or breathe fast with feedings, which may slow growth and weight gain
- breathing may sound crackly or wet when listening with a stethoscope.

Is there a cure or treatment for BPD?

There is no quick cure for BPD, but there are many treatments that help babies breathe easier:



- Oxygen is used to make breathing easier and more comfortable. Some babies need to use oxygen at home. Oxygen may be needed for many weeks or months.
- Medications are sometimes used to help babies with BPD breathe easier. Surfactant and caffeine therapy in premature babies helps prevent BPD. Bronchodilators open the airways in the lungs. Corticosteroids help reduce inflammation in the lungs. Diuretics decrease fluid buildup in the lungs. Antibiotics treat bacterial lung infections, which are common in babies with BPD.
- High-calorie breast milk or formula gives your baby extra calories and nutrients to help growth and healing. Because some babies use so much energy just to breathe, they may need to be fed by a tube in the nose or stomach to make sure they take in enough calories to grow.
- Growth is the best treatment for BPD. With time, your baby will grow new, healthy lung tissue.
- In rare cases, some babies will have severe lung damage and need the help of a breathing machine (ventilator) for many months or more. If so, a tracheostomy is often used to help with breathing. A tracheostomy is a small hole in the neck that enables a special breathing tube to be put into the windpipe with a ventilator to support breathing.

Good News About BPD

- New devices (machines) make oxygen therapy and breathing machines more gentle on the baby's lungs.
- Medications help make breathing easier and decrease breathing problems.
- Most babies will outgrow BPD because they rapidly grow new lung tissue during the first 2 years of life.
- Babies with BPD can usually be cared for at home in close partnership with the baby's provider and pediatric pulmonologist. A *pediatric pulmonologist* is a doctor who specializes in the treatment of lung disease in children.

Going Home

Call your baby's provider right away if your baby has

- breathing problems that become worse or signs of respiratory infection:
 - fever

- breathes faster than usual
- works harder to breathe than usual
- coughs, wheezes, or breathes more noisily than usual
- pale, dusky, or blue lips or fingernails
- more irritable or fussy than usual
- tires more easily with breathing or feeding
- spits up more than usual or doesn't want to eat.

If your baby stops breathing, start cardiopulmonary resuscitation (CPR) and call 911 or local emergency medical services right away.

Important Things to Remember

- Babies with CLD or other complications are at greater risk for ongoing lung problems. It will be important for you to know how your baby breathes "normally" and how his or her chest muscles look if he or she is having trouble breathing.
- Prevent lung infections. Always wash your hands before touching your baby or preparing your baby's food. Only allow people to visit your home when they are not sick. Keep young children away from your baby. Avoid crowds and day care centers.
- No smoking should happen around your baby. Limit exposure to pollution and other lung irritants.
- Encourage all people who care for your baby to get a flu shot before the start of cold and flu season and a pertussis (whooping cough) vaccine booster shot.
- Take your baby for all regular well-child check-ups and follow the recommended schedule for immunizations.
- Talk to your baby's provider about palivizumab (Synagis), a medication used to prevent respiratory syncytial virus infection in young children.
- Each follow-up appointment with the pediatric pulmonologist is important and is in addition to well-child check-ups with your baby's provider.
- If your baby needs to take special medications to help breathe easier, always follow the directions on the bottle or container that came from the pharmacy.
- You may be nervous at first, but with practice, you will become more comfortable caring for your baby with BPD. *Remember, it's always OK to ask for help!*



Cardiac Defects: Aortic Stenosis

When the heart squeezes, the left ventricle (the lower left chamber) contracts, pushing blood out into the aorta, the main artery that takes blood to the body. The aortic valve is located on the way out of the heart, to prevent blood from leaking back into the heart between beats. A normal aortic valve is made up of three thin leaflets.

In aortic stenosis, either the annulus is too small or the leaflets are fused or too thick, or there are fewer than three. As a result, the valve is too narrow, and the heart has to work harder to pump enough blood to the body. Aortic stenosis, or obstruction at the aortic valve, can be trivial, mild, moderate, severe, or critical.

Sometimes the stenosis is below the valve, caused by a fibrous membrane or a muscular ridge; this is called *sub-aortic stenosis*. The stenosis also can occur above the valve, in the aorta itself; this is called *supravalvar aortic stenosis*.

Symptoms

Aortic stenosis usually won't cause symptoms in infants or small children. As the child gets older, signs and symptoms of aortic stenosis may appear, including fatigue; a heart murmur (an extra heart sound when a doctor listens with a stethoscope); or rarely, chest pain, fainting, or arrhythmias (abnormal heart rhythm).

How is aortic stenosis in children diagnosed?

In rare cases, newborns have critical aortic stenosis, which requires immediate medical attention. Sometimes these severe cases are diagnosed before birth through a fetal heart program.

In most cases, cardiologists diagnose aortic stenosis after a primary care doctor detects a heart murmur and refers the child to a cardiologist.

Diagnosis may require some or all of these tests:

- pulse oximetry—a painless way to monitor the oxygen content of the blood

- chest X ray
- echocardiogram (also called echo or cardiac ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- cardiac magnetic resonance imaging (MRI)—a three-dimensional image shows the heart's abnormalities
- cardiac catheterization—a thin tube (catheter) is inserted into the heart through a vein or artery in either the leg or through the umbilicus ("belly button").

Aortic stenosis can run in families, so be sure to tell your cardiologist if there is a history of a heart murmur in other close family members to allow for testing of the fetus before birth.

What are the treatment options for aortic stenosis?

The exact treatment required for aortic stenosis depends on each child's heart anatomy. Trivial and mild aortic stenosis typically require no treatment. However, moderate, severe, and critical aortic stenosis require treatment.

Cardiac Catheterization

In most cases, aortic stenosis is treated with balloon valvuloplasty, which requires cardiac catheterization. Doctors advance a thin tube (catheter) to the heart through an artery in the leg. The catheter has a balloon on the end of it. To open up the narrow valve, the balloon is briefly inflated, deflated, and withdrawn. Sometimes, two catheters and balloons are used. Sometimes, in newborns, the blood vessels in the umbilical cord are used as the site where the catheters are inserted and advanced toward the heart.

Older children will spend one night in the hospital after this procedure. They will need to rest the next day but then can resume normal activity. Newborns with critical aortic stenosis will usually stay in an intensive care unit before and after the procedure and will require some time to recover.



Valvuloplasty Surgery

Surgery to repair or to replace the valve often is necessary in severe cases. Depending on the age, gender, and particular needs of your child, as well as the valve anatomy, surgeons may attempt to repair the valve, or at least improve its function, with a surgery called a valvuloplasty. Some research suggests that a surgical approach rather than a balloon approach has a slightly higher chance of avoiding aortic regurgitation in the future, yet the nature of the procedure poses a more immediate risk to the neonate (Benson, 2016).

Artificial Valves

Another option to treat aortic stenosis includes the use of mechanical (artificial) valves as replacement valves. If this is the case, your child may need to stay on blood-thinning medicines for the rest of his or her life.

Ross Procedure

Yet another option to treat aortic stenosis is the Ross Procedure. In this operation, the aortic valve is replaced with the patient's pulmonary valve. The pulmonary valve is then replaced with one from a donated heart. This procedure allows the patient's own pulmonary valve (now in the aortic position) to grow with the child.

Subaortic and Supravalvar Stenosis Treatment

Subaortic and supravalvar stenosis do not get better with balloon dilation and will require surgery if the amount of obstruction is moderate or severe or, with subaortic stenosis, the aortic valve begins to leak significantly. Surgery for subaortic stenosis involves cutting out the ridge. Surgery for supravalvar aortic stenosis involves enlarging the aorta with a patch.

Follow-Up Care Through Age 18

Children with aortic stenosis require regular check-ups with a pediatric cardiologist. Some children must remain on medicine and limit physical activity.

As a child with aortic stenosis grows, blood may begin to leak through the abnormal valve. This is called aortic regurgitation or aortic insufficiency (AI). In other children, the stenosis can reoccur. Neonates have an increased risk of AI and re-intervention, which may be related to their valve morphology prior to treatment (Petit et al., 2016). When stenosis happens, balloon valvuloplasty can be repeated, as long as there isn't significant aortic regurgitation. In severe cases, additional surgery may be necessary. The incidence of AI and repeat surgeries contributes to the debate of whether a balloon or surgical valvuloplasty leads to better future health.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care providers.

Into Adulthood

Adults with aortic stenosis must continue to see a cardiologist regularly. Your child's pediatric cardiologist will help with the transition to an adult cardiologist. All patients with aortic valve disease need some form of life-long follow-up with a cardiologist. Because of enormous strides in medicine and technology, today most children with heart conditions go on to lead healthy, productive lives as adults.

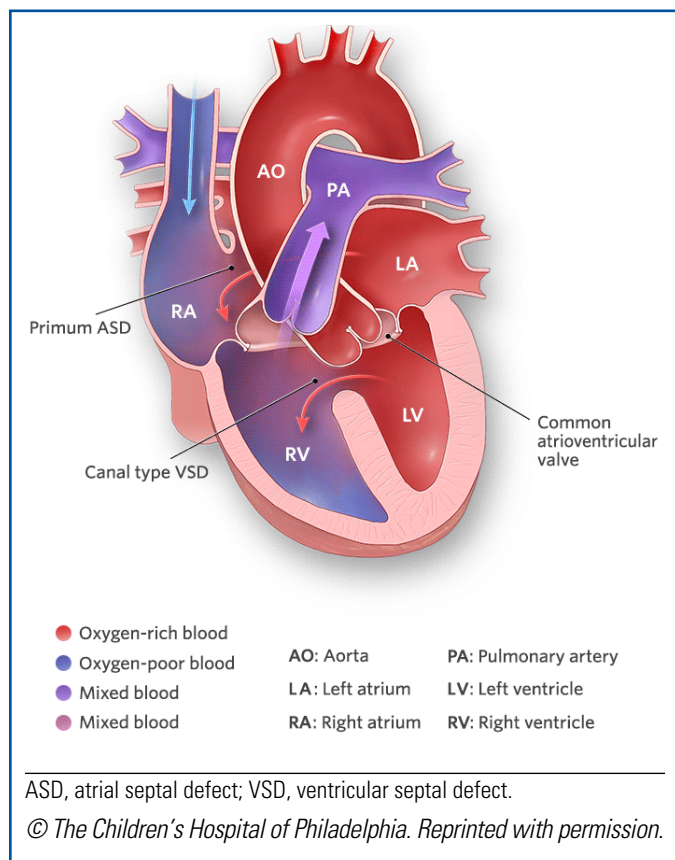
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Cardiac Defects: Atrioventricular Canal Defects



An *atrioventricular canal defect* is a problem in the part of the heart that connects the upper chambers (atria) to the lower chambers (ventricles). There are two types of atrioventricular canal defects: complete and partial.

Complete Atrioventricular Canal (CAVC)

Complete atrioventricular canal (CAVC) defect is a severe defect in which there is a large hole in the tissue (the septum) that separates the left and right sides of the heart. The hole is in the center of the heart, where the upper chambers (the atria) and the lower chambers (the ventricles) meet.

Because the heart formed abnormally, with this large hole, the valves that separate the upper and lower chambers also developed abnormally. In a normal heart, two valves separate the upper and lower chambers of the heart: the tricuspid valve separates the right chambers

and the mitral valve the left. In a child with CAVC defect, there is one large valve that may not close correctly.

As a result of the abnormal passageway between the two sides of the heart, blood from both sides mix and too much blood circulates back to the lungs before it travels through the body. This means the heart works harder than it should have to, and it will become enlarged and damaged if the problems aren't repaired.

Partial Atrioventricular Canal Defects

A *partial atrioventricular canal defect* is the less severe form of this heart defect. The hole does not extend between the lower chambers of the heart and the valves are better formed. Usually it is necessary only to close the hole between the upper chambers (this hole is called an *atrial septal defect*, or ASD) and to do a minor repair of the mitral valve. Partial atrioventricular canal also is called *atrioventricular septal defect (AVSD)*.

What are the symptoms of atrioventricular canal defects?

In CAVC defect, the following symptoms may be present within several days or weeks of birth:

- blue or purple tint to lips, skin, and nails (cyanosis)
- difficulty breathing
- poor weight gain and growth
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope.

Partial atrioventricular canal defects cause fewer symptoms and sometimes aren't diagnosed until the child reaches his or her 20s or 30s and begins to experience irregular heartbeat (arrhythmia), leaky valves, or other effects.

How are atrioventricular canal defects diagnosed?

The healthcare provider who evaluates the newborn in the hospital might make the diagnosis, or a primary care provider might notice a murmur and other symptoms and refer the baby to a cardiologist.



Diagnosis of atrioventricular canal defects may require some or all of these tests:

- echocardiogram—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein and/or artery in either the leg or through the umbilicus (“belly button”)
- cardiac magnetic resonance imaging—a three-dimensional image shows the heart’s abnormalities.

Sometimes a complete atrioventricular canal defect is diagnosed on a fetal ultrasound or echocardiogram. Your baby’s providers can prepare a plan for delivery and care immediately after birth.

Complete atrioventricular canal defects often occur in children with Down syndrome.

What are the treatment options for atrioventricular canal defects?

Complete atrioventricular canal defects require surgery, usually within the first 2 or 3 months of life. The surgeon will close the large hole with one or two patches. The patches are stitched into the heart muscle. As the child grows, the tissue grows over the patches.

The surgeon also will separate the single large valve into two valves and reconstruct the valves so they are as close to normal as possible, depending on the child’s heart anatomy.

Partial atrioventricular canal defects also require surgery, whether it is diagnosed in childhood or adulthood. The surgeon will patch or stitch the atrial septal defect closed and will repair the mitral valve or replace it with either an artificial valve or a valve from a donated organ.

After surgery, patients recover in an intensive care unit as they improve.

What kind of follow-up care is required for atrioventricular canal defects?

Through Age 18

A child who has had surgical repair of an atrioventricular canal defect will require lifelong care by a cardiologist. Most children recover completely and won’t need additional surgery or catheterization procedures.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care provider. Patients will need to carefully follow providers’ advice, including staying on any medications prescribed and, in some cases, limiting exercise.

Sometimes children with an atrioventricular canal defect experience heart problems later in life, including irregular heartbeat (arrhythmia) and leaky or narrowing valves. Medicine, additional surgery, or cardiac catheterization may be required.

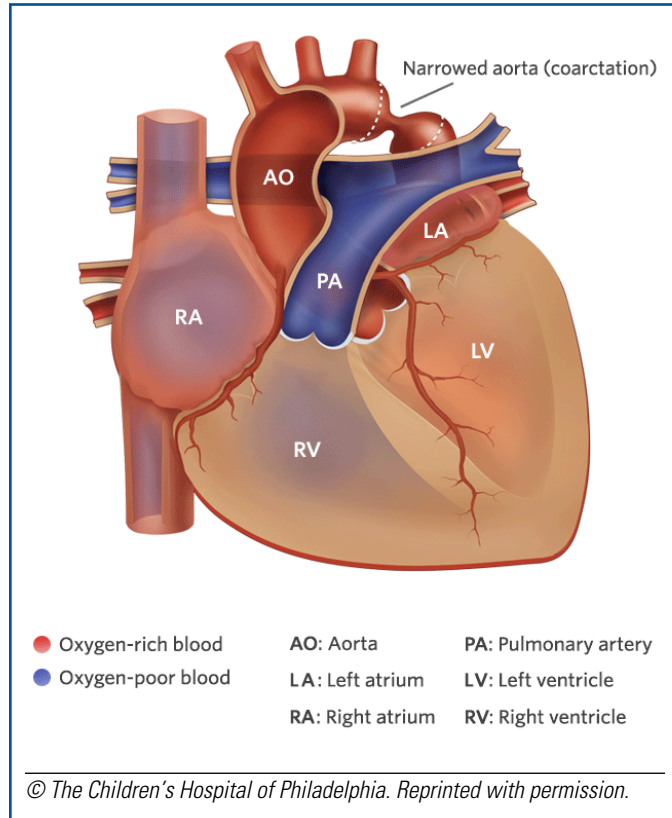
Into Adulthood

Pediatric cardiologists will help patients transition care to an adult congenital heart disease specialist. Because of enormous strides in medicine and technology, today most children born with atrioventricular canal defects go on to lead productive lives as adults.

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Cardiac Defects: Coarctation of the Aorta



The *aorta* is the main artery that carries oxygenated blood out of the heart to the body. It starts at the left ventricle of the heart as one large vessel and branches out into the smaller vessels in the body. From the heart, the aorta arches up and then curves around. Arteries that deliver blood to the head, arms, and other parts of the upper body branch off at the top of the arch. Arteries that deliver blood to the abdomen, legs, and other parts of the lower body branch off from the descending aorta.

With coarctation of the aorta in children, the aorta is too narrow at the portion just after the upper-body arteries branch off—this obstructs blood flow. Because of this narrowing, the left ventricle of the heart must pump much harder than normal to move blood through the aorta to the lower body. This can lead to damage to the heart, or heart failure, and high blood pressure in the heart and brain as well as damage to organs in the lower body that don't get enough blood.

Sometimes children with coarctation of the aorta also can have a ventricular septal defect, a hole between the lower chambers of the heart, or a bicuspid aortic valve, which means the valve has two flaps instead of three.

What are the symptoms of coarctation of the aorta?

In severe cases, coarctation of the aorta symptoms will appear within the first few days of life. The more the aorta is narrowed, the more severe the symptoms will be.

In infants where the coarctation of the aorta is severe or moderate, symptoms can include

- labored or rapid breathing
- weak femoral artery pulse (taken in the groin area)
- heavy sweating
- poor growth
- pale or gray appearance
- heart murmur—extra heart sound heard when the doctor listens with a stethoscope.

If the narrowing is mild, coarctation of the aorta symptoms may go unnoticed until the child is older or even an adult. In those cases, symptoms can include

- high blood pressure
- cold feet or legs
- difficulty exercising (gets out of breath quickly)
- dizziness
- fainting
- nosebleeds
- headaches
- leg cramps
- heart murmur.

How is coarctation of the aorta diagnosed in children?

Although more difficult, coarctation of the aorta may be diagnosed prenatally using specific markers in a sonogram. When an infant has severe coarctation of the aorta, in most cases, a doctor in the birth hospital will notice symptoms. Milder cases of coarctation of the aorta sometimes aren't diagnosed until the child is older. Healthcare



providers refer children to cardiologists for evaluation after parents notice symptoms or if the child has high blood pressure.

Diagnosis of coarctation of the aorta may require some or all of these tests:

- echocardiogram—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein and/or artery in either the leg or through the umbilicus (“belly button”)
- cardiac magnetic resonance imaging—a three-dimensional image shows the heart’s abnormalities.

What are the treatment options for coarctation of the aorta?

Coarctation of the aorta requires either cardiac catheterization or open-heart surgery, depending on the severity of the narrowing and on other factors, such as the child’s age and overall health.

Surgeons can remove the narrowed section of the aorta and then sew the ends of the aorta back together, or they can enlarge the aorta with a patch.

In catheterization, a cardiologist will thread a thin tube (catheter) with a balloon on the end of it through an artery in the leg up to the heart. Then, using the catheter, the cardiologist can inflate the balloon in the narrowed section of the aorta to open it, and might also place a stent, or a stiff metal cage, to keep it open.

Your child will recover from these procedures in the intensive care unit.

What is the follow-up care for coarctation of the aorta?

Through Age 18

Most children with repaired coarctation of the aorta recover completely and won’t require additional procedures. Rarely, the aorta becomes narrow again and balloon catheterization or surgery will be required.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care provider. Patients will need to carefully follow healthcare providers’ advice. Sometimes, these children can have persistently elevated blood pressure, despite removal of the obstruction. These children will need to take medicines to lower their blood pressure and may need to avoid certain isometric activities, like football, weight training, and wrestling.

Into Adulthood

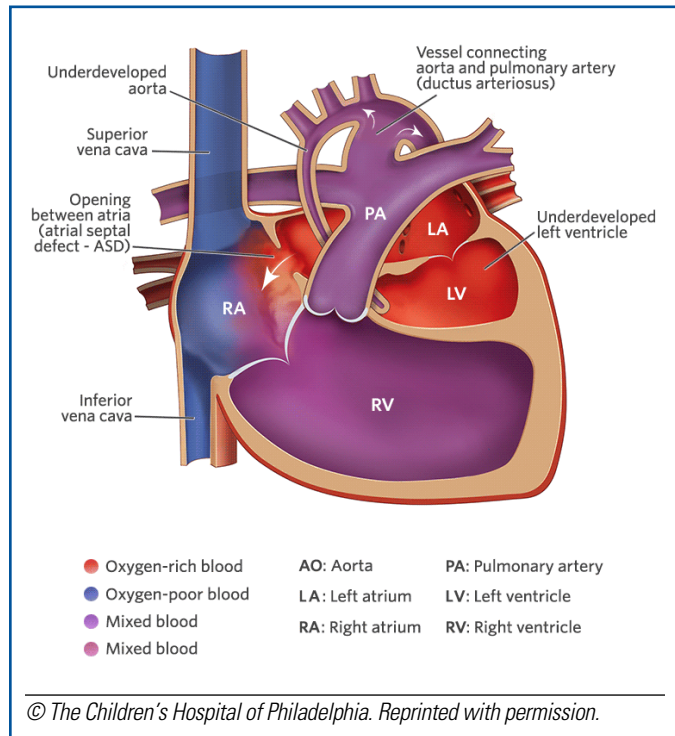
It is important that children born with coarctation of the aorta continue to see a cardiologist annually at a minimum. Your child’s pediatric cardiologist will help patients transition care to an adult cardiologist.

Because of enormous strides in medicine and technology, today most children born with coarctation of the aorta go on to lead productive lives as adults.

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Cardiac Defects: Hypoplastic Left Heart Syndrome



Hypoplastic left heart syndrome (HLHS) is a severe congenital heart defect in which the left side of the heart is underdeveloped.

The heart's left side has the job of pumping oxygenated blood into the aorta, the large artery that carries blood to the body. In a child with HLHS

- The mitral valve, which separates the two left chambers of the heart, may be too small or completely closed (atretic).
- The left ventricle (the lower, pumping chamber) may be very small.
- The aortic valve, which separates the left ventricle and the aorta, may be too small or completely closed (atretic).

In addition to the most common form of HLHS, there are a number of complex cardiac conditions with variations in the structures as described. In these children, where one ventricle also is small (sometimes called "HLHS variants"), the treatment strategy is similar to those with the more typical HLHS.

What are the symptoms of HLHS?

The following symptoms of HLHS may be present at birth or several days later:

- blue or purple tint to lips, skin, and nails (cyanosis)
- difficulty breathing
- difficulty feeding
- lethargy (sleepy or unresponsive).

How is HLHS diagnosed?

Often, HLHS is diagnosed before birth, with fetal echocardiogram (ultrasound). Your baby's provider will prepare a plan for delivery and care immediately after birth.

Sometimes HLHS is diagnosed hours or days after birth and the baby will need immediate therapy. Diagnosis of HLHS may require some or all of these tests:

- echocardiogram (also called echo or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein and/or artery in either the leg or through the umbilicus ("belly button")
- cardiac magnetic resonance imaging—a three-dimensional image shows the heart's abnormalities.

Your baby will need intravenous medicines and, possibly, a ventilator for help with breathing. Cardiologists and cardiac nurses will immediately begin procedures to help stabilize your baby.

What are the treatment options?

HLHS is most often fatal without early intervention. It will typically require open heart surgery to redirect the oxygen-rich ("red") blood and oxygen-poor ("blue") blood in a series of three reconstructive operations known as staged reconstruction.



Stage I—Norwood Procedure

Stage I, known as the Norwood procedure, occurs within a few days of birth. In Stage I of reconstruction of a heart with HLHS, the shunt used is called a Blalock-Taussig shunt. Alternative types of shunts may be used based upon a child's individual anatomy.

Alternative approaches to the Stage I Norwood procedure may be recommended for neonates who are in more critical condition, such as heart transplantation or a combination of surgery and catheter-based treatment called a hybrid procedure. The hybrid treatment has been shown to be a feasible alternative to the Norwood procedure. Hybrid treatment avoids major surgery for your child while still providing adequate survival rates and potential neurodevelopmental improvement (Yerebakan et al., 2016). Compared with 25 years ago, there are now many different options for treatment of this complex heart condition; an individualized approach is taken for each and every child. Your baby's provider will explain each individual option, and why one particular approach might be recommended for your child.

Stage II—Glenn Procedure

Stage II, known as the *bidirectional Glenn* or the *hemi-Fontan*, typically occurs within 4 to 6 months of birth.

Stage III—Fontan Procedure

Stage III, known as the *Fontan procedure*, typically occurs between 1 ½ to 4 years of age. In Stage III of reconstruction of a heart with HLHS, a technique called an extracardiac Fontan is used. The small hole intentionally placed to connect the conduit to the right atrium is called a *fenestration*. In some children, a different modification, termed a *lateral tunnel fenestrated Fontan* is used. Your baby's provider will explain the differences and why one might be recommended for your child.

Frequent surveillance in infancy and early childhood is important to minimize risk factors for the eventual Fontan operation. Your child also will need a customized series of diagnostic tests between the planned stages of surgery, and throughout childhood. Additional surgical or catheter therapies, or in rare cases heart transplantation, also may be recommended.

After these operations

- The right side of the heart will do what is usually the job of the left side—pumping oxygenated blood to the body.
- The deoxygenated blood will flow from the veins to the lungs without passing through the heart.

What is the follow-up care for HLHS?

Between the Norwood and Glenn Procedures

Though early outcomes for patients with single ventricle heart defects after staged reconstruction have improved dramatically, the period between the Norwood procedure and the Glenn procedure remains a very vulnerable time for infants. Your baby's provider will focus on the care and monitoring of your baby between the first and second reconstructive surgeries.

Through Age 18

Children who have had surgical reconstruction for HLHS require lifelong care by a cardiologist experienced in congenital heart disease. Sometimes they experience serious health problems. Many remain on medication, and additional surgeries may be required.

Patients with Fontan circulation are referred to as single ventricle patients. As these patients get older, doctors are recognizing that, although some do fine, many experience complications, including lung, liver, and gastrointestinal diseases.

In addition, as a group, children with complex congenital heart defects who have had open-heart surgery as infants are at a higher risk for neurodevelopmental issues when compared with children without congenital heart defects.

Your baby's cardiologist will follow your baby until he or she is a young adult, coordinating care with the primary care providers.

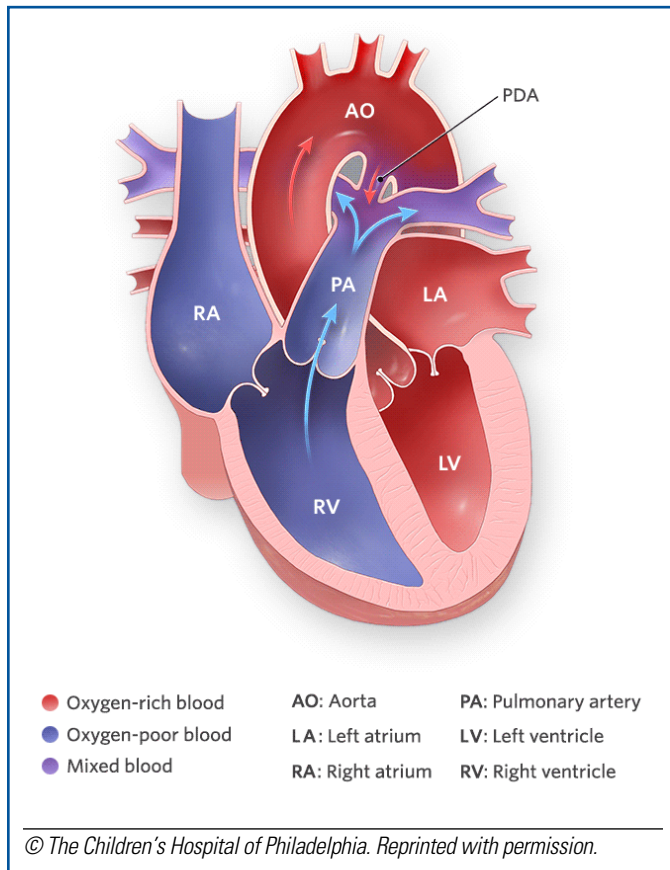
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Cardiac Defects: Patent Ductus Arteriosus



Blood flow is different in the fetus, and most blood bypasses the lungs. An extra blood vessel (passageway) called the *ductus arteriosus* (DA) allows blood from the right side of the heart to flow to the aorta, one of the largest arteries, and back out into the body without going through the lungs.

After the baby is born and begins to breathe, the flow of blood changes to include the lungs. The pulmonary artery opens to carry blood from the right side of the heart to the lungs, and the DA is supposed to close.

Patent ductus arteriosus (PDA) is a condition in which the ductus arteriosus doesn't close. *Patent* means "open." Sometimes the open passageway is wide (a large PDA) and sometimes it is narrow (a small PDA). A large PDA is dangerous because blood flow to the lungs isn't as

controlled as it should be, leading to problems with the lungs and heart.

PDA is most common in premature infants, but it also can be seen in term infants.

What are the symptoms of PDA?

Symptoms vary depending on the size of the PDA, and include

- breathing difficulties soon after birth (especially in premature babies)
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope
- rapid breathing
- difficulty feeding, poor growth
- lung infections (pneumonia).

How is PDA diagnosed?

Neonatologists, doctors who care for premature babies, work with the cardiac doctors to diagnose and treat PDA in newborns. Older infants and children with PDAs are most often sent to cardiac doctors after their primary care providers notice a heart murmur.

Diagnosis of PDA may require

- echocardiogram (also called echo or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray.

Some babies with PDA have other heart defects and will require other tests, including cardiac catheterization and cardiac magnetic resonance imaging.

What are the treatment options for PDA?

If the PDA is not life threatening, doctors might wait until the child is 1 or 2 years old before recommending treatment. Small PDAs often close on their own.



The condition may be dangerous for premature babies, so doctors immediately give medication to help close the PDA.

If the PDA does not close or narrow significantly in response to medicine, an interventional procedure may be necessary. In most cases, the PDA can be closed through cardiac catheterization. Healthcare providers insert a thin tube (catheter) through a vein or artery in the leg, guide it to the heart, and insert a tiny device to block the PDA. In more complex cases, surgery may be required. Cardiothoracic surgeons use stitches or clips to close the PDA.

What kind of follow-up care is required for PDA?

Once a PDA is closed, no long-term follow-up care is necessary unless there are other cardiac concerns.

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Cardiac Defects: Pulmonary Stenosis

When the heart squeezes, the right ventricle (the lower right chamber) contracts and pushes blood out into the pulmonary artery (the artery that takes blood to the lungs). The pulmonary, or pulmonic, valve sits on the way out of the heart between the right ventricle and the main pulmonary artery to prevent blood from leaking back into the heart between beats. A normal pulmonary valve is made up of three thin leaflets.

In pulmonary stenosis, the leaflets are fused or are too thick, or there are fewer than three. As a result, the pulmonary valve is too narrow, and the heart has to work harder to pump enough blood to the body. Pulmonary stenosis, or obstruction at the pulmonary valve, can be trivial, mild, moderate, severe, or critical. This condition also is called *pulmonic stenosis* or *pulmonary valve stenosis*.

Sometimes the stenosis is below the pulmonary valve, caused by muscular bundles. This is called *subpulmonic stenosis*. Also, the stenosis can occur above the pulmonary valve, in the pulmonary artery itself. This is called *supravalvar pulmonic stenosis*.

What are the symptoms of pulmonary stenosis in children?

Pulmonary stenosis usually does not cause symptoms in infants or small children. As the child gets older, abnormal signs and symptoms may appear, including fatigue, a heart murmur (an extra heart sound when a healthcare provider listens with a stethoscope) and, rarely, chest pain or fainting.

How is pulmonary stenosis diagnosed?

In rare cases, newborns have critical pulmonary stenosis, which requires immediate medical attention. Sometimes severe cases of pulmonary stenosis are diagnosed before birth.

Cardiac specialists usually diagnose pulmonary stenosis after a primary care provider detects a heart murmur and refers the child to them.

Diagnosis of pulmonary stenosis may require some or all of these tests:

- pulse oximetry—a painless way to monitor the oxygen content of the blood
- chest X ray
- echocardiogram (also called echo or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- cardiac magnetic resonance imaging—a three-dimensional image shows the heart's abnormalities
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”).

Pulmonary stenosis can run in families, so be sure to tell your cardiologist if there is a history of a murmur in other close family members.

What are the treatment options for pulmonary stenosis in children?

The exact treatment required for pulmonary stenosis depends on each child's heart anatomy. Trivial or mild pulmonary stenosis typically require no treatment. However, moderate, severe, and critical pulmonary stenosis require treatment.

Cardiac Catheterization

In most cases, pulmonary stenosis is treated with balloon valvuloplasty, which requires cardiac catheterization. Healthcare providers advance a thin tube (catheter) to the heart through a vein in the leg. The catheter has a balloon on the end of it. To open up the narrow valve, the balloon is briefly inflated, deflated, and withdrawn. Sometimes, two catheters and balloons are used. Sometimes, in newborns, the blood vessels in the umbilical cord are used as the site where the catheters are inserted and advanced toward the heart.

Older children may spend one night in the hospital after this procedure and will need to rest the next day but then



can resume normal activity. Newborns with critical pulmonary stenosis will stay in an intensive care unit before and after the procedure and will require some time to recover.

Surgery

In rare cases, surgery will be required. Surgeons use a procedure called *valvotomy* to separate fused leaflets in the pulmonary valve. Another option includes the surgical placement of a valve called a *pulmonary homograft*, which is a donated pulmonary valve and artery. This valve may grow with the child, and blood-thinners are not required.

New Valve

An exciting future option is a tissue-engineered valve that is grown with the patient's own cells on a biodegradable mesh. This may be the future of all valve replacement but is still in the research and development phase.

Surgery for Subpulmonic and Supravalvar

Subpulmonic and supravalvar pulmonic stenosis do not get better with balloon dilation and will require surgery if the amount of obstruction is moderate or severe. Surgery for subpulmonic stenosis involves cutting out the muscle bundles. Surgery for supravalvar pulmonic stenosis involves enlarging the pulmonary artery with a patch.

Follow-Up Care Through Age 18

Children with pulmonary stenosis require regular check-ups with a pediatric cardiologist. Some children must remain on medicine and limit physical activity.

As the child grows, blood may begin to leak through the abnormal valve. This is called pulmonary regurgitation or pulmonic insufficiency. In other children, the stenosis can reoccur. When this happens, balloon valvuloplasty can be repeated, as long as there isn't significant regurgitation. In severe cases, additional surgery may be necessary.

Pediatric cardiologists follow patients with pulmonary stenosis until they are young adults, coordinating care with the primary care providers.

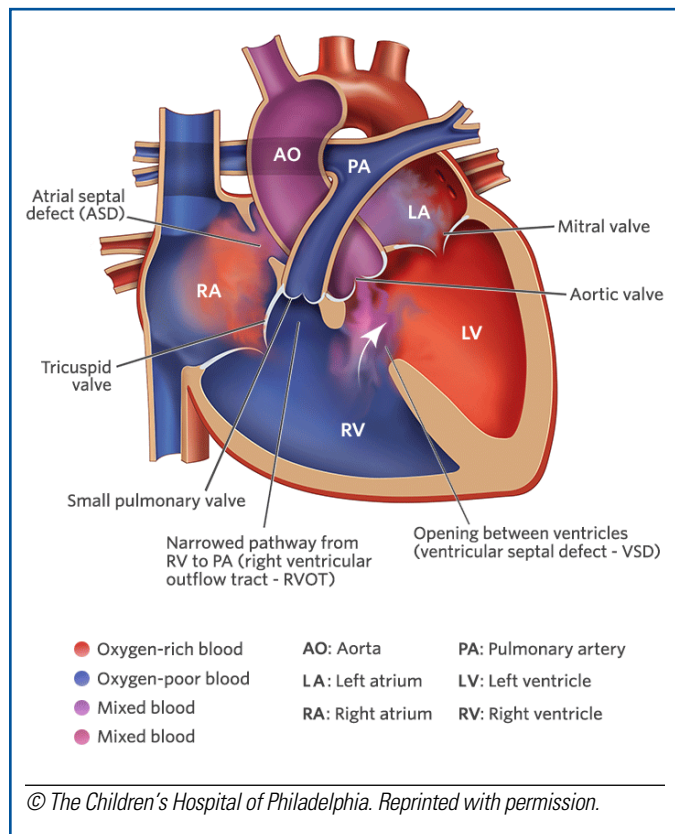
Into Adulthood

Adults who were born with pulmonary stenosis must continue to see a cardiologist. Pediatric cardiologists will help with the transition to an adult cardiologist. All patients with pulmonary valve disease need some form of lifelong follow-up with a cardiologist. Because of enormous strides in medicine and technology, today most children with heart conditions go on to lead healthy, productive lives as adults.

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Cardiac Defects: Tetralogy of Fallot



Tetralogy of Fallot has four characteristics:

- Ventricular septal defect (VSD)—There is a hole between the two bottom chambers (the ventricles) of the heart that eject blood to the body and lungs.
- Overriding aorta—The aorta, the large artery that takes blood to the body, is on top of both ventricles, instead of just the left ventricle as in a normal heart.
- Pulmonary stenosis—There is a narrowing of the pulmonary valve, the area below the valve, or the pulmonary arteries, which carry blood from the heart to the lungs.
- Hypertrophy—The right ventricle becomes thicker and more muscular than normal as a result of working harder to pump blood through the narrow pulmonary valve.

Symptoms

The symptoms of tetralogy of Fallot include

- blue or purple tint to lips, skin, and nails (cyanosis)

- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope
- abnormal shape of the fingertips (“clubbing”) in older children
- spells in which oxygen levels drop—lips and skin will become bluer, and the child will become fussy or irritable and then sleepy or unresponsive.

How is tetralogy of Fallot diagnosed?

Tetralogy of Fallot may be diagnosed with fetal echocardiogram (ultrasound). Your baby’s provider will prepare a plan for delivery and care immediately after birth.

Your baby’s providers might make the tetralogy of Fallot diagnosis before your baby leaves the hospital if they hear a murmur or see a blue tint to the skin. A primary care provider might detect the same symptoms during a checkup, or you might notice the symptoms and bring your baby to a doctor or hospital.

Diagnosis of tetralogy of Fallot may require some or all of these tests:

- pulse oximetry—a painless way to monitor the oxygen content of the blood
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- echocardiogram (also called echo or ultrasound)—sound waves create an image of the heart
- chest X ray
- cardiac magnetic resonance imaging—a three-dimensional image shows the heart’s abnormalities
- cardiac catheterization—a thin tube (catheter) is inserted into the heart through a large vein in the leg.

A number of children with tetralogy of Fallot also have genetic syndromes such as DiGeorge syndrome (22q11 deletion syndrome), Trisomy 21 (Down syndrome), or Alagille syndrome. Genetic testing (a blood test) may be part of the evaluation.



What are the treatment options for tetralogy of Fallot?

Surgery is required to repair tetralogy of Fallot. Typically, in the first few months of life, surgeons will perform open-heart surgery to patch the hole and widen the pulmonary valve or artery. In some cases, depending on the unique needs of the patient, they will perform a temporary repair until a complete repair can be done. The temporary repair involves connecting the pulmonary arteries (which carry blood from heart to lungs) with one of the large arteries that carry blood away from the heart to the body. This increases the amount of blood that reaches the lungs, and so increases the amount of oxygen in the blood. Both the primary complete surgical repair and the staged repair give comparable outcomes, but infants undergoing the staged repair might have better neurodevelopmental outcomes (associated with early surgery and shorter length of stay in the hospital; Bailey, Mercer-Rosa, Mascio, Elci, & Goldmuntz, 2016).

What is the follow-up care for tetralogy of Fallot?

Through Age 18

A child who has had surgical repair of tetralogy of Fallot will require lifelong care by a cardiologist.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care provider. Parents will need to carefully follow the advice of their baby's provider, including staying on any medications prescribed and, in some cases, limiting exercise.

Sometimes children with tetralogy of Fallot experience heart problems later in life, including a leaky heart valve and irregular heartbeat (arrhythmia). Medicine or repeat surgery may be required.

Into Adulthood

Because of enormous strides in medicine and technology, today most children born with heart conditions like tetralogy of Fallot go on to lead healthy, productive lives as adults.

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Cardiac Defects: Total Anomalous Pulmonary Venous Return

Arteries carry blood away from the heart; veins carry it toward the heart. The pulmonary veins are very important. They carry the “red” blood that has picked up oxygen in the lungs back to the heart to be pumped out to the body.

Typically, there are four pulmonary veins, two from each lung, and normally they all connect directly into the heart’s left atrium (left upper chamber). From the left atrium, blood travels into the left ventricle (left lower chamber), which pumps it out to the aorta and to the body.

Anomalous means abnormal. In a child born with total anomalous pulmonary venous return (TAPVR), the pulmonary veins connect to other veins and ultimately drain their blood into the right atrium. You also may hear the term *total anomalous pulmonary venous connection* (TAPVC). Ordinarily, the right atrium only receives “blue” blood coming back from the body without oxygen, which then passes into the right ventricle and is pumped to the lungs. In TAPVR, the right atrium receives both “blue” blood from the body and “red” blood from the lungs.

As a result, the right side of the heart is overworked, pumping the extra blood it receives. Frequently, there is obstruction (blockage) to the veins that receive blood from the pulmonary veins, which causes a backup of blood in the lungs. This disrupts the normal flow of blood between the lungs and the body. In addition, the blood leaving the heart for the body doesn’t have as high a level of oxygen as it should.

Children with TAPVR also have other heart defects. They have a hole in the wall separating the two upper chambers of the heart (atrial septal defect) and may have a patent ductus arteriosus, an extra blood vessel between the pulmonary arteries and the aorta. These heart defects actually can help a child with TAPVR survive by allowing

more blood to get from the right side of the heart to the left side and out to the body.

Your baby’s cardiologist will explain your baby’s heart anatomy in detail. Generally, there are four types of TAPVR:

- Supracardiac TAPVR: The pulmonary veins drain into the right atrium through the superior vena cava. (Normally this large vein carries only deoxygenated, or “blue,” blood into the right atrium.)
- Infracardiac TAPVR: The pulmonary veins drain into the right atrium through the liver (hepatic) veins and the inferior vena cava (another large vein that normally carries only deoxygenated blood).
- Cardiac TAPVR: In one type, the pulmonary veins can directly enter into the right side of the heart, into the right atrium. In the second type, the pulmonary veins can drain into the coronary sinus, a vein that usually only carries blood coming out of the heart muscle. This vein is usually very small but becomes quite large with this abnormal amount of blood.
- Mixed TAPVR: The pulmonary veins split up and drain partially to more than one of these options.

Symptoms

TAPVR symptoms include

- blue or purple tint to lips, skin, and nails (cyanosis)
- rapid breathing or working harder while breathing, especially while eating
- heart murmur (an extra heart sound when a doctor listens with a stethoscope).

The severity of TAPVR symptoms varies.

How is TAPVR diagnosed?

In some cases, newborns with TAPVR have difficulty breathing and quickly become very ill. This occurs when the pulmonary veins are too narrow or are obstructed at some point, and blood can’t flow from the lungs as quickly as it should. This is called *TAPVR with pulmonary obstruction*.



In other cases, TAPVR is diagnosed in the first few months of life after a child demonstrates milder symptoms such as a heart murmur or cyanosis.

Diagnosis of TAPVR may require some or all of these tests:

- echocardiogram—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”)
- cardiac magnetic resonance imaging—a three-dimensional image shows the heart’s abnormalities.

What are the treatment options for TAPVR?

TAPVR requires open-heart surgery in all cases. Critically ill newborns will have surgery immediately. If the child is not critically ill, surgeons may wait up to 2 months to perform surgery, depending on the strength of the child and on the heart anatomy.

To understand the surgery, one important thing to know about TAPVR is that the pulmonary veins, despite their abnormal connections to other veins, all end in a collection (called a confluence) at the back of the left atrium. The surgeon opens the confluence so that the veins can drain into the left atrium and then ties off all abnormal connections between the pulmonary veins and other veins, so that blood can follow only the path to the left atrium. The surgeon also closes septal defects (the abnormal holes) with tiny patches or stitches and closes the

patent ductus arteriosus. As the child ages, the lining of the heart grows over the stitches.

Another surgical option is a sutureless open-heart surgery, which may provide certain benefits and decreased mortality for patients with a pulmonary valve obstruction (PVO; Zhang et al., 2016).

What is the follow-up care for TAPVR? Through Age 18

Children who were born with TAPVR and had it repaired must continue to see a pediatric cardiologist regularly. Children who were critically ill as newborns may have a longer road to recovery. In most cases, however, children won’t experience long-term effects—they won’t have to remain on any medicines or limit physical activity.

Rarely, the pulmonary veins become obstructed later in life and additional surgery or a catheterization procedure is required. Also rarely, children experience arrhythmia (abnormal heart rhythm), which may be treated with medicines, radiofrequency ablation, or a pacemaker.

Into Adulthood

It is important that children who were born with TAPVR continue to see a cardiologist. Because of enormous strides in medicine and technology, today most children born with TAPVR go on to lead productive lives as adults.

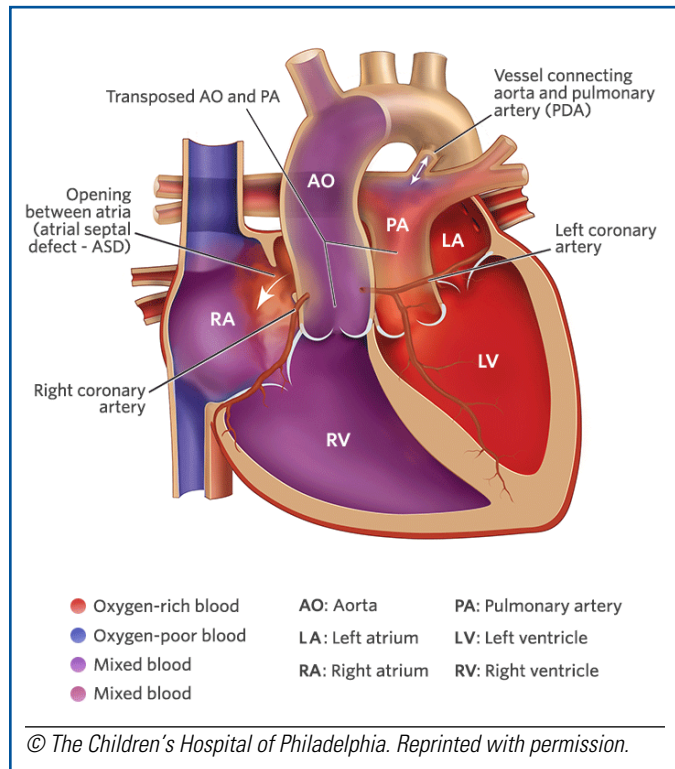
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Cardiac Defects: Transposition of the Great Arteries



Transposition of the great arteries (TGA) is a complex congenital heart defect in which the two large arteries that carry blood out of the heart are connected to the heart abnormally:

- The aorta is attached to the right-sided pumping chamber (ventricle), instead of the left.
- The pulmonary artery is attached to the left-sided pumping chamber (ventricle), instead of the right.

Normally, blood flows in this pattern: body to right side of heart, to lungs, to left side of heart, and back to body. The pulmonary artery carries blood from the right side of the heart to the lungs, and the aorta carries blood from the left side of the heart to the body. In children with TGA, the normal pattern of flow does not exist, and the body doesn't get enough oxygenated blood.

What are the symptoms of TGA?

The symptoms of TGA include

- blue or purple tint to lips, skin, and nails (cyanosis)
- rapid breathing
- difficulty feeding, poor appetite, and poor weight gain.

How is TGA diagnosed?

TGA may be diagnosed before birth with a fetal echocardiogram (ultrasound). Your baby's provider will prepare a plan for delivery and care immediately after birth.

TGA may be diagnosed when an infant is a few hours or days old, or in some cases, infants may not have visible symptoms for weeks or months. Pediatricians refer newborns to a pediatric cardiologist when they notice symptoms or abnormal values on screenings such as pulse oximetry.

Diagnosis of TGA may require some or all of these tests:

- echocardiogram (also called echo or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- pulse oximetry—a noninvasive way to monitor the oxygen content of the blood
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus ("belly button")
- cardiac magnetic resonance imaging—a three-dimensional image shows the heart's abnormalities.

What are the treatment options for TGA?

TGA is unpredictable. Approximately one-third of newborns with the condition will require an urgent intervention called a *balloon atrial septostomy* (BAS) within hours after birth. This procedure creates or enlarges a hole between the upper chambers of the heart to allow blood to mix.



For babies requiring a BAS procedure, access to immediate expert care is essential.

All children with TGA will require open-heart surgery to treat the defect. Without surgical repair, the overwhelming majority of patients with TGA will not survive their first year. The surgery, known as the *arterial switch operation*, is typically performed within a few days of birth. Pediatric cardiac surgeons reconstruct the heart so that the aorta is attached to the left ventricle and the pulmonary artery is attached to the right ventricle.

After surgery your child will recover in a neonatal or pediatric intensive care unit.

What is the follow-up care for TGA? Through Age 18

Children who have had surgical repair of TGA require life-long care by a cardiologist. Ongoing medication use is uncommon. More surgery may be required as the child grows.

Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care physicians.

Into Adulthood

The pediatric cardiologist will help your child transition to an adult cardiologist.

Until approximately 25 years ago, infants with TGA were managed by alternative surgical procedures, sometimes referred to as the *Senning* or *Mustard* operations. As a result, the long-term effects of the arterial switch operation beyond young adulthood are not known. Although some studies have shown that a proportion of patients display a slight cognitive and psychosocial disparity, there still is a need for more prospective research on the long-term health of these patients (Heinrichs et al., 2014; Kalfa et al., 2017). It is anticipated that the overwhelming majority of children born with TGA will go on to lead healthy, productive lives. Limitations to day-to-day activities, including sports, are rare.

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Cardiac Defects: Tricuspid Atresia

The right side of the normal heart receives oxygen-poor blood (“blue” blood) from the body’s veins and pumps it to the lungs to receive oxygen. The oxygen-rich blood (“red” blood) returns from the lungs to the left side of the heart, which pumps the blood to the body. The tricuspid valve is the opening between the right atrium (the upper chamber) and the right ventricle (the lower chamber). A heart with tricuspid atresia is characterized by poorly developed right heart structures and

- no tricuspid valve
- a smaller-than-normal, or hypoplastic, right ventricle
- a hole between the right atrium and left atrium, so that oxygen-poor and oxygen-rich blood mix inside of the heart
- a hole between the right ventricle and left ventricle.

Tricuspid atresia in children often is associated with pulmonary stenosis or narrowing of the pulmonary valve, or pulmonary atresia, where the pulmonary valve is completely closed. Tricuspid atresia also can be associated with transposition of the great arteries, where the aorta, the large artery that carries blood to the body, is connected to the small right ventricle.

Tricuspid atresia is a single-ventricle lesion because the heart has only one functioning ventricle (the left ventricle).

Symptoms

Tricuspid atresia symptoms in children include

- blue or purple tint to lips, skin, and nails (cyanosis)
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope
- shortness of breath
- difficulty feeding
- poor weight gain
- fatigue
- abnormal shape of the fingertips (“clubbing”) in older children.

How is tricuspid atresia diagnosed?

Tricuspid atresia in children may be diagnosed before birth with a fetal echocardiogram. Your baby’s providers

can prepare a plan for delivery and care immediately after birth.

Tricuspid atresia is usually diagnosed a few hours or days after birth. Pediatricians refer newborns to pediatric cardiologists when they notice symptoms and signs such as a “blue baby with a heart murmur.” Pulse oximetry is a painless way to monitor the oxygen level of the blood.

Some or all of these tests may be required for diagnosis of tricuspid atresia in children:

- chest X ray
- blood tests
- electrocardiogram (EKG)—this test shows the electrical activity of the heart
- echocardiogram (also called echo or ultrasound)—sound waves create an image of the heart. This test usually confirms the diagnosis.
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”).

What are the treatment options for tricuspid atresia?

Your baby will be admitted to the cardiac intensive care unit. The baby may require oxygen and a medication called prostaglandin to maintain adequate oxygen levels in the blood. *Prostaglandin* is an intravenous medication that keeps open the connection between the pulmonary artery (the artery that normally carries blue blood to the lungs to receive oxygen) and the aorta (the artery that carries red blood to the body). This connection, called patent ductus arteriosus (PDA), is open in the fetus and closes soon after birth. When the PDA closes, some babies with tricuspid atresia turn quite blue (cyanosed). An infusion of prostaglandin can reopen the PDA and is a lifesaving intervention. Not all babies with tricuspid atresia require prostaglandin.

If the baby has labored breathing or poor effort, he or she may need help with a breathing machine or ventilator.



It is not uncommon for babies to have poor respiratory effort or apnea while on prostaglandin infusion.

At least two and possibly three surgeries will be required:

Blalock-Taussig Shunt

Babies who require prostaglandin to maintain adequate oxygen levels will require surgery soon after birth. The surgery involves the creation of a shunt, which is a tube that connects one of the branches of the aorta and the pulmonary artery, and thus replaces the PDA. This operation is called the *Blalock-Taussig* (BT) shunt. Many babies with tricuspid atresia are well enough to be discharged home soon after birth. However, some of these babies may require the shunt operation at a few weeks of life if the level of oxygen in their blood is decreasing.

Some babies with tricuspid atresia are too “pink” or have too much blood flow to the lungs and will require an operation called *pulmonary artery banding* to narrow the pulmonary artery and regulate blood flow to the lungs. Babies with tricuspid atresia and transposition of great arteries may require the Norwood procedure if the aorta is too small (see *Hypoplastic Left Heart Syndrome* in Diagnoses).

Hemi-Fontan/Glenn

The second operation, called the *hemi-Fontan/Glenn*, usually occurs within 6 months of birth. During this surgery, the superior vena cava, one of the two large veins attached to the heart to return deoxygenated or blue blood from the upper half of the body, is disconnected from the heart and attached to the pulmonary artery. During this operation, the surgeon also removes the BT shunt. After this operation, deoxygenated or blue blood from the upper body goes to the lungs without passing through the heart.

Fontan

The third operation, called the Fontan, occurs at approximately 18 months to 3 years of age. During this surgery, the inferior vena cava, the other large vein that returns deoxygenated blood to the heart from the lower half of the body, is disconnected from the heart and attached to the pulmonary artery. This means that deoxygenated or

blue blood from the whole body goes to the lungs without passing through the heart.

The cardiac team will explain the surgical procedures to you in more detail, based on your child’s heart anatomy.

What is the follow-up care for tricuspid atresia?

Between the Norwood and Glenn Procedures

Although early outcomes for patients with single ventricle heart defects after staged reconstruction have improved dramatically, the period between the Norwood and Glenn procedures remains a very vulnerable time for infants.

Through Age 18

Children with tricuspid atresia require lifelong care by a cardiologist. Many remain on medications for life. Additional surgeries may be required.

As single ventricle survivors get older, doctors are recognizing that, although some do fine, many experience complications, including lung, liver, and gastrointestinal diseases.

In addition, as a group, children with complex congenital heart defects who have had open-heart surgery as infants are at a higher risk for neurodevelopmental issues compared with children without congenital heart defects. Pediatric cardiologists follow patients until they are young adults, coordinating care with the primary care physicians.

Into Adulthood

It’s important that your child continues to see a cardiologist as an adult. The pediatric cardiologist will help with the transition to an adult cardiologist. Because of enormous strides in medicine and technology, today many children born with tricuspid atresia go on to lead healthy, productive lives as adults.

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Cardiac Defects: Truncus Arteriosus

When the fetus develops during pregnancy, the heart has a single large blood vessel coming from the heart called the *truncus arteriosus*. If fetal development progresses normally, the truncus divides into two arteries that carry blood out of the heart:

- The pulmonary artery, which is attached to the right bottom chamber (ventricle) of the heart, divides into two arteries carrying oxygen-poor (“blue”) blood to each side of the lungs.
- The aorta, which is attached to the left bottom chamber (ventricle) of the heart, carries oxygen-rich (“red”) blood to the body.

Sometimes the single large blood vessel fails to divide during fetal development, and the baby is born with a heart that has one artery carrying blood out of it. This condition is known as *truncus arteriosus* or *persistent truncus arteriosus* (the trunk “persists”).

The undivided trunk is attached to the heart as one artery straddling the bottom chambers and then divides into arteries taking blood to the lungs and body. The oxygen-poor blood from the right ventricle (bottom chamber) and the oxygen-rich blood from the left ventricle (bottom chamber) mix when ejected out into the trunk, and more blood than normal goes back to the lungs, making it harder for the infant to breathe.

In almost all cases, children with the congenital heart defect truncus arteriosus also have a large hole between the bottom chambers of the heart. This is called a *ventricular septal defect* (VSD).

As a result of these abnormalities, the baby’s blood isn’t as oxygenated as it should be when it circulates through the body.

Signs and Symptoms

Signs and symptoms of truncus arteriosus include

- blue or purple tint to lips, skin, and nails (cyanosis)
- poor eating and poor weight gain
- rapid breathing or shortness of breath

- profuse sweating, especially with feeding
- more sleepiness than normal
- unresponsiveness (the baby seems “out of it”)
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope.

How is truncus arteriosus diagnosed?

Truncus arteriosus is a life-threatening congenital heart defect; most babies won’t live for more than a few months without treatment.

Usually truncus arteriosus is diagnosed before the baby leaves the hospital if the doctor hears a murmur or sees a blue tint to the lips or skin. In some cases, a primary care pediatrician might detect the symptoms of truncus arteriosus during a checkup, or a parent might notice symptoms and bring the baby to a doctor or hospital.

Diagnosis of truncus arteriosus may require some or all of these tests:

- pulse oximetry—a painless way to monitor the oxygen content of the blood
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- echocardiogram (also called echo or ultrasound)—sound waves create an image of the heart
- chest X ray
- cardiac magnetic resonance imaging—a three-dimensional image shows the heart’s abnormalities
- cardiac catheterization—a thin tube is inserted into the heart through a vein or artery in either the leg or through the umbilicus (“belly button”).

Sometimes truncus arteriosus is diagnosed on a fetal ultrasound or echocardiogram. Your baby’s providers can prepare a plan for delivery and care immediately after birth.

A number of children with truncus arteriosus also have a genetic syndrome called 22q11 deletion syndrome (also known as *DiGeorge*, *velocardiofacial*, or *conotruncal*



anomaly face syndromes). Genetic testing (a blood test) for this syndrome may be part of the evaluation.

Truncus Arteriosus Treatment

Open-heart surgery is required to treat truncus arteriosus, usually before the baby is 2 months old. More than one operation may be required.

Cardiothoracic surgeons place a patch to close the hole (the ventricular septal defect). They separate the pulmonary arteries from the trunk and then connect the pulmonary arteries to the right bottom chamber (ventricle) of the heart using different kinds of conduits (tubes). They repair the trunk so that it becomes a complete, functioning aorta. Other repairs may be needed, based on each child's unique needs.

What is the follow-up care for truncus arteriosus?

Through Age 18

A child who has had surgical repair of truncus arteriosus will require lifelong care by a cardiologist.

Pediatric cardiologists follow patients with truncus arteriosus until they are young adults, coordinating care with the primary care provider. Patients will need to carefully follow providers' advice, including staying on any medications prescribed and, in some cases, limiting certain types of exercise.

Sometimes children with truncus arteriosus experience heart problems later in life, including irregular heartbeat (arrhythmia), a restricted conduit or pulmonary artery, or a leaky aortic valve. Medicine, surgery, or cardiac catheterization may be required.

Into Adulthood

Your baby's pediatric cardiologist will help patients who have had truncus arteriosus treatment transition to an adult cardiologist.

Because of enormous strides in medicine and technology, today most children with heart defects go on to lead healthy, productive lives as adults.

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Cardiac Defects: Ventricular Septal Defect

A *ventricular septal defect* (VSD) is an opening in the tissue (the septum) between the heart's lower chambers (the ventricles). A VSD is one of the defects referred to as "a hole in the heart."

When the VSD is large, the heart may have to pump harder to deliver enough oxygen to the body. Patients with a small VSD usually do not have any symptoms.

Sometimes children with a VSD also have other heart abnormalities.

What are the symptoms of a VSD?

If the hole is large, a child might exhibit symptoms including

- rapid heartbeat
- difficulty feeding
- heart murmur—the heart sounds abnormal when a doctor listens with a stethoscope.

How is a VSD diagnosed?

A VSD might be diagnosed before birth with a fetal echocardiogram. In this case, your baby's providers will prepare a plan for care after birth.

In some cases, a VSD might be diagnosed soon after birth if the newborn exhibits symptoms or a doctor notices a heart murmur. Sometimes a VSD isn't diagnosed until the child is older.

Diagnosis of a VSD may require some or all of these tests:

- echocardiogram (also called echo or ultrasound)—sound waves create an image of the heart
- electrocardiogram (ECG)—a record of the electrical activity of the heart
- chest X ray
- cardiac catheterization—a thin tube (catheter) is inserted into the heart through a large vein in the leg
- cardiac magnetic resonance imaging—a three-dimensional image that shows the heart's abnormalities.

It is important that a VSD be diagnosed and treated, as needed, or the heart and the arteries between the heart and lungs might be damaged.

What are the treatment options for a VSD?

Treatment will depend on your child's health and on the size of the VSD. Doctors may wait to see if the VSD will close on its own. Many small VSDs will do so before the child is 2 years old.

If the VSD requires surgery, doctors might wait until your baby is older and stronger. During that time, your baby may have to take medicines as well as have higher calorie intake to help with the symptoms. If surgery is needed, surgeons will place a patch or stitches to close the hole during open-heart surgery.

What kind of follow-up care is required for a VSD?

Through Age 18

After VSD repair, many children recover quickly and don't experience additional cardiac problems. They must see a pediatric cardiologist for checkups, and some remain on medicine. Rarely, additional surgery is required.

If the child has other heart abnormalities, more follow-up care will be required.

Pediatric cardiologists follow patients until they are young adults, coordinating care with primary care providers.

Into Adulthood

It's important that adults who were born with a VSD continue to see a cardiologist. The pediatric cardiologist will help your child transition to adult cardiologists.

Because of enormous strides in medicine and technology, today most children with heart conditions go on to lead healthy, productive lives.

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Congenital Diaphragmatic Hernia

Background

Approximately one in 2,200 to 3,000 live births is affected by a congenital diaphragmatic hernia (CDH). This congenital defect allows abdominal organs to enter the thoracic cavity through a defect in the diaphragm during gestational development. CDH is a life-threatening condition, and prompt identification and management is needed in the delivery room because of the physical compression of the lung tissue on the affected side and the displacement of the heart and opposite lung within the thoracic cavity.

Definition

Approximately 85% of CDH defects occur in the left diaphragm, with defects occurring on the right or bilaterally much less frequently (Bradshaw, 2015). Of the left-sided defects, the majority occur in the posterior area of the diaphragm (Bochdalek hernia). Male newborns are more commonly affected. This defect carries a 2% recurrence risk in subsequent pregnancies (Carley, 2007). The severity of the defect is related to the timing and degree of herniation of abdominal contents during fetal development.

Some defects are very small and can be difficult to identify. Others are large, even progressing to complete absence of the diaphragm. Larger defects that herniate into the thoracic cavity have a higher incidence of bilateral pulmonary hypoplasia, persistent pulmonary hypertension, and intrapulmonary shunts. The abdominal contents that have herniated into the thoracic cavity compress the lung tissue, limiting the lung's growth and ability to oxygenate and ventilate. This pulmonary compression causes marked diminution of bronchial branching, limited multiplication of alveoli, and the persistence of muscular hypertrophy in the pulmonary arterioles. These abnormalities occur on the affected side, but they may affect the "nondefect" side as well, usually to a lesser degree. The exact etiology for CDH is unknown, and it may present as an isolated defect or as part of a syndrome.

Associated Conditions

Associated anomalies occur in more than 40% of infants with a CDH. The most common anomalies involve the central nervous, cardiovascular, musculoskeletal, gastrointestinal, and genitourinary systems. CDH also has been noted to be a component of chromosomal abnormalities such as trisomies 13, 18, and 21.

Diagnosis

CDH commonly is diagnosed on prenatal ultrasound. A common maternal association is polyhydramnios. The hallmark finding on prenatal ultrasound is a fluid-filled stomach behind the left atrium. However, CDH is not always diagnosed prenatally due to the size of the defect and the positioning of the fetus during the ultrasound evaluation.

Clinical Presentation

These infants often will present with significant respiratory distress and cyanosis in the delivery room or within the first few minutes of life. The amount of work it takes for them to breathe typically gets worse over time. If the infant received bag and mask ventilation, their condition will significantly worsen because the ventilation inflates the bowel along with the lungs. As the bowel becomes distended from the ventilation, it further compresses the lung tissue. Other signs include a scaphoid abdomen, barrel chest, heart sounds shifted from the normal point of maximal impulse location, decreased breath sounds, signs of decreased cardiac output such as poor perfusion, bowel sounds auscultated in the chest, and decreased oxygen saturations. The hypoxemia noted in these infants often is related to right to left shunting through their ductus arteriosus, foramen ovale, and intrapulmonary shunts.

Laboratory Findings

It is common to obtain an arterial blood gas on a patient with this degree of respiratory distress and cyanosis. The blood gas will often reveal hypoxemia, hypercapnia, and a metabolic and/or respiratory acidosis.



On chest X ray, the gastric bubble may be displaced. This is not always the case, depending on whether the stomach has migrated to above the diaphragm. Typically, the bowel gas pattern is noted in the thorax. This bowel gas may not be seen immediately after birth.

Delivery Room Management

Ideally, if the baby's defect is identified prior to birth, the mother will deliver in a center capable of providing inhaled nitric oxide, extra corporeal membrane oxygenation (ECMO), pediatric surgery, and genetic evaluation to the infant. Late preterm and term infants who present with significant respiratory distress and cyanosis in the delivery room should be evaluated for a CDH. These infants do not respond well to bag and mask ventilation for reasons addressed above.

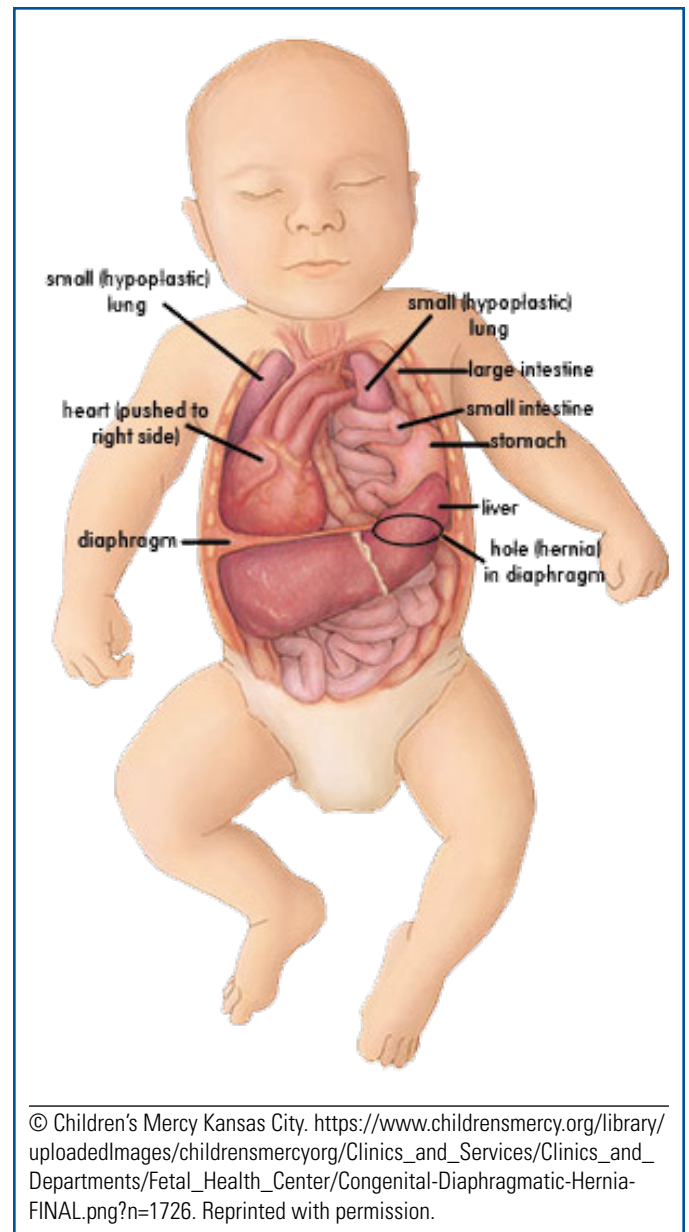
For infants with a known CDH, immediate endotracheal intubation and ventilation is done to minimize the overdistention of the stomach and intestines. This overdistention could lead to further compression of the lung tissue. To further improve the ability to ventilate and oxygenate this newborn, a Replogle or orogastric (OG) tube should be inserted. Another priority in the immediate care of this newborn is to minimize pulmonary hypertension (see *Persistent Pulmonary Hypertension in the Neonate* in Diagnoses) by evaluating and treating systemic hypotension, respiratory acidosis, and metabolic acidosis.

Preoperative Care

CDH is no longer considered a surgical emergency. Stabilization of this newborn is very important. This extra time also allows for thorough evaluation of any associated conditions that may preclude ECMO or surgery.

From a respiratory standpoint, the baby will be intubated and receive mechanical ventilation. Avoid bag or mask ventilation whenever possible. It also is important to evaluate for any signs of a pneumothorax. The pulmonary hypoplasia makes the newborn's lungs less compliant and more at risk for a pneumothorax. For these reasons, many babies with CDH will be managed with high-frequency ventilation. Other important aspects of care

include maintaining adequate perfusion, identifying and correcting any acid base imbalances, maintaining adequate oxygenation, and administering surfactant. If mechanical ventilation is not effective, the baby may require escalation of care, including inhaled nitric oxide or ECMO. If not already done, a Replogle or OG tube should be inserted to decompress the bowel. Central vascular access (umbilical lines or peripherally inserted central catheter and peripheral intravenous [IV] lines) will be needed for IV fluid and medication administration as well as arterial blood-pressure monitoring and frequent blood draws.





Surgical Care

At this time, in utero repair of the CDH does not seem to improve overall survival when compared with the standard postnatal repair (Gomella, 2013). Usually, a primary closure is possible. Synthetic patches may be used in the repair of large defects or when the diaphragm is absent.

Postoperative Care

Important aspects of postoperative care for a baby with CDH include pain management, maintaining adequate ventilation and oxygenation, continued gastric decompression, fluid and electrolyte management, and continued monitoring. The baby may be restricted to nothing by mouth for several days, so parenteral nutrition will be important for this baby. If right-to-left shunting is a problem, then inotropes (dopamine or dobutamine) may be used to decrease this shunting. Chest tubes (see *Chest Tubes* in Procedures) always should be placed to gravity or water seal; suction is avoided to prevent any acute mediastinal shifts.

Long-Term Follow-Up and Prognosis

Survival rates vary depending on the size of the defect, the amount of herniation (bowel in the chest), lung development, the presence of pulmonary hypertension, and any other associated conditions. As with other

congenital defects, early intervention has been shown to help improve outcomes. The mortality for newborns with CDH is approximately 50%. Follow-up evaluation is an essential component of the care of babies with CDH. It has been noted that some survivors have abnormal tone and delayed neurocognitive and language skills.

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Congenital Diaphragmatic Hernia: Information for Parents

Around one in 2,200 to 3,000 newborns is born with a congenital diaphragmatic hernia (CDH). The diaphragm is the muscle that separates the chest cavity from the abdominal cavity. It is a very important part of breathing normally. This defect allows the stomach organs to enter the space in the chest where the baby's heart and lungs are. When this happens while the baby is still developing, it can be a life-threatening condition. It is important that the medical team identify this condition as soon as possible.

Most CDHs occur on the baby's left side; male babies tend to have them more often. Some CDHs are very small and can be difficult to find. Others are large, sometimes with a complete absence of the diaphragm. Because the stomach contents are inside the area where the heart and lungs are, the normal growth of the heart and lungs may be affected.

Many babies with CDH have other problems. The most common problems involve the brain or spinal cord, the heart, the bones or muscles, the intestines, or the kidneys and bladder. Babies with CDH also may have issues with their chromosomes.

Although CDH is commonly diagnosed during a prenatal ultrasound, it is not always found before delivery. Ideally, if your baby's CDH is known before birth, you should deliver in a hospital with a level III or IV neonatal intensive care unit so that your baby will receive the care he or she needs right away. If not diagnosed before delivery, medium to large CDH defects will be diagnosed after birth. If this happens, your baby may need to be moved to another hospital. Often these babies will look blue in the delivery room, or within a few minutes after

birth, and will have a hard time breathing. You may notice that their chests are big and their stomachs are sunken in. There may be signs that their hearts are having trouble pumping blood to the body (weak pulses and pale skin). These babies usually require a breathing tube to be placed in their windpipes to make breathing easier.

A soft plastic tube will be placed in your baby's mouth to remove air from his or her stomach. This will help get more oxygen to your baby. He or she will not be fed for several days. An intravenous (IV) catheter will need to be placed to provide fluids, nutrition, and medications.

When your baby is stable, he or she will go to surgery to correct the CDH. Depending on the size, your baby may require heart-lung bypass before or after surgery. The heart-lung bypass machine helps do the job of the lungs and heart to allow them to heal.

Most times, the CDH can be repaired with one surgery. After surgery, the baby's care will include receiving baby pain medicine and nutrition and medication through an IV. Your baby may have a chest tube (see *Chest Tubes in Diagnoses*). This is a soft plastic tube that removes the air from the area outside of the baby's lungs. This will be taken out at the bedside a few days after surgery.

Survival rates vary depending on the size of the CDH and the complications both before and after surgery. Unfortunately, about 50% of babies do not survive. Follow-up appointments are very important in the care of babies with CDH. Some babies who survive can have abnormal muscle tone and delayed neurocognitive and language skills.



Congenital Microcephaly

Background

Congenital microcephaly is an abnormal smallness of the head, a congenital condition associated with incomplete brain development. This condition most commonly occurs between the third and fourth month of gestation. Microcephaly is a neural proliferation defect. In the United States, it has been estimated that the incidence of microcephaly is approximately 2–12 babies per 10,000 live births (Centers for Disease Control [CDC], 2018).

Definition

Microcephaly is a rare condition in which the frontal occipital circumference (FOC) is equal to or less than two standard deviations below the mean for age and gender or less than the 10th percentile for gestational age.

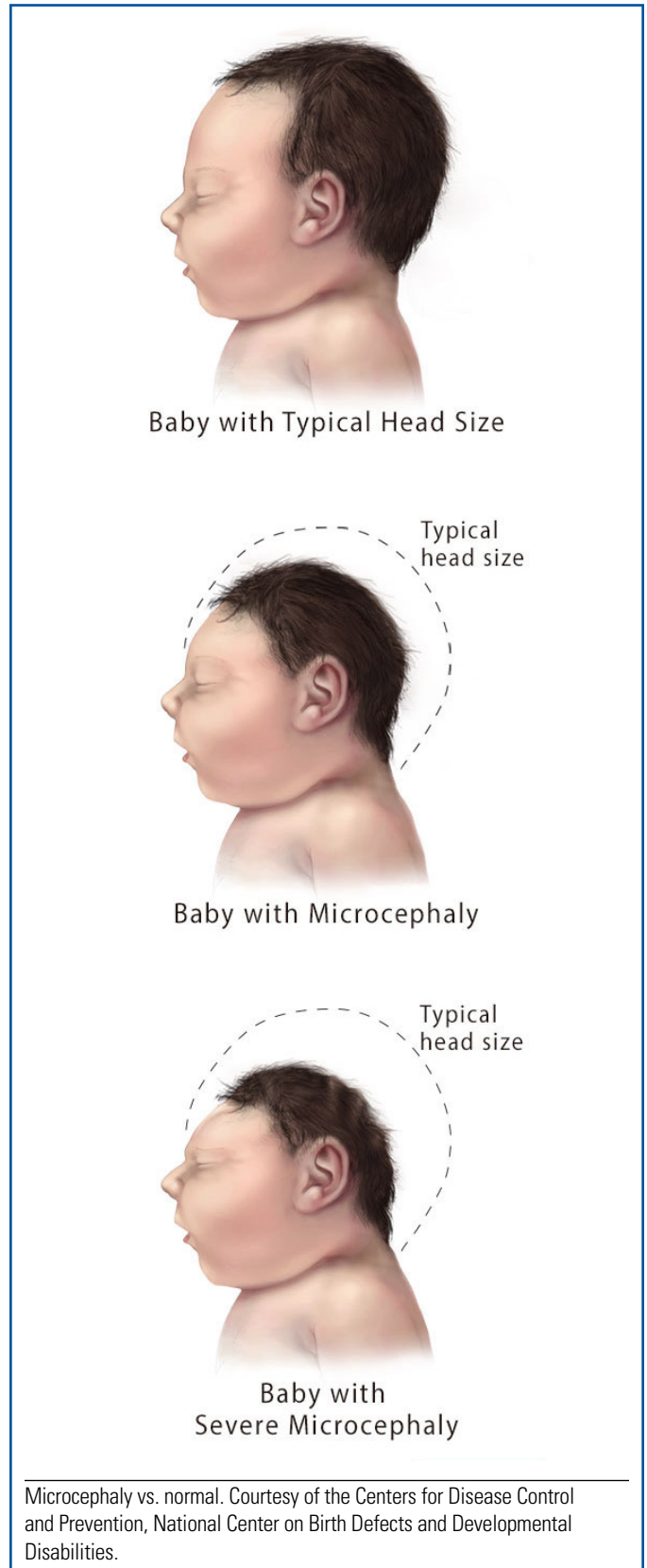
Risk Factors

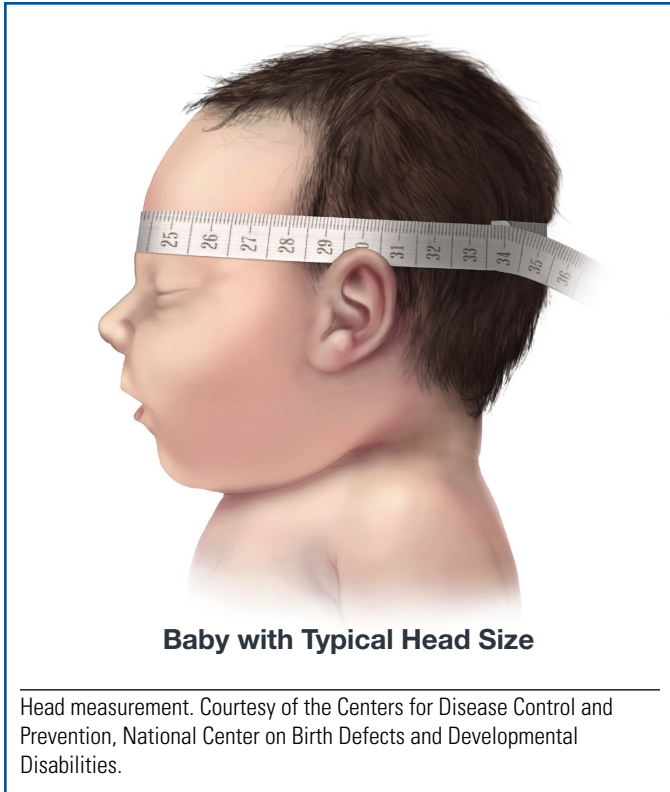
The exact etiology for microcephaly is unknown, but it can be caused by maternal, fetal, or neonatal factors. Maternal causes may include viral infections (toxoplasmosis, syphilis, rubella, cytomegalovirus, or herpes simplex), radiation exposure, metabolic disorders (PKU), exposure to harmful toxins (toxic chemicals, alcohol, and drugs) particularly during the first trimester, genetic conditions, and malnutrition. Fetal causes may include a prenatal or perinatal insult such as inflammation, hypoxia, or an interruption of the blood flow to the brain during a critical period of development, or birth trauma. Malnutrition, hypoxic ischemic encephalopathy, and very low birth weight (less than 1,500 grams at birth) can be neonatal causes. In recent years, maternal infection with the Zika virus during pregnancy has been identified as a risk factor for congenital microcephaly or other severe brain and nervous system disorders.

Associated Problems

Depending on the severity, microcephaly may be associated with other lifelong problems such as

- seizures
- developmental delays, such as problems with speech
- intellectual deficits
- difficulties with movement and balance





- feeding problems, such as difficulty with swallowing
- hearing loss
- visual disturbances.

Clinical Presentation

On visual inspection, the head appears small in relation to the rest of the body. This suspicion is confirmed when the head circumference is measured. Optimally, this measurement is obtained within the first 24 hours of life. Head circumference is measured with a tape that cannot be stretched. Securely wrap the tape around the widest point of the head's circumference to include the broadest part of the forehead above the eyebrows, above the ears, and the most prominent part of the occiput (Tappero & Honeyfield, 2015).

Congenital Zika Syndrome

Infants whose mother's were infected with the Zika virus during pregnancy will need to be closely evaluated for congenital Zika syndrome. This syndrome has five unique features:

- severe microcephaly in which the skull has partially collapsed

- decreased brain tissue with a specific pattern of brain damage
- damage to the back of the eye
- congenital contractures (CDC, 2018)
- hypertonia that restricts body movement after birth.

This infection has also been linked to other brain abnormalities such as brain atrophy, abnormally formed or absent brain structures, hydrocephalus, and neuronal migration disorders.

Diagnosis

Congenital microcephaly may be diagnosed prenatally during ultrasound evaluations, most accurately if the ultrasound is obtained late in the second trimester or early in the third trimester. This condition is confirmed or diagnosed after delivery during physical examination. Further studies may include a computed tomography (CT) or magnetic resonance imaging (MRI) of the head after birth.

Laboratory Findings

Depending on the specific risk factors, additional laboratory tests may be ordered. For example, if the cause is suspected to be a viral infection, labs may be drawn to confirm or rule out this cause.

Treatment

Microcephaly is a lifelong condition in which there are no treatment options available. Because the effects of microcephaly can range from mild to severe, care should be tailored to the individual child. Early intervention programs that include speech, physical, and occupational therapies will maximize the potential for these children.

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Congenital Microcephaly: Information for Parents

Congenital microcephaly is a rare condition in which the baby's head does not grow as expected in utero. During pregnancy, the fetus's head increases in size because his or her brain is growing. Therefore, when a baby has a smaller head than expected, the concern is that the brain is not growing as it should. This condition most commonly occurs during the first trimester of the pregnancy.

Microcephaly also may develop after birth (acquired microcephaly) and would be identified during well-baby checkups. In the United States, about five of every 10,000 babies born will have microcephaly.

The exact reason for microcephaly is not always clear, but it can be caused by many different things. Microcephaly may be the result of a viral infection the mother had during pregnancy (especially during the first few months of pregnancy). Other causes may include radiation exposure; metabolic disorders such as maternal phenylketonuria (PKU) disease; exposure to toxic chemicals, alcohol, or drugs (especially during the first trimester); genetic conditions; and decreased nutrition during pregnancy. Other causes may include inflammation, an interruption of the blood flow and oxygen to the brain of the baby during the critical period of development, and birth trauma. In recent years, research has shown that babies of mothers who were infected with the Zika virus during pregnancy are at risk for developing microcephaly or other severe brain and nervous system disorders.

Microcephaly can be mild or severe. If severe, microcephaly may be associated with other lifelong problems such as

- seizures
- developmental delays, such as speech problems
- intellectual deficits, such as learning difficulties
- difficulties with movement and balance
- feeding problems, such as difficulty with swallowing
- hearing loss
- visual issues.

When looking at your baby, his or her head appears small in proportion to the rest of the body. This suspicion is confirmed when the head circumference is measured. Optimally, this measurement is obtained soon after birth. On some babies with microcephaly, you may also notice a backward slope of the forehead.

Congenital microcephaly may be diagnosed before birth during ultrasound evaluations, especially when the ultrasound is done late in the second trimester or early in the third trimester. Sometimes, microcephaly is diagnosed after delivery, when the physician or nurse practitioner does their physical exam. Your baby may need a scan (CT or MRI) of the head to further evaluate this issue.

Depending on the risk factors for your baby, additional tests may be ordered. For example, if the suspected cause is a viral infection, blood will be drawn to confirm or rule this out.

Microcephaly is a lifelong condition, and currently, there are no treatments for it. Because the effects of microcephaly can range from mild to severe, each baby will have a different care plan. Early intervention programs that include speech, physical, and occupational therapies will be the most helpful for these children.

Babies infected with the Zika virus before birth will need to be closely evaluated for congenital Zika syndrome. This syndrome has five unique features:

- severe microcephaly
- decreased brain tissue with a specific pattern of brain damage
- damage to the back of the eye
- congenital contractures (a condition that shortens and/or tightens the muscles and tendons in the arms and legs, leading to deformity)
- increased muscle tone that restricts body movement after birth.

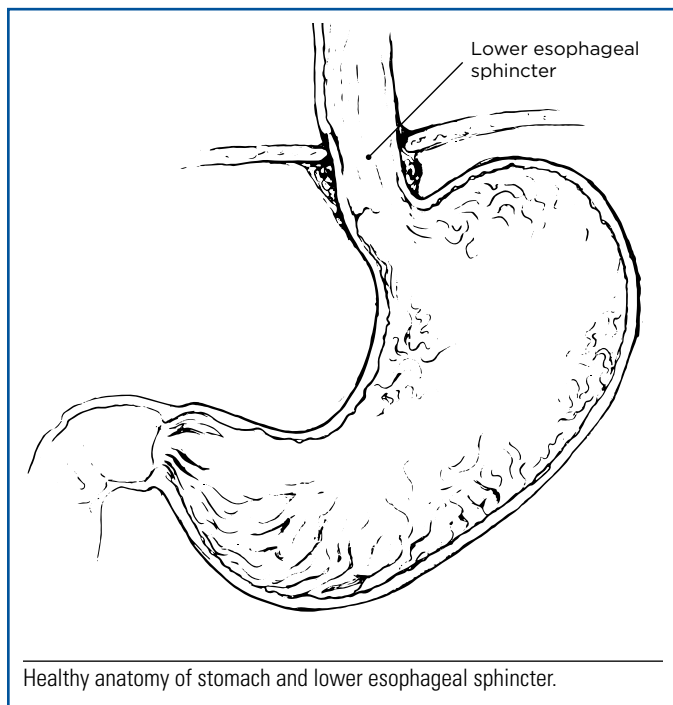


If your baby has had this infection, he or she also may have other brain abnormalities. Because of the lifelong consequences of microcephaly, it is very important that your baby has regular well-baby visits with his or her primary care or pediatric providers.



Gastroesophageal Reflux

Gastroesophageal reflux (GER) is the involuntary passage of gastric contents into the esophagus. Physiologic GER occurs on a regular basis in healthy infants and is characterized by passive spitting up without other associated complications. It usually resolves by 12 months of age. Less frequently, pathologic GER occurs when regurgitation of gastric contents is accompanied by other symptoms or complications and may be particularly problematic for premature infants. Severity may be related to the pH and volume of fluid that is refluxed into the esophagus, larynx, or mouth. Symptomatic GER may be referred to as gastroesophageal reflux disease (GERD) and is characterized by forceful vomiting (rather than the more passive spitting up of GER) and often poor weight gain or weight loss, irritability, and dysphagia. Other complications include esophagitis, neurobehavioral changes, hematemesis, growth failure, and respiratory problems such as apnea (controversial).



Some proposed causes and contributing factors for GERD in the neonatal population include

- delayed gastric emptying time (controversial)

- presence of an indwelling naso- or oral gastric feeding tube
- large fluid volume relative to size
- supine positioning
- short or narrow esophagus
- shorter lower esophageal sphincter positioned slightly above the diaphragm (rather than below as in adults)
- exposure to tobacco
- medications such as theophylline and caffeine as well as antenatal steroids
- certain clinical conditions and syndromes (such as gastroschisis and omphalocele; bronchopulmonary dysplasia; congenital diaphragmatic hernia; tracheo-esophageal fistula; neurologic and neuromuscular abnormalities including myotonic dystrophy, cystic fibrosis, cerebral palsy, hiatal hernia, laryngomalacia, swallowing dysfunction, and genetic abnormalities including Trisomy 21 and Cornelia de Lange).

Diagnosis is based on patient history and physical exam, with full exploration of the differential diagnosis to rule out other disorders that may present with vomiting. A thorough feeding history, growth patterns, and relevant medical and familial history are requisite to the diagnosis of GERD. Diagnostic tests such as upper gastrointestinal series, gastric emptying study, video swallow study, esophagogastroduodenoscopy with biopsy, esophageal pH probe monitoring, or dual pH-multichannel intraluminal impedance (pH-MII) may be considered to aid with diagnosis (Mousa et al., 2011).

Management of GERD aims to prevent and alleviate symptoms while promoting normal growth and the resolution of inflammation in the esophagus. A stepwise approach starting with the least invasive and inexpensive therapies is recommended, because reflux may improve with maturity without unnecessary and unproven therapies. Nonpharmacologic treatment may include

- left lateral positioning after feedings (right side down)
- slowing bolus feeding times or changing to continuous feedings



- removing the naso- or oral gastric tube in between feedings
- smaller, more frequent feedings (which may require higher calorie formulas to meet nutritional needs)
- placement of nasojejun tube for continuous feedings if there are airway concerns
- using extensively hydrolyzed protein formula (which can improve gastrointestinal mobility; Corvaglia, Mariani, Aceti, Galletti, & Faldella, 2013).

Pharmacologic management is only used in an infant who continues to have pathologic GERD despite nonpharmacologic intervention. Benefits versus adverse effects of the medications should be carefully considered. Recent findings have shown that acid-suppressive medications, including H₂ antagonists and proton-pump inhibitors, and motility agents have little evidence to support prolonged use and are associated with an increased risk of necrotizing enterocolitis and infection (Ho et al., 2015). One goal is acid suppression or neutralization, which may be achieved by using histamine antagonists (ranitidine, famotidine) or proton-pump inhibitors (omeprazole, lansoprazole). Prokinetic agents (metoclopramide, erythromycin) may be used to improve motility of the esophagus and stomach. Surgical intervention is considered only when medical management fails, leading to failure to thrive, reflux-induced aspiration and pneumonia, esophagitis, Barrett's esophagus, and acute life-threatening

events. A Nissen fundoplication is the most common surgical procedure performed to treat GERD and may be performed openly or laparoscopically. There is a higher risk of mortality associated with the Nissen procedure for infants with neurological impairments (Zhang et al., 2016).

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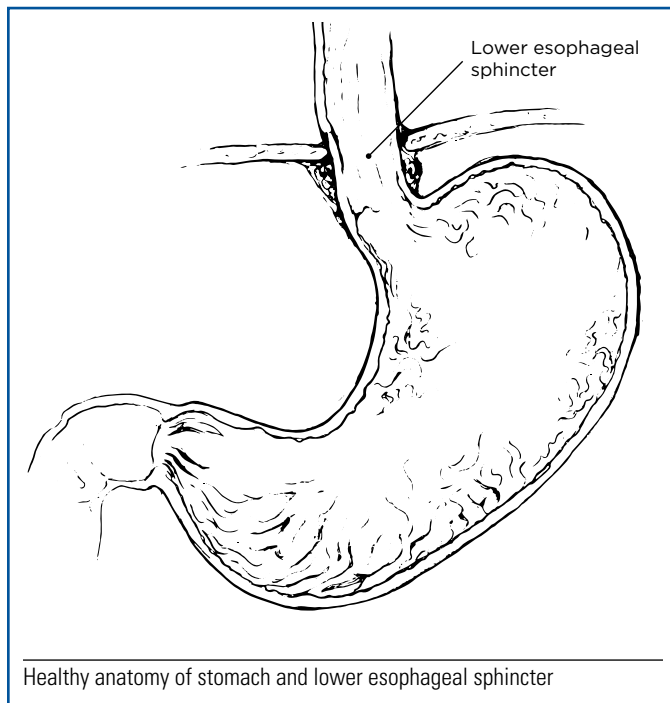
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Gastroesophageal Reflux: Information for Parents

You may have been told that your baby has reflux, which is short for *gastroesophageal reflux* (GER). Reflux happens when food from the stomach moves back into the esophagus or mouth. This can happen in healthy babies and adults. A baby with “normal” reflux may spit up often but does not have any other problems. This usually goes away before your baby is 1 year of age.



A more serious form of reflux, called *gastroesophageal reflux disease* (GERD), can cause problems, especially for babies in the neonatal intensive care unit. This kind

of reflux is defined by stronger vomiting and other symptoms. Your baby may have trouble gaining weight or may lose weight. He or she may cry a lot or act like he or she has trouble swallowing. Your baby may have blood-tinged vomit and problems with breathing and may need some tests to be sure that there is nothing else causing the vomiting. To help your baby with reflux, your baby’s provider may try positioning your baby a certain way after feedings, giving smaller feedings more often, or increasing the time of a feeding. If these things do not work, medicine may be used. If you have any questions, ask your baby’s provider about what you can do to help your baby have less reflux or about the side effects and possible risks of medications being given to your baby.

Surgery is only considered when medicine does not help. Surgery will be discussed if your baby cannot gain enough weight or if the vomiting causes a lot of problems with breathing (sometimes this is due to aspiration).

When you take your baby to see your pediatric provider after you have gone home, let him or her know how much and how often your baby is spitting up or vomiting. If your baby is going home on medication, please make sure to give the right amount at the right times. It is important not to change your baby’s diet or medicines without talking to your pediatric provider. Talk about how well you think the feedings are going so that the medicines can be changed or stopped as needed.



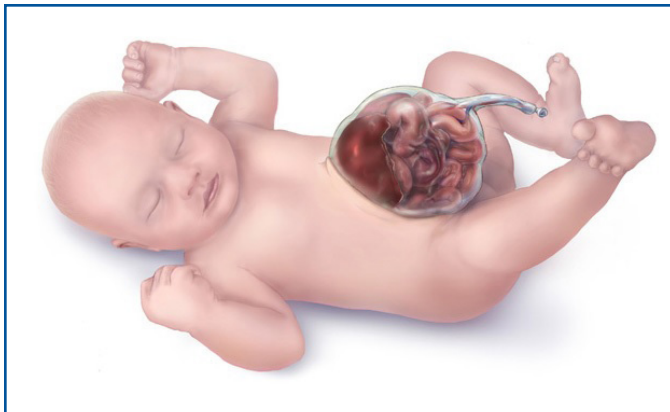
Gastroschisis and Omphalocele

The two most common congenital abdominal wall defects are gastroschisis and omphalocele. Both involve incomplete closure of the abdominal wall during fetal development, and for both, their cause is unknown. A gastroschisis is usually an isolated congenital defect, whereas a baby with an omphalocele often has chromosomal anomalies, cardiac conditions, and other major birth defects.

A *gastroschisis* is a herniation of abdominal contents through a defect in the abdominal wall, usually just to the right of the umbilicus. An *omphalocele* is a herniation of abdominal contents into the umbilical cord itself. The contents of a gastroschisis are directly exposed to amniotic fluid, whereas the contents of an omphalocele are usually covered with a protective membranous sac.



Gastroschisis. Courtesy of the Centers for Disease Control and Prevention.



Omphalocele. Courtesy of the Centers for Disease Control and Prevention.

At delivery, the ABC (airway, breathing, circulation) rule should be followed for babies with gastroschisis or omphalocele. Immediately afterward, protection of the herniated contents and management of evaporative loss should be accomplished. Abdominal contents should be wrapped in warm, saline-soaked gauze and covered with plastic wrap. Alternatively, the baby should be placed in a sterile bowel bag up to the nipple line. Preventing evaporative fluid loss is particularly important for the baby with gastroschisis because of the lack of the protective membranous covering of the abdominal contents. Diligent observation of the color and perfusion of the abdominal contents of a baby with gastroschisis is imperative. The baby should be placed on his or her right side with abdominal contents supported with additional gauze or blankets to prevent kinking of the mesentery blood vessels. An echocardiogram also should be considered to rule out potential cardiac anomalies (Escobar & Caty, 2016).

Babies will need IV fluids started; the baby with a gastroschisis will need a higher than normal IV fluid rate to prevent dehydration. Both will need placement of a Replogle tube to low intermittent wall suction (30–40 mmHg) to prevent gastrointestinal distention. Both will need to have broad-spectrum antibiotics started.

These babies will require surgical intervention after birth, but the timing of surgery in each case may differ. If the defect is small, surgery may be done shortly after birth with a primary closure. Closure for a gastroschisis must be done on a more urgent basis than that of an omphalocele to prevent continued damage to the exposed abdominal contents. If the defect is large, the size of the abdominal cavity may not be spacious enough to safely replace all of the herniated contents. If the contents are replaced under pressure, this could compromise respiratory function and vascular perfusion and result in the loss of bowel tissue. Therefore, with a large gastroschisis, a silo (sterile bag suspended above the abdomen) will be placed surrounding the abdominal contents so they can



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be gradually reduced into the abdomen over a period of days to weeks. The contents of an omphalocele also may be reduced in this manner.

Multiple alternative staged methods of closing omphaloceles also have been described. Some use the baby's own tissue; others use grafts from other sources. A nonsurgical way of initially closing a particularly large omphalocele, a so-called giant omphalocele in which multiple organs have herniated, has been to harden the membranous sac covering the contents with various topical chemicals. This method provides long-term protection, allowing skin to eventually grow over the sac. Once skin has covered the sac, closure is then surgically performed. Another recent method for closing giant omphaloceles is negative pressure wound therapy, which has a low complication rate (Aldridge et al., 2016).

Outcome for the baby with a gastroschisis depends on time of closure (Gonzalez, Cooper, St Peter, Minneci, & Deans, 2017), how much viable intestine is available, whether or not there were associated atresias, and

how long it takes for gastrointestinal function to take place. Outcome for the baby with an omphalocele largely depends on the extent of complications with the other associated congenital defects. For babies with either defect, it can be a long road to achieve full feeds; gastroschisis babies usually take longer to accomplish this. It is common for babies with either defect to have many episodes of feeding intolerance. These babies also are subject to short- and long-term dependence on parenteral nutrition with all their associated potential problems of infection, poor growth, and liver failure. Parents of these babies need substantial encouragement and support.

It may take a long time for babies with gastroschisis and omphaloceles to be able to eat normally and have normal intestinal function, especially those with gastroschisis. However, using human milk for feedings has been shown to reduce length of hospital stay for infants with gastroschisis (Gulack et al., 2016). In many cases, it is "two steps forward and one step back" for feedings. There also can be complications with the IV and special IV fluids these babies need to grow until they are able to digest their food well. However, almost all of these babies are eventually able to eat on their own.

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Gastroschisis and Omphalocele: Information for Parents

Gastroschisis and omphalocele are the two most common abdominal wall birth defects. Their causes are unknown, and they are not due to anything a mother did or didn't do during pregnancy.

Babies with gastroschisis and omphaloceles are the same in some ways and different in other ways. Both are types of hernias where the parts of the body that should be inside the abdomen are on the outside instead. With a *gastroschisis*, the hernia is through a hole in the muscle wall of the abdomen. With an *omphalocele*, the hernia is through the area of the belly button. Babies with omphaloceles also are more likely to have other birth defects



When babies are born with these hernias, they will have several extra things done in the delivery room. The parts that are on the outside will be carefully protected. The abdomen may be covered with warm, wet sterile gauze and plastic wrap, or the baby's whole body may be put in a big clear plastic bag up to the chest. This is done to keep the babies from losing fluid from the parts that shouldn't be exposed to the air. These babies also will have a tube hooked up to a suction machine and put through their mouth or nose to their stomachs. This will keep air from getting in and swelling their intestines. An intravenous (IV) line and IV fluids will be started. Antibiotics will be started, too.

Surgery will be needed to put the herniated parts back into the abdomen. If there is enough space in the abdomen, it may be possible to do this in one step. But sometimes the space is not big enough; in that case, it may take a few days to weeks to put everything back in comfortably. Your baby also may have a sonogram of their heart (to rule out any problems) and their abdomen (to make sure the organs on the inside are normal).

It can take a long time for babies with gastroschisis or omphaloceles to be able to be held and eat normally and have normal intestinal function, especially babies with gastroschisis. Once the baby recovers from surgery and the abdomen is closed, they can be held. Starting feedings is a slow process. Your baby may have an IV for a long time until he or she can digest food well. However, almost all of these babies are eventually able to eat on their own.



Hydrops Fetalis

Hydrops fetalis comes from a Greek term meaning the pathological accumulation of fluid in the fetal soft tissues and body cavities. It is a severe, life-threatening pathology in a fetus and newborn that is characterized by severe edema. The mortality rate for this condition ranges from 60%–90%. There are two different types of hydrops: immune and nonimmune.

Immune Hydrops Fetalis

Immune hydrops fetalis (IHF) occurs when the mother's immune system sees the infant's red blood cells as dangerous and destroys them, known as *alloimmunization*. RhoGAM®, or Rho (D) immunoglobulin, is given to Rh-negative mothers after they give birth to an Rh-positive baby. It is then given prophylactically to all Rh-negative mothers (and sometimes to other mothers) during each subsequent pregnancy at 26 to 28 weeks gestation.

Pathophysiology of IHF

As the mother's antibodies attack the fetal red blood cells, they begin to break down and are destroyed, leading to fetal anemia. As the fetal anemia continues, the baby's organs try to compensate for the anemia and begin to fail. The fetal heart weakens, leading to progressive heart failure with decreased pump efficiency. This leads to progressive pressure differential between the heart and body, resulting in third-spacing of fluid in the skin, heart, and lungs.

Nonimmune Hydrops Fetalis

Nonimmune hydrops fetalis (NIHF) accounts for approximately 90% of all cases. It occurs in one in 1,700 to 3,000 pregnancies. Unfortunately, in 85% of cases causation cannot be determined. Overall, 60% of the cases of NIHF are diagnosed prenatally (Bellini et al AV channel, 2015).

Pathophysiology of NIHF

The pathophysiology of NIHF often is the same as IHF in that severe chronic fetal anemia causes the neonate's organ systems (especially the heart) to fail. This leads to a pressure differential between the heart and body,

resulting in third-spacing of fluid in the skin, heart, and lungs. Although IHF has a causative factor of alloimmunization, the cause of NIHF can be fetal cardiac dysrhythmias or twin-to-twin transfusion. Several factors have been associated with NIHF but no reasons have been found that can directly be linked to causation.

While each fetus/neonate will experience symptoms differently, some common factors may be seen both prenatally and after birth. Prenatal ultrasound diagnosis is determined by

- two or more abnormal fluid collections in the fetus
- ascities
- pleural and/or pericardial effusion
- generalized skin edema greater than 5 mm that may include polyhydramnios and placental thickening.

Postnatal symptoms include

- respiratory distress or failure requiring intubation at birth
- pallor with decreased perfusion
- severe edema overall, especially in the abdominal area
- hepatosplenomegaly and coagulopathies
- pleural effusion, may be unilateral or bilateral, requiring emergent evacuation in the delivery room
- pericardial effusion
- hypotension
- decreased urine output
- increased capillary permeability
- increased hydrostatic pressure caused by the volume overload from heart pump failure
- decreased colloid osmotic pressure
- lymphatic dysfunction.

Organ system dysfunction that is responsible for NIHF includes the following:

Cardiac

- Hypotension due to intravascular depletion
- Cardiovascular malformations such as atrioventricular canal or hypoplastic left heart



- Arrhythmias: either tachy or brady
 - Tachy-arrhythmias include paroxysmal supraventricular tachycardia, atrial flutter, or premature atrial contractions.
 - Brady-arrhythmias can be caused by conduction disorders and maternal autoimmune diseases such as systemic lupus erythematosus.

Pulmonary

Airway and pleural lesions such as

- laryngeal atresia
- tracheal atresia
- congenital cystic adenomatoid malformation
- bronchopulmonary sequestration
- diaphragmatic hernia
- bronchial cysts.

Hypoplastic lungs also can develop depending on the amount of ascites and edema that is present. These two types of edema will determine the space available in the thoracic cavity for the lungs to grow.

Urinary

Edema is caused by the above mentioned pathophysiologies, which can cause hydropnephrosis due to severe hypoproteinemia (consistent with prune belly syndrome presentation).

Gastrointestinal

Edema is due to liver tumors or hemangiomas, meconium peritonitis, or intestinal obstruction.

Neurological

Any condition that affects fetal breathing and limb movement leading to reduced lymphatic return, as seen in conditions such as anencephaly.

Infectious Disease

Parvovirus B19, cytomegalovirus, syphilis, and listeria monocytogenes also were found to be causal in HINF due to mechanisms causing severe anemia (An, Wang, Zhuang, & Yan, 2015). In an update of the original systematic review performed by Bellini and his colleagues, the causes of NIHF could be divided into 14 classification groups: cardiovascular, hematologic, chromosomal, syndromic, lymphatic dysplasia, inborn

errors of metabolism, infections, thoracic malformations, urinary tract malformations, extra thoracic tumors, placental twin-to-twin transfusion, gastrointestinal issues, miscellaneous, and idiopathic causes (Bellini et al., 2015). It is interesting to note that the number one pathology according to this review was cardiovascular (20.1%). However, idiopathic causes came in second at 19.8% (Bellini et al., 2015). In another study by Turgal and colleagues, it was determined that if NIHF occurs before 24 weeks gestation, it is related to aneuploidy, whereas cardiac, pulmonary, and infectious causes accounted for the majority of cases after 24 weeks (Turgal, Ozyuncu, Boyraz, & Beksac, 2015).

Treatment

The treatment plan for hydrops is based on the following factors:

- the baby's overall health, gestational age, and extent of the disease
- the presumed cause of the hydrops
- parental wishes for treatment as related to the disease for their neonate.

Supportive measures require careful management of respiratory status and fluid and electrolyte status. Other measures may include pleural drainage, pain management, nutrition management, intravascular volume replacement, blood pressure support and immune support and correction of anemia. Chest tubes may need to be inserted to drain pleural effusions.

Prognosis

Overall prognosis for NIHF is related to gestation at diagnosis, presumed cause, and response to treatment. Morbidity ranges from 60%–90% (Ota, 2016).

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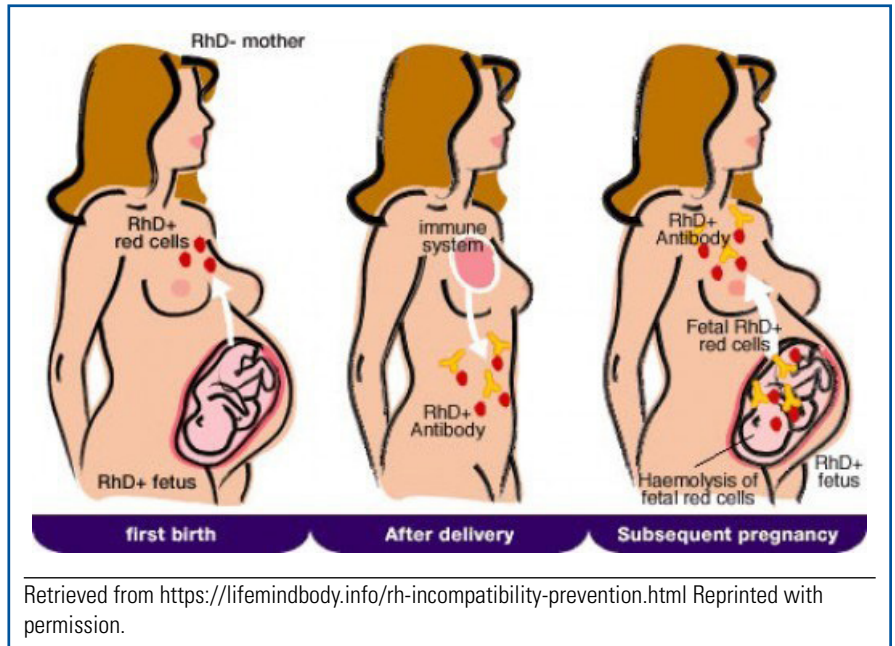


Hydrops Fetalis: Information for Parents

Your baby has been diagnosed with a condition referred to as *hydrops fetalis*—meaning the abnormal accumulation of fluid in the baby’s soft tissues, organs, and cavities. There are two types of hydrops fetalis: immune and nonimmune. Neither of these conditions are related to something that the mother has done; said another way, there is nothing she could have done to prevent either of these conditions.

Immune hydrops fetalis (IHF) results when the mother’s immune system sees the baby’s red blood cells as dangerous and starts to break them down. This is called alloimmunization. Alloimmunization occurs when a mother with a negative blood type is pregnant with a baby whose blood type is positive. The Rh antigen is an inherited protein found on the red blood cells. If the protein is present, then the person is Rh+. A negative blood type does not have the Rh antigen attached to it, so when the mom’s blood and the baby’s blood come in contact with each other, the mom’s blood cells mount an immune response. An immune response happens when the cells of the body do not recognize the foreign cells (Rh antigen) and try to rid the body of any danger from the foreign cells. This is the same response that would happen if an infection was present. When the immune response is triggered, the mother’s blood cells begin fighting the baby’s blood cells and start making antibodies against them. It takes a very small amount of baby’s blood (about a drop or two) to get into a mother’s bloodstream to cause this antibody reaction. Usually during pregnancy a mother’s blood and baby’s blood do not mix. Mixing can occur if there is a leak in the placenta, which is very rare. Mixing can occur until birth.

Alloimmunization can occur with any pregnancy, not just your first. You might not be aware of the blood type issue the first time it happens, so after the baby is born,



you will receive a shot called RhoGAM®. RhoGAM®, or Rho (D) immunoglobulin, is given to Rh-negative mothers after they give birth to a Rh-positive baby. Then, it is given as a preventative to all Rh-negative mothers during each subsequent pregnancy between 26 and 28 weeks gestation. Before the invention of RhoGAM® in the 1960s, this condition occurred in 10% of all pregnancies. Today, it is a very rare occurrence.

Nonimmune hydrops fetalis (NIHF) accounts for about 90% of all nonalloimmunization cases. Unfortunately, in most cases, the cause for the hydrops is unknown. In the babies where a cause is found, it will typically be related to an issue with the baby’s heart or genetic or chromosome problems that affect the baby. Overall, 60% of the cases of NIHF are diagnosed prenatally.

NIHF results when a disease or complication during pregnancy causes the baby’s blood cells to be continually broken down, which causes severe chronic anemia. Anemia means that there aren’t enough red blood cells circulating in the body to carry oxygen. When this happens, the body tries to compensate by making the heart and other organs work harder to get the blood



through the body. However, it eventually tires out and extra fluid starts to build up in one or more of the following places: under the skin, in the lungs, and in the heart.

Symptoms of NIHF

While each baby's experience will differ, common symptoms seen at a prenatal ultrasound may include

- two or more abnormal areas of fluid collection in the fetus
- ascities, or swelling around the abdominal area
- fluid present in the lungs or around the heart
- generalized skin swelling of greater than 5 mm.

One symptom mothers may experience during pregnancy is a large amount of amniotic fluid. This is called polyhydramnios. Symptoms that can be seen after the baby is born include

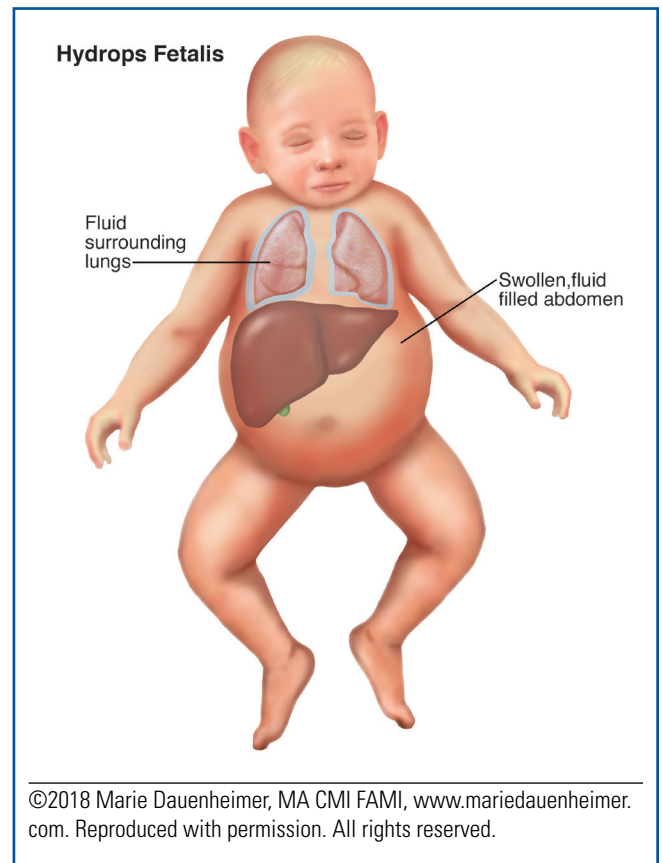
- difficulty breathing and needing some type of oxygen therapy
- pale coloring
- severe skin swelling overall, especially in the abdominal area
- an enlarged liver or spleen seen on ultrasound or X ray
- fluid collection in either one or both lungs as seen on ultrasound or X ray
- fluid collection in the sac around the heart as seen on ultrasound or X ray.

Treatment Options

There are many treatments for NIHF. The treatment your baby gets will depend on many different factors, including your baby's gestational age, your pregnancy history, severity of the condition, and how your baby tolerates different medications and procedures.

Treatments that might be used to help your baby include

- using supplemental oxygen to help with breathing. Oxygen can be delivered in many ways. It can be given by a cannula placed in the nose or by a mechanical breathing machine (ventilator) with a breathing tube.
- removal of the extra fluid from the spaces around the lungs, heart, or abdomen
 - Thoracentesis is removal of air or fluid from around the lungs.



- Paracentesis is removal of fluid from the abdominal area.
- Paracardiocentesis is removal of fluid from the sac around the heart.
- X rays and ultrasounds
- blood draws to check on the baby's chromosomes.

Surgery is usually not needed. However, surgical procedures such as thoracentesis, paracentesis, and paracardiocentesis may be performed in the neonatal intensive care unit.

Long-Term Implications

The long-term outcome for babies born with NIHF varies. Of all the cases that are diagnosed during pregnancy, only about 20% will survive to delivery. Approximately half of these cases will die during the first month of life; however, research is showing that the outlook for babies who do survive is very optimistic.



In summary, NIHF is a very serious complication during pregnancy and immediately after birth. However, there are many treatment options that the neonatologist or nurse practitioner will discuss with you. It is important for you to keep notes of your discussion and write down any questions you have. The whole healthcare team wants

you to understand the plan of care and to be involved in the decision-making process for your baby.

Resource

The American College of Obstetrics and Gynecology. Rh Factors: How it can affect your pregnancy. Retrieved from www.acog.org/Patients/FAQs/The-Rh-Factor-How-It-Can-Affect-Your-Pregnancy#what



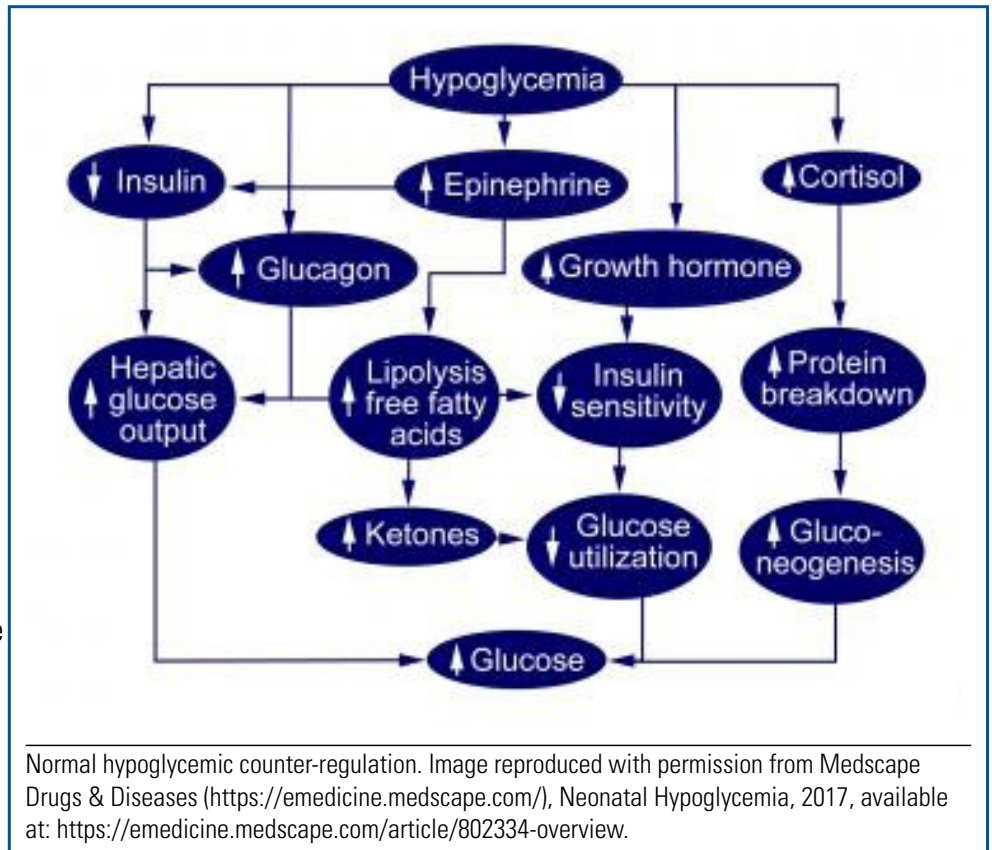
Hypoglycemia

An absolute blood or plasma glucose concentration that defines hypoglycemia in the neonate as a pathologic condition has not yet received universal consensus, with no one absolute value having been established. There have been “no evidence-based studies that can define what clinically relevant neonatal hypoglycemia is,” according to the American Academy of Pediatrics (AAP) Committee on Fetus and Newborn (2011). Many clinicians believe neonatal hypoglycemia is better determined by a continuum of low blood glucose values of varying duration and severity, rather than one specific value. Hypoglycemia also has been defined clinically as a glucose concentration in the neonate with associated clinical symptoms that resolve when treated with glucose therapies. Some institutions have established threshold targets within their neonatal population and have developed algorithms that drive the approach to appropriate screening and treatment.

A neonate’s blood sugar value can be influenced by a number of factors, including

- presence or absence of symptoms
- conceptual and postmenstrual age
- general health status and age of neonate
- adequacy of gluconeogenic pathways.

An essential part of the infant’s successful transition after birth is to be able to maintain a normal glucose level. Hypoglycemia occurs when there is not enough glucose in the blood, which then causes an alteration in organ system function.



Etiologies and Precipitating Factors

Normally, the body controls the level of serum glucose. When serum glucose is low, the body will release glucagon if it is available. Conversely, when serum glucose is elevated, the body will release insulin to drive glucose into cells, lowering the serum glucose level. Inadequate supply of glucose or inadequate glycogen stores account for the more common causes of neonatal hypoglycemia. These conditions include inadequate glycogen stores, abnormal endocrine regulation of glucose metabolism, and increased rate of glucose utilization.

Some examples of these conditions are

- prematurity—influenced by decreased or inefficient oral and parenteral intake, insufficient glycogen stores, and ability to release glucose



- intrauterine growth restriction and small for gestational age (SGA)—creates increased glucose utilization as well as low glycogen and fat stores
- nutritional issues—delayed feedings, fluid restriction, or insufficient breastfeeding are all important contributors.
- alteration in homeostasis of neonate—illness (e.g., sepsis), perinatal stress, or hypoxia, hypothermia, polycythemia, congenital cardiac anomalies, and endocrine disorders all impact availability of glucose stores and utilization.

The neonate also can have an increased uptake of glucose related to hyperinsulinism. Examples include

- infant of a diabetic mother and large for gestational age infants
- certain genetic syndromes such as Beckwith-Wiedemann or other autosomal recessive disorders thought to be caused by regulatory defects in beta cell function
- Rh incompatibilities (Gomella, Douglas Cunningham, & Eyal, 2013)
- iatrogenic causes such as a maternal tocolytics administered prior to birth, or positioning of an umbilical arterial catheter (UAC) tip near the pancreas.

Clinical sign and symptoms of hypoglycemia are nonspecific and may be present at varying blood glucose levels. Signs and symptoms of hypoglycemia include

- central nervous system signs such as tremors, jitteriness, irritability, exaggerated Moro reflex, high-pitched or weak cry, and seizures
- respiratory symptoms such as respiratory depression or apnea, tachypnea, or cyanosis
- hypothermia or temperature instability
- alteration in status such as hypotonia, lethargy, and refusal to feed.

Diagnosis

Laboratory measurements of serum glucose levels are the most reliable method for determining hypoglycemia. However, bedside glucose analyzers can provide key screening values if the test is performed carefully with

awareness of any limited accuracy for that particular device.

Most cases of neonatal hypoglycemia have an identifiable cause (e.g., infant of a diabetic mother, SGA). In the term infant with no known risk factors for hypoglycemia, sepsis must be considered as a possible cause of hypoglycemia. Use the following questions to evaluate the infant for other possible causes:

- Are dysmorphic features present?
- Is the neonate plethoric, suggesting polycythemia?
- Is the fetal growth pattern abnormal?
- Is the physical exam normal?

Treatment

Treatment options may include

- early and frequent feedings with breast milk, donor breast milk, or formula
- 40% glucose gel that may be administered on the buccal mucosa (in term and late preterm infants only)
- IV dextrose, which may include variation of concentrations depending on infant's condition and response to therapy
- adjunct therapies, which may also need to be implemented to adequately treat persistent hypoglycemia that is unresponsive to therapy, such as corticosteroids (describe why and when you might use each of these therapies)
- glucagon
- diazoxide.

The goal is to recognize at-risk infants, evaluate early and frequently for low serum glucose, treat when indicated, and provide glucose and enteral feeding as needed to achieve and maintain glucose concentrations in the range that are most desirable for the infant.

Clinicians should maintain a target glucose level that is considered acceptable and have a standardized protocol for treatment. The Pediatric Endocrine Society recommends that 50 mg/dL be the lower end of the threshold for infants at risk for hypoglycemia. Ongoing monitoring of the neonate's blood sugar should continue until the blood sugar is stable and the infant is able to



maintain stable blood sugar values with feedings of breast milk or formula only.

Complications

The outcomes for neonates with neonatal hypoglycemia appear to be related to the duration and severity of the hypoglycemia, repetitive reoccurrences, and the underlying etiology.

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Hypoglycemia: Information for Parents

Definition

Glucose is a form of sugar in the blood and is a main source of fuel for all organs in the body, especially the brain. An important part of your baby's successful transition after birth is to be able to maintain a normal glucose level (aka "sugar" level) so his or her body safely adapts. Hypoglycemia occurs when there is not enough sugar in the blood. Hypoglycemia is difficult to define by an absolute number; many resources better define hypoglycemia by the presence of particular signs or symptoms.

Causes

Normally, your baby's body will naturally try to control the level of glucose in the blood. When there is not enough glucose (hypoglycemia), his or her body will release stored sugar. When there is too much sugar, the body will release insulin to help lower the glucose level. It is common for newborns to experience low blood sugar levels soon after birth. This is usually a temporary situation as a newborn's body tries to adjust the blood sugar level.

Factors that can increase your baby's risk of hypoglycemia due to low glucose stores include

- premature birth
- low birth weight
- situations that use high amounts of glucose, such as stress during delivery, temperature of the environment making your baby's temperature drop, infection, fever, respiratory distress, and seizures
- birth defects
- certain conditions in which the infant has been exposed to high insulin levels, such as the mother having diabetes, the infant being large for gestational age, and certain syndromes.

Symptoms

Symptoms of hypoglycemia your baby might have include

- irritability (i.e., not being consoled easily)
- trembling or jitteriness
- abnormal cry (high pitched or weak)
- seizures

- bluish skin
- refusal to feed
- breathing problems
- abnormal vital signs, such as low temperature.

Diagnosis

Your baby will receive a full exam and a medical history will be obtained in order to make the diagnosis. Your baby's blood will be tested to determine a glucose value. Your care provider will want to determine the cause of your baby's low blood sugar. Based on the cause(s), your baby will receive tests and therapies that will best treat the low blood sugar.

Treatment

Talk with your baby's care provider about the best treatment plan for your baby. Treatment will focus on increasing the glucose in your baby's blood. Underlying issues also may need to be treated. Options may include

- frequent feedings and therapies—Frequent feedings may help raise blood glucose levels in your baby. Your baby may also be given glucose in to their blood system through an intravenous (IV) catheter. This may be done until your baby's blood glucose level is stable.
- medications—Certain medications may be needed if your baby continues to have low blood sugars despite frequent feedings or IV treatment. Your care provider will discuss these medications with you to provide specific information on the medications your baby needs.

Ongoing monitoring of your baby's blood sugar should continue until the blood sugar is stable and your baby has stable blood sugar values with only feedings of breast milk or formula.

Prevention

- Feed your baby early and often.
- Watch your infant for any of the above signs and symptoms and report them immediately to your care team.
- Keep your baby warm and follow your nurses' instructions for skin-to-skin with your baby.



Hypoxic Ischemic Encephalopathy and Hypothermia

Hypoxic ischemic encephalopathy (HIE) is defined as an acute brain injury diagnosed by clinical and laboratory findings. HIE affects 6 in 1,000 live births in the United States (Zanelli, Stanley, & Kaufman, 2018). There are several causes of HIE in newborns, including interrupted circulation in the umbilical cord, abruption of the placenta or other insufficiencies of the placenta, maternal hypotension, and maternal hypoxia or difficulties during an infant's resuscitation. HIE results in death for about 50% of infants impacted. Survivors may develop devastating complications that include mental retardation, epilepsy, and cerebral palsy.

There are several pathophysiologic mechanisms that cause the brain injury associated with HIE. The sympathetic nervous system is stimulated by asphyxia, which results in a redistribution of blood flow. Cardiac output is redistributed to the vital organs including the brain, heart, and lungs. Initially, systemic blood pressure increases to maintain cerebral blood flow, but with continued hypoxic insult, the neonate is unable to maintain adequate

cardiac output and cerebral perfusion is compromised. With continued hypoxic insult, the brain converts to anaerobic metabolism, resulting in an increase in lactic acid formation in the brain. The combination of energy failure, acidosis, free-radical formation, calcium accumulation, lipid peroxidation, and neurotoxicity from glutamate and nitric oxide disrupts the structure of the cell and ultimately result in cell death.

Approximately 6–15 hours after the initial event, a secondary reperfusion injury occurs. In this phase, there is a brief period of restored cellular function, followed by decreased cerebral blood flow and clinical deterioration due to increased calcium influx into the cell and continued cell injury. This phase involves irreversible cell death, either by necrosis or apoptosis.

Table 1 shows clinical findings associated with moderate and severe HIE.

Table 1. Moderate and Severe HIE

Category	Signs of HIE	
	<i>Moderate</i>	<i>Severe</i>
1. Level of consciousness	Lethargy	Stupor/coma
2. Spontaneous activity	Decreased activity	No activity
3. Posture	Distal flexion, complete extension	Decerebrate
4. Tone	Hypotonia (focal or general)	Flaccid
5. Reflexes		
–Suck	Weak	Absent
–Moro	Incomplete	Absent
6. Autonomic System		
–Pupils	Constricted	Deviation/dilated/non-reactive to light
–Heart rate		Variable
–Respiration	Bradycardia Periodic breathing	Apnea

From *The New England Journal of Medicine*, Seetha Shankaran, Abbot R. Laptook, Richard A. Ehrenkranz, et al, Whole-Body Hypothermia for Neonates with Hypoxic–Ischemic Encephalopathy, 353, 1574-1584. Copyright © 2005 Massachusetts Medical Society. Reprinted with permission from Massachusetts Medical Society.

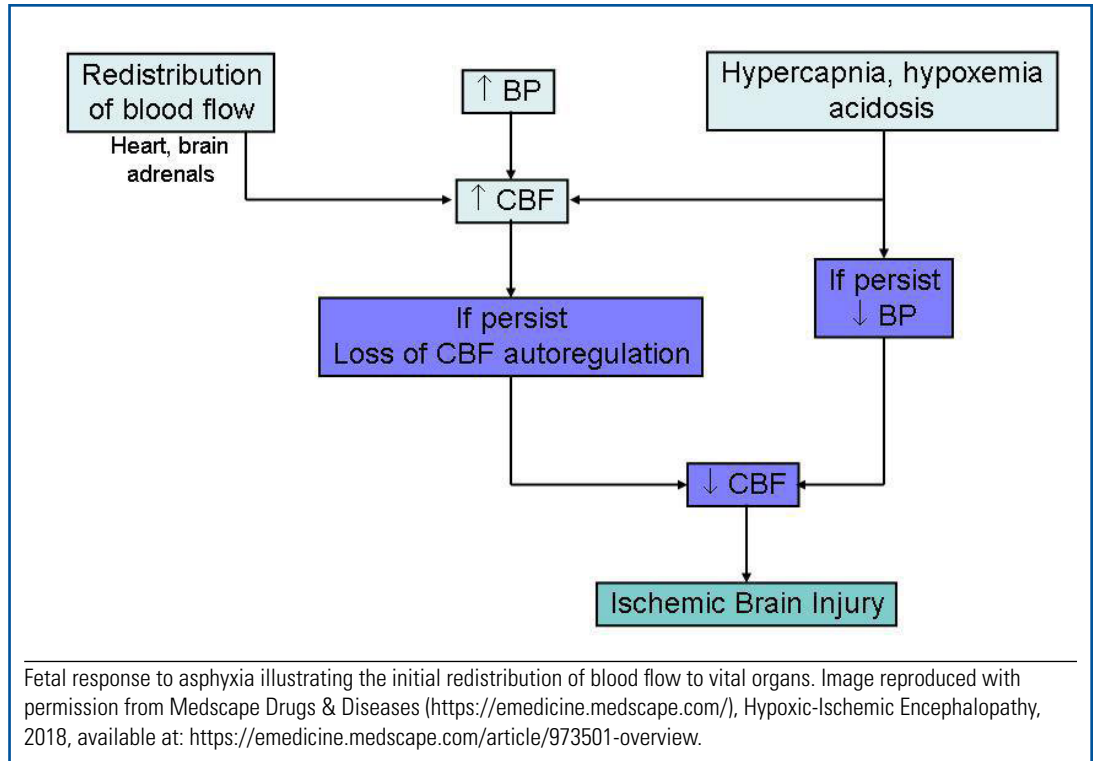


There is no treatment available for HIE; however, induced hypothermia is thought to provide neuroprotection to the brain and also may reduce the severity of the secondary reperfusion injury. The cerebral metabolic rate decreases by 6%–7% for every 1 °C decrease in body temperature. Induced hypothermia can be done via two interventions: head cooling or body cooling. Research has not yet shown which method is most effective. Currently, research has shown induced hypothermia should be used only on neonates older than 37 weeks gestational age at birth who have at least one of the following:

- a history of an acute perinatal event and are exhibiting signs of moderate to severe HIE
- a cord or neonatal pH less than 7.0
- base deficit greater than 16 on a cord gas or postnatal gas
- Apgar score less than 5 at 10 minutes.

In addition, treatment should begin within 6 hours of the injury to prevent a secondary reperfusion injury from occurring.

When caring for an infant with HIE, the most critical element of resuscitation is maintaining a stable airway and ensuring adequate circulation to prevent additional injury. These infants may exhibit seizures shortly after birth; therefore, an electroencephalogram to determine the presence of seizures and treatment with anticonvulsants often are required. Prior to induced hypothermia, infants often require mechanical ventilation and inotropic support to increase cardiac contractility. To initiate hypothermia treatment, the infant is placed on a precooled blanket per the



manufacturer's instructions. Ensure that all heat sources, such as the radiant warmer, are shut off. The infant's core temperature is monitored by an esophageal probe that is secured to the nose with tape; placement is verified with an X ray. The infant's body temperature is lowered to a range of 32.5 °C–34.5 °C. To prevent increased metabolic activity, sedatives and paralytics may be administered. Frequent evaluation of blood gases and electrolytes are critical for the management of these infants due to the many different complications of asphyxia. Nursing interventions when caring for the infant with induced hypothermia include clustering care to avoid excessive stimulation, decreasing light and noise in the immediate area, frequent skin assessments, and pain assessment and management.

Induced hypothermia continues for 72 hours after treatment begins, even if the infant's condition seems to improve. After 72 hours, the infant is rewarmed over a period of 6 hours by increasing the blanket temperature 0.5 °C every hour until 36.5 °C is reached. It is important for vital signs to be closely monitored because hypotension (secondary to vasodilation) may occur during rewarming. Once the infant is rewarmed, neurologic function will be assessed (physical exam, EEG, weaning of



anticonvulsants) to evaluate the effectiveness of the treatment. Parents should be educated on the possible long-term outcomes associated with HIE, including cerebral palsy, delayed neurodevelopment, and possible learning disorders.

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Hypoxic Ischemic Encephalopathy: Information for Parents

What is (HIE)?

Hypoxic ischemic encephalopathy (HIE) refers to a brain injury resulting from too little blood flow or oxygen delivery to the brain. It affects nearly 6 in 1,000 births per year in the United States.

What causes HIE?

There are many causes, but sometimes the exact cause can be unknown. Possible causes are too little oxygen supplied by the placenta during labor, a blockage in the baby's umbilical cord, a clot in the baby's brain, shock or sudden blood loss, or infection.

What are the symptoms of HIE?

Symptoms can include lethargy, weak-to-absent muscle activity, flaccid or "floppy" arms and legs, a weak or absent suck reflex, weak-to-absent breathing, seizures, and coma.

What is the treatment for HIE?

Treatment is meant to prevent any further damage due to low oxygen levels. Infants who are older than 36 weeks gestational age may qualify for treatment. Some babies may benefit from hypothermia, which is cooling of the head or the entire body, and is done by using a cooling blanket or cooling cap. Cooling limits the amount of damage to the brain after a low-oxygen event. The hypothermia treatment usually will last 72 hours, and the infant will be cooled to a temperature of 33.5 °C, or 92.3 °F; then the baby will slowly be rewarmed to a normal temperature.

Your baby may need to be sedated with medication. He or she is monitored for pain on a regular basis, and medication is given as needed. Due to the cooling and lack of movement by your baby, skin assessments will frequently be performed by your baby's provider. Optimal nutrition is important because of decreased blood flow to your baby's bowels. Total parenteral nutrition therapy may be started through an intravenous (IV) line so your baby can receive the nutrients he or she cannot get through eating.

How is HIE diagnosed?

Symptoms of HIE include

- history of an acute perinatal event
- an Apgar score of 5 or less at 10 minutes (Apgar scores are a simple way for your baby's provider to assess your baby's health right after being born.)
- continued need for ventilation initiated at birth and continued for at least 10 minutes
- low pH on blood in the umbilical cord
- level of alertness, ranging from being sluggish to being in a coma
- decreased or no spontaneous activity
- inappropriate posture, such as arching of back or neck; rotation of arms or legs
- weak or absent reflexes
- seizures
- constricted to nonreactive pupils
- decreased to absent breaths.

Electroencephalograms (EEG) often are performed after the infant has been rewarmed to evaluate the treatment and to look for seizures.

Not all babies with HIE will survive. Depending on the severity of the injury, some babies may have long-term problems.

Babies with moderate to severe HIE often have serious long-term problems, such as learning disorders, delayed development, or cerebral palsy. Follow up with a developmental specialist after discharge will be important to assess your baby's progress.



Intraventricular Hemorrhage and Periventricular Leukomalacia

Intraventricular Hemorrhage

Intraventricular hemorrhage (IVH) is bleeding inside the lateral ventricles. Bleeding frequently occurs in areas of high arterial and capillary blood flow, which most commonly occur in the subependymal germinal matrix of the brain in preterm infants. Bleeding occurs in the first 72 hours of life for about 90% of affected infants, with at least half of affected infants experiencing bleeding in the first 24 hours (Gardner, Carter, Enzman-Hines, & Hernandez, 2016). IVH is the most common type of intracranial hemorrhage present in infants.

Risk factors for IVH are prematurity and hypoxic events. Any event that results in hypoxia, alteration of cerebral blood flow, or intravascular pressure increases the risk of an infant developing IVH (Robinson, 2012). IVH also is associated with perinatal asphyxia, low Apgar scores, low birth weight, respiratory distress requiring mechanical ventilation, rapid volume expansion, and pneumothorax.

Depending on the degree of bleeding, infants with IVH may present with a range of symptoms. Some infants will not have a noticeable change in clinical condition; others will present with sudden deterioration or shock-like symptoms.

The extent of the bleed in the ventricles and brain will predict what future complications may occur. Bleeding may be confined to the germinal matrix or may enter the ventricular system. When blood enters the ventricular system, it can cause the ventricles to dilate due to increased pressure.

There are different grades assigned to IVH based on their severity. These include

- grade I (slight)—isolated germinal matrix hemorrhage
- grade II (small)—IVH with normal ventricular size

- grade III (moderate)—IVH with acute ventricular dilation
- grade IV (severe)—both intraventricular and brain parenchyma hemorrhage.

The diagnosis of IVH is determined via cranial ultrasound. For monitoring of an extensive bleed, serial ultrasounds may be used.

Periventricular Leukomalacia

Periventricular leukomalacia (PVL) refers to necrosis of white matter in the brain that occurs in a characteristic pattern. PVL is believed to be the long-term outcome of ischemia and injury to the fragile cerebral white matter in the premature infant. PVL can be caused by systemic hypotension, cerebral infarction and ischemia, and episodes of apnea and bradycardia (de Vries, 2015).

Additional complications that may arise from PVL depend on the size of the initial lesion and how much time has passed since the injury first occurred. Clinically, at about 6–10 weeks of age, an infant with PVL will present with irritability, hypertonicity, frequent tremors, and may have an abnormal Moro reflex. Diagnosis is made via cranial ultrasound, computed tomography scan, or magnetic resonance imaging. The long-term outcome of an infant with PVL may include spastic diplegia, motor deficits, intellectual deficits, visual impairments, upper arm involvement, and lower limb weakness.

Neonates who are born at younger than 30 weeks should be screened with cranial ultrasound at 7–14 days of age. Many units will rescreen again at 36–40 weeks of age to determine if PVL is present.

To help prevent IVH and PVL in the premature infant, care must be taken to avoid events that create swings in arterial and venous pressures. The immature neonatal brain does not have mature autoregulation of cerebral

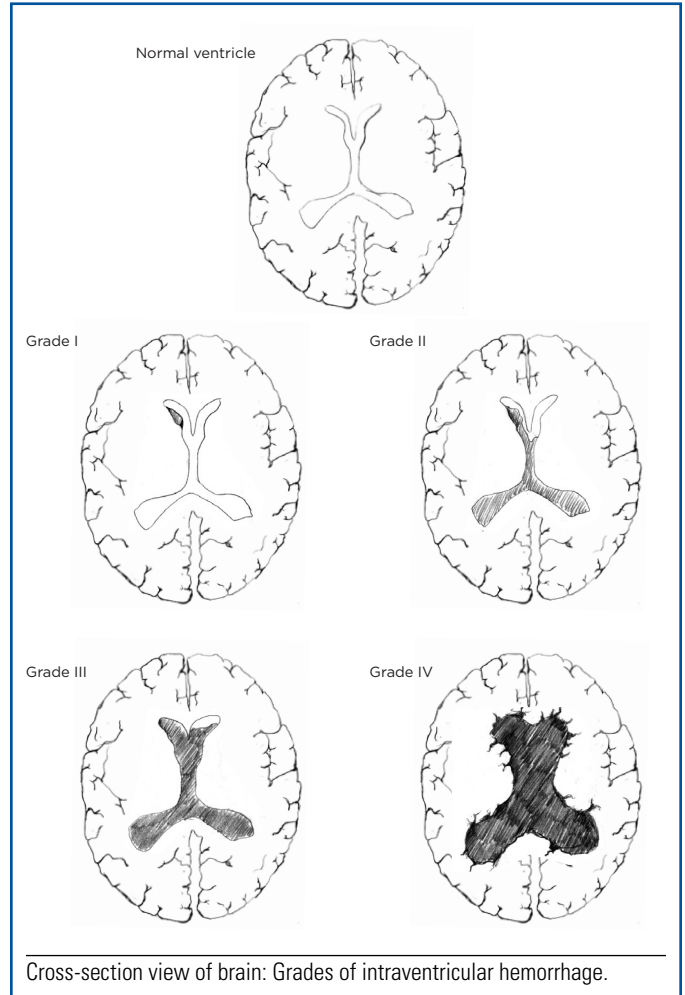


circulation in place to compensate for changes in blood pressure (Ballabh, 2014). Prenatal interventions such as preventing preterm delivery, maternal transport to a regional neonatal center, and prenatal glucocorticoids may help prevent IVH.

Postnatal interventions include delayed cord clamping, minimized handling and suctioning, synchronized and gentle ventilation, prompt treatment of patent ductus arteriosus, maintaining normal O₂ and CO₂ levels, preventing apneic episodes and seizures, and correction of coagulopathies and bleeding disorders. The intervention that has shown the most benefit in preventing IVH is prenatal administration of glucocorticoids (Ballabh, 2014). Treatment for IVH and PVL is supportive in nature.

Hemorrhage alone will not account for all neurological deficits in the neonate with IVH. Ironically, half of premature infants with IVH will be free of neurologic symptoms. Outcome will depend on the severity of the hemorrhage. For a small hemorrhage, neurodevelopment disability is similar to that in premature infants without hemorrhage. For a moderate hemorrhage, major neurodevelopmental disability occurs in about 31% of infants; for severe hemorrhage, especially those diagnosed with post-hemorrhagic hydrocephalus and requiring shunt placement, major neurodevelopmental disability occurs in 80%–92% of infants (Ballabh, 2014). Other impairments include hearing and vision impairments. Hearing impairment, ranging from 2% to 6%, and visual impairment, ranging from 17% to 33%, may occur in infants with severe IVH (Patel, 2016).

Posthemorrhagic hydrocephalus (PHH) is a major complication of moderate to severe IVH and is defined as an abnormal accumulation of cerebrospinal fluid (CSF) in the brain that results in enlargement of cerebral ventricles. About 80% of CSF in the brain is produced by the choroid plexus within the four ventricles in the brain and the remaining 20% is produced by the brain parenchyma (Chen et al., 2017). CSF circulates to bathe the brain and spinal cord and is reabsorbed by the arachnoid granulations, or villi, within the subarachnoid space. In PHH, there are several mechanisms that result in PHH. Large

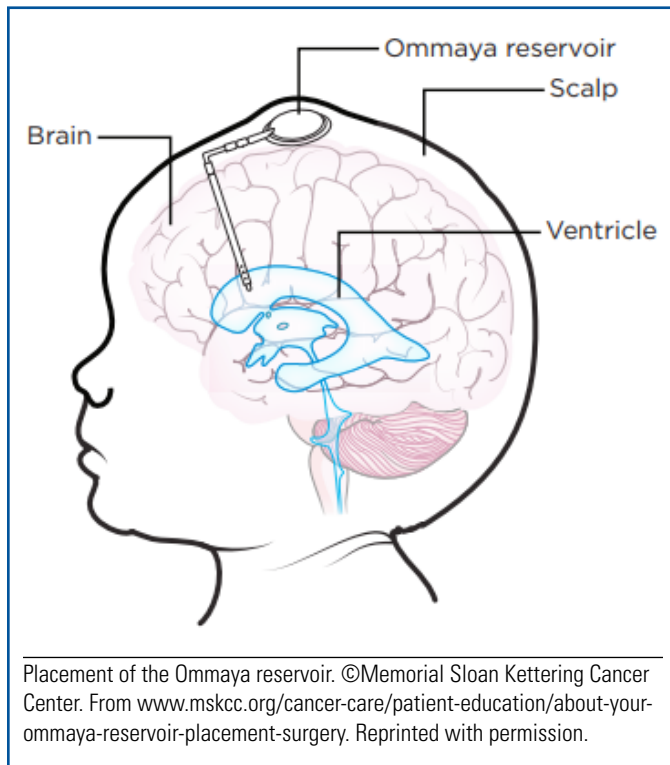


blood clots can form and block the cerebral aqueducts and fourth ventricle outlet, resulting in ventricular dilatation. Small blood clots can enter the ventricular system and block the arachnoid villi, thereby reducing absorption of CSF and resulting in hydrocephalus (Chen et al., 2017). In the presence of a large bleed, lysis of the red blood cells causes the release of hemoglobin and iron. Both can lead to hydrocephalus (Chen et al., 2017). Currently, there is no effective means available to prevent PHH. Long-term outcomes for infants with PHH who require shunts may include neurocognitive impairment, motor dysfunction, and growth impairment.

Medical management to treat PHH has shown little success, and most infants will require surgical intervention. Serial lumbar punctures to remove CSF and prevent shunt placement is no longer recommended because it failed to reduce disability or the need for a shunt and



was associated with an increased risk of infection (Ellenbogen, Waqar, & Pettorini, 2016). In the past, diuretics such as acetazolamide and furosemide were used to treat PHH, but they did not prevent shunt placement and neurodevelopment outcomes were worse on the drugs, thus they should not be used (Ellenbogen, Waqar, & Pettorini, 2016). Streptokinase, a fibrinolytic, is ineffective and may increase risk of infection and secondary IVH, thus it should not be used to treat PHH (Ellenbogen, Waqar, & Pettorini, 2016).



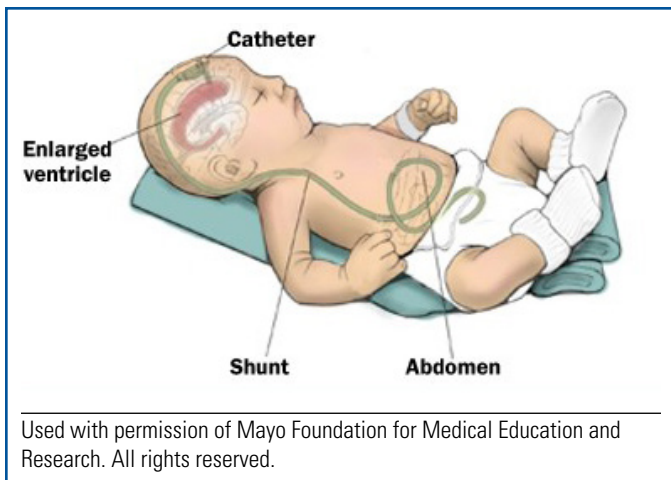
The most common surgical procedures to temporize PHH prior to insertion of a ventricular peritoneal (VP) shunt include ventricular access devices (VADs), external ventricular drainage (EVD), and ventriculosubgaleal shunts (VSGSs).

VADs are implanted with the tip of the catheter in the ventricle and a small bladder or reservoir directly under the skin. The reservoir can be tapped daily to remove 10–20 mL/kg of CSF. Complications of VADs include infection, skin breakdown, and CSF leaks (Ellenbogen, Waqar, & Pettorini, 2016). EVD has been used, but is not as common as VADs and VSGSs. EVD involves the placement of

a catheter through the frontal horn of the lateral ventricle and connected to an external closed drainage system. Infection is the main complication. The benefit of EVD is questionable compared with VADs and VSGSs, therefore it may not be used often (Ellenbogen, Waqar, & Pettorini, 2016). VSGSs involve implanting a catheter from the ventricle leading into the subgaleal space. The VSGS provides consistent drainage to relieve hydrocephalus. Complications include infection and shunt failure (Ellenbogen, Waqar, & Pettorini, 2016). VADs and VSGSs are both very effective in reducing hydrocephalus. According to a recent study conducted by the Hydrocephalus Clinical Research Network, there was no difference in the proportion of infants who needed conversion to a VP shunt from a VAD or a VSGS (Wellons et al., 2017). Estimates are that 60%–80% of infants with PHH and a VSD or a VSGS will ultimately need a permanent VP shunt (Wellons et al., 2017).

VP shunts are the primary treatment to permanently relieve hydrocephalus resulting from moderate to severe bleeds in preterm newborns (Wellons et al., 2017). VP shunts involve surgically placing a catheter in the ventricle and connecting it to a tube that runs under the skin to the peritoneum. The shunt drains fluid from the distended ventricles to the peritoneum. Complications of a VP shunt include infection, obstruction, and primary shunt failure (Robinson, 2012). Studies indicate that for shunts placed before 1 year of age, up to 45% may require shunt revision within 9 months. For babies with poor peritoneal absorption, ventriculoatrial or ventriculopleural shunts may be used (Robinson, 2012).

Because of the high rate of shunt infection or failure, it is important to know the signs of shunt malfunction or infection include fever of 38.3° C, distended veins on the head or scalp, irritability, redness or swelling at the incision site, vomiting, high-pitched cry, bulging anterior fontanel, and edema around the valve behind the ear and seizures. About 5% of premature infants with IVH will need a VP shunt (Rosenberg, 2016).



The long-term outcome of an infant with PVL may include spastic diplegia, motor deficits, intellectual deficits, visual impairments, upper arm involvement, and lower limb weakness.

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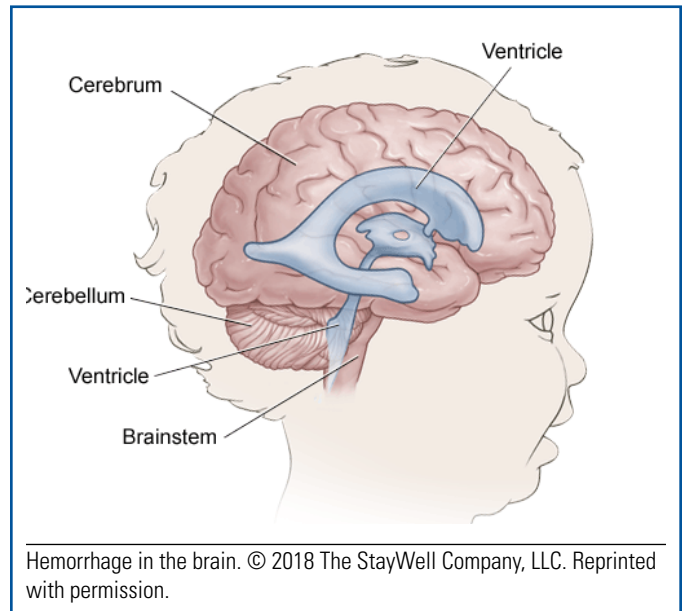
Intraventricular Hemorrhage and Periventricular Leukomalacia: Information for Parents

Your baby is very weak, including the way that his or her brain is forming. Right now, your baby's body is not able to control blood pressure changes in the same way that an older infant or adult body can. When the body can't control blood pressure changes, sometimes a baby's brain gets more blood than it needs, which can cause the vessels that carry the blood to rupture. When these vessels rupture, blood can build up inside your baby's brain and cause what is known as an intraventricular hemorrhage (IVH). The term *intraventricular* refers to the inside of the brain. The term *hemorrhage* refers to bleeding. Both terms together mean there is bleeding inside the brain.

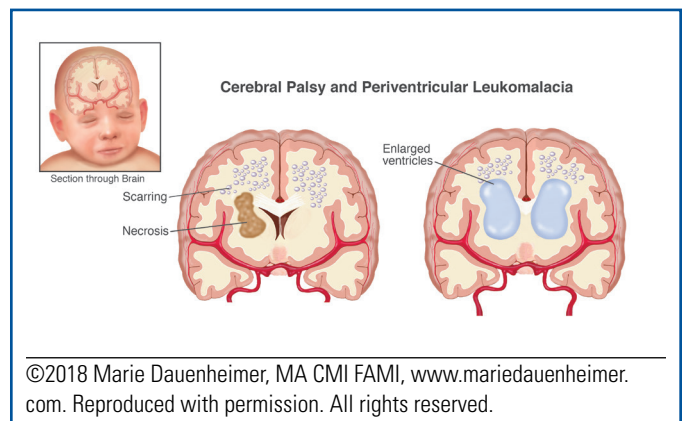
There are different levels of bleeding in the brain with IVH. These levels also are called grades:

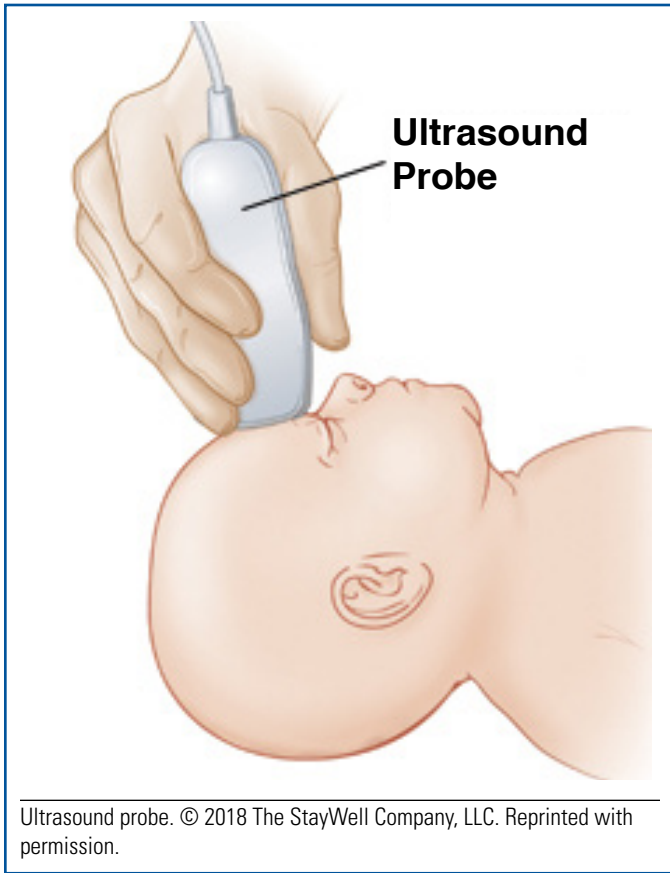
- Grade I means that there is a small bleed in the brain.
- Grade II means that there is a little more bleeding in the brain than Grade I, but it has not affected the inner part of the brain.
- Grade III means that there is bleeding that also has affected the inner parts of the brain. This includes the way that blood moves out of the brain.
- Grade IV means that there is more bleeding than in Grade III, and that the blood is pushing the brain against the bones of the head.

Periventricular leukomalacia (PVL) is different than IVH. *Periventricular* refers to the brain, whereas *leukomalacia* describes the way the baby's brain looks. PVL occurs when not enough blood gets to some parts of the baby's brain. These areas that have died leave little holes in the brain tissue (cysts). Babies with severe bleeding may develop a condition called posthemorrhagic hydrocephalus (PHH), which means the baby has a lot of fluid in the ventricles (where the bleeding was) or spaces in the brain. There may be so much fluid that it puts pressure on the brain tissue and may require a surgical procedure to drain the extra fluid.



Your baby's provider will tell you if your baby has any bleeding in his or her brain (IVH) or if your baby has PVL. To test for IVH or PVL, your baby will need an ultrasound. An ultrasound is a painless test that uses a special wand with a jelly-like substance to take a video of your baby's brain. These videos can be broken down into pictures that a doctor will look at. Your baby's provider will then let you know the results of the test. Expect your baby to have an ultrasound after about a week of being in the hospital. Not all babies will have an ultrasound done. This is only done if your baby was born before 32–34 weeks. The ultrasound may be done again when your baby is close to 36 weeks gestation.





Your baby is at risk for bleeding in the brain because he or she was born early. Some other risks are if your baby had a low amount of oxygen during birth, had a low birth weight, or needs a machine to help with breathing. If your baby is diagnosed with IVH or PVL, the outcome will depend on how much of your baby's brain is affected. Talk to your baby's provider to find out what the future needs will be for your baby. It is hard for your baby's providers to predict what will happen in the future for your baby, but it is important that you ask questions about any concerns that you have. Please ask your provider if you do not understand any part of the process of caring for your baby. It is OK to ask the same question more than once, so you get all the information you need to understand the diagnosis and treatment plan for your baby.



Malrotation and Volvulus

Due to the risk for loss of bowel, any infant with bilious emesis must be evaluated for malrotation and volvulus. Malrotation is in itself harmless, and an infant can have malrotation without a volvulus. However, because having malrotation places the infant at an increased risk for a midgut volvulus, surgical correction will be needed at some point.

Embryology

Normal Intestinal Rotation

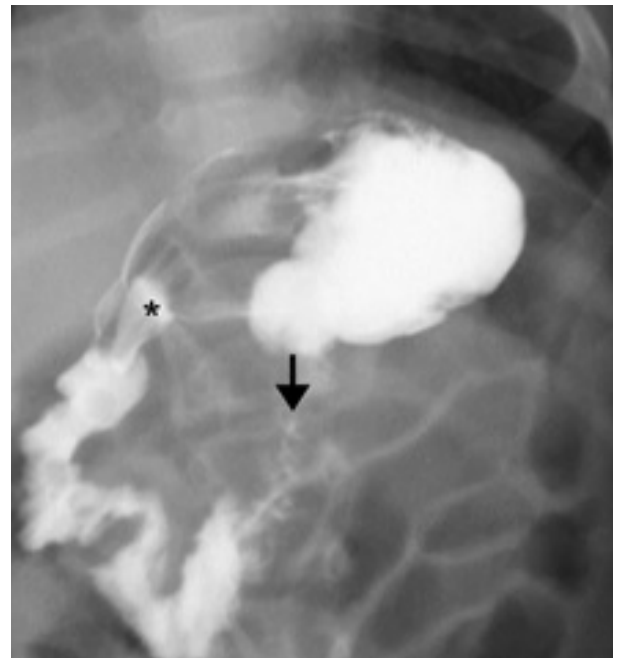
The duodenum makes a C-loop to the infant's left, and the third portion of the duodenum—at the ligament of Treitz—is to the left of the spine. The superior mesenteric artery (SMA) then runs in front of the third portion of the duodenum, and the mesentery attaches posteriorly from the left upper quadrant by the ligament of Treitz to the right lower quadrant by the cecum. This prevents the mesentery from twisting on itself. In the fourth week of gestation, the intestinal tract rapidly elongates, leaves the abdominal cavity, and undergoes rotational changes. The duodenum and colon both have to rotate 270 degrees counterclockwise, and the midgut needs to return to the abdominal cavity by the 12th week of gestation. If these events do not occur, malrotation or an incomplete rotation will result.

Abnormal Intestinal Rotation

When normal intestinal rotation fails to happen, the third portion of the duodenum lies to the right of the spine and the SMA never crosses it. There is a narrow mesenteric base that then connects the duodenojejunal junction with the cecum. The bands between the duodenum and cecum place the mesentery at risk for complete volvulus, because it cuts off the vascular supply to the SMA. This results in ischemic necrosis of the entire midgut from the duodenum to the proximal transverse colon.

Diagnosis

An upper gastrointestinal (GI) series is the gold standard for the diagnosis of malrotation and volvulus. Upon evaluation, contrast will leave the stomach and enter the duodenum. The duodenum will be to the right of the spine, the small intestine will be on the right side of the abdomen, and the colon will be on the left side of

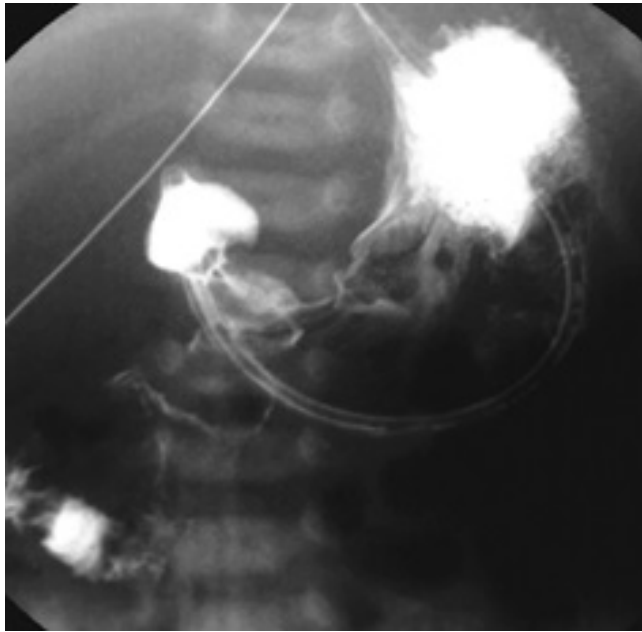


Malrotation. Arrow = inferior position of the duodenojejunal junction; * = duodenal bulb

From Applegate, K.E., Anderson, J.M., & Klatte, E.C. (2006). Intestinal malrotation in children: A problem-solving approach to the upper gastrointestinal series. RadioGraphics, 26, 1485–1500. Used with permission.

the abdomen. In an infant with a volvulus you will see a “corkscrew” or “beaking” appearance of the duodenum and proximal jejunum.

Other diagnostic tools that can be used are plain abdominal X rays and ultrasound. With abdominal X ray, when Ladd's bands are present a “double bubble” may be seen, or if a midgut volvulus is present, radiographic signs and symptoms similar to necrotizing enterocolitis may be seen. Ultrasound has been used to visualize a swirl or whirlpool pattern on Doppler of the SMA—which is useful in detecting volvulus—as well as free peritoneal fluid, portal venous gas, pneumatosis, and intestinal wall edema.



Malrotation with volvulus. "Corkscrew" appearance of duodenum to right of the spine

From Applegate, K. E., Anderson, J. M., & Klatte, E. C. (2006). *Intestinal malrotation in children: A problem-solving approach to the upper gastrointestinal series*. *RadioGraphics*, 26, 1485–1500. Reprinted with permission.

Treatment

Infants with suspected malrotation or volvulus will be given nothing by mouth (NPO) and have a Replogle tube placed to low intermittent wall suction. A peripheral intravenous (PIV) line will be placed and intravenous fluids will be started. Laboratory studies will be collected, especially a Type and Screen so the patient can go to the operating room, followed by complete blood count with differential and electrolytes. Additional fluids will be given to correct any fluid deficits. Prophylactic antibiotics also will be administered.

As initially stated, an infant presenting with bilious emesis must have a volvulus ruled out. If the patient is stable, an upper GI series should be performed immediately. If a volvulus is revealed, the patient is either immediately taken to the operating room for emergency surgery or bedside surgery is performed. As a bedside nurse, expect hypovolemia due to vomiting and third spacing of fluid.

Once in the operating room, the volvulus is addressed first by untwisting the intestine in a counterclockwise fashion that allows blood flow to be restored to the intestines. One must then assess the viability of the intestine. Only intestine that is necrotic should be resected; over-resection will lead to short bowel syndrome. If necessary, the surgeon will re-explore the abdomen at 24–48 hours to check the viability of the remaining intestine. Depending on the remaining bowel, an ostomy may need to be created.

After the volvulus has been corrected, the malrotation must be addressed to prevent reoccurrence. A Ladd's procedure is performed by widening the mesenteric base; any bands that cross anteriorly to the duodenojejunal junction are divided. The duodenum is then placed on the right side of the abdomen, and the cecum and ascending colon are placed on the left side of the abdomen. An appendectomy completes the Ladd's procedure. A laparoscopic approach also may be used, but it is not advised for patients with volvulus or at risk for volvulus, considering the time-sensitive nature of treatment. Advantages of a laparoscopic approach include less postoperative pain and quicker return to normal bowel function; however, its use and capability of avoiding recurrent volvulus is still controversial.

Postoperative Care

In the immediate postoperative period, routine postoperative nursing care is provided. A salem sump or Replogle is inserted and placed to low intermittent wall suction to maintain abdominal decompression. Pain is assessed at least every 4 hours using the appropriate pain assessment tool; appropriate analgesic therapy is then administered.

Many patients have a prolonged ileus, especially if a volvulus or bowel ischemia was present. Some will even have symptoms of duodenal dysmotility or a pseudo-obstruction. There is the possibility that a volvulus will occur again, so the infant should be monitored for several weeks after repair for the symptoms characteristic of a volvulus. A central line will be needed to provide adequate nutrition via parenteral nutrition and intralipids. Those who lost a



significant portion of bowel and are considered to have short bowel syndrome are faced with malabsorption and failure to thrive.

Once the return of bowel function has been achieved, enteral feedings will be initiated. The extent of the injury will determine how quickly feedings will be advanced. During this time, the bedside nurse will observe signs and symptoms of feeding intolerance. As the patient advances on enteral feedings, parenteral nutrition is titrated to meet total fluid needs and is eventually discontinued.

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Malrotation and Volvulus: Information for Parents

What is malrotation?

It is when the intestines do not sit in the belly the right way.

What is volvulus?

When the intestines do not sit in the belly the right way (malrotation), the intestines can twist around one of the big arteries that supplies blood to the intestine and cut off the blood supply to part of the intestines. The twist is known as the volvulus.

What causes malrotation and volvulus?

Both malrotation and volvulus are problems that happened when your baby was developing. They are not caused by anything you did or did not do. The intestines did not rotate and move around inside the amniotic sac like they should have.

What is the treatment for malrotation?

Malrotation by itself is harmless and your baby can have malrotation without a volvulus. However, having malrotation places your baby at an increased risk for a volvulus; therefore, surgery will be needed at some point to correct this.

What is the treatment for a volvulus?

Immediate surgery is needed for any baby who has a volvulus, because the blood supply to the intestines is being cut off.

More Information

Some babies with a volvulus may have a lot of intestine that has to be removed because there was not enough blood flow to it for a long period of time. If this is the case for your baby, the surgeon will have to create an ostomy (an intestine loop that sits on the outside of the abdomen, as pictured). This is not usually permanent, but your baby may go home with an ostomy.



Babies with a volvulus will need to receive intravenous (IV) nutrition through a special IV called a peripheral inserted central catheter line. This will allow your baby to grow while the intestines heal.

Your baby's providers will be waiting for your baby to have a bowel movement before feedings are restarted. Breast milk feedings are preferred and will be given in small amounts in the beginning. As feedings are advanced, the IV nutrition will be decreased.

Your baby may have a recurrent volvulus after surgery. It is important to watch for symptoms for several weeks after surgery.



Meconium Aspiration Syndrome

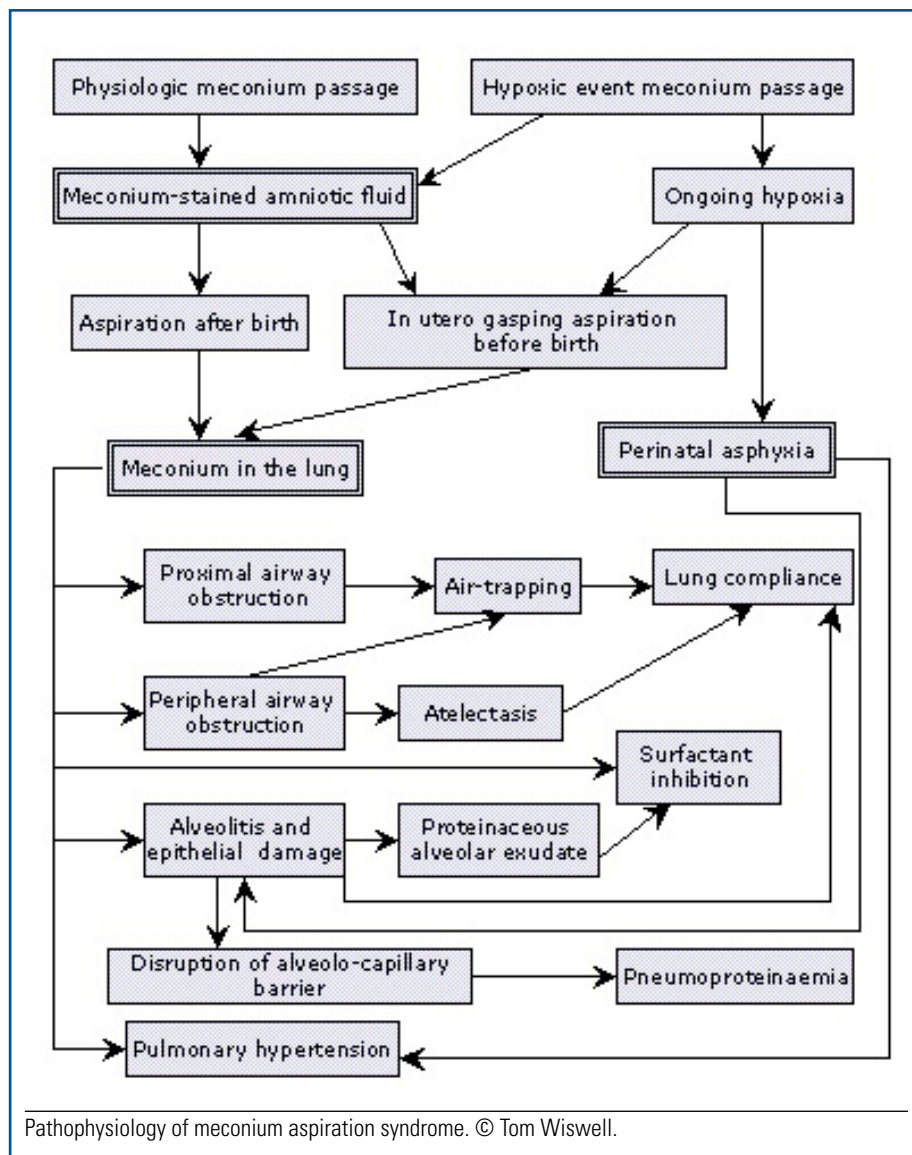
Meconium aspiration syndrome (MAS) happens when fetal stress occurs and the fetus/newborn gasps then aspirates meconium-stained amniotic fluid into his or her lungs before, during, or immediately after birth. MAS can be caused by placental insufficiency, maternal hypertension, preeclampsia, tobacco use, maternal infections, and fetal hypoxia, and most commonly postdates pregnancy. MAS can be a serious respiratory condition causing respiratory failure, acute inflammatory response, and air leaks. Some infants with MAS will develop persistent pulmonary hypertension. MAS can range from mild to severe.

A team trained in neonatal resuscitation should attend all births with meconium-stained fluid. Not all infants delivered with meconium-stained fluid will develop MAS. Initial resuscitation steps are critical to prevent MAS. Please refer to current Neonatal Resuscitation Program guidelines to manage newborn during delivery.

Newborns with mild to moderate MAS may present with meconium-stained skin, fingernails, or umbilical cord; tachypnea; rales; cyanosis; nasal flaring; grunting; and retractions. In severe cases of MAS, gasping respirations, pallor, and an increase in the anteroposterior diameter of the chest may be noted. Babies experiencing severe MAS may require oxygen, intubation, and ventilator support; inhaled nitric oxide; hypothermia treatment; and even extracorporeal membrane oxygenation. Newborns usually require placement of central lines and frequent arterial blood gases to observe for hypoxia and hypercarbia. If your unit does not have these

capabilities, a transfer to a higher-level-of-care NICU should be initiated as soon as possible.

Severe complications of MAS may include persistent pulmonary hypertension, pneumomediastinum, pneumothorax, and pulmonary hemorrhage. The infant may require a chest tube if a pneumothorax needs to be evacuated. Although surfactant therapy is not routinely recommended, it may be helpful in certain circumstances, because meconium inactivates surfactant in the baby's lungs.



Pathophysiology of meconium aspiration syndrome. © Tom Wiswell.



Newborns with MAS require a multidisciplinary team approach to manage their many medical challenges, and parents will need support and education throughout their baby's NICU stay to ensure the family's needs are met during this difficult time.

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Meconium Aspiration Syndrome: Information for Parents

A baby's first stool is called *meconium*. It is green and black in color and thick in consistency. In some cases, a baby passes stool inside the womb before he or she is born. This can happen when the baby is under stress during labor. If the baby breathes in the stool before or during delivery, the baby can develop meconium aspiration syndrome (MAS). Not all babies who have a bowel movement before birth will develop MAS.

MAS happens when the baby breathes this thick fluid into his or her lungs before, during, or right after birth. MAS babies may develop trouble breathing and will need help to breathe. A skilled team will attend your delivery if you have meconium-stained fluid noted during labor.

If your baby is crying and active, treatment may not be needed. If the baby is not crying or active right after delivery, a tube is placed in the infant's windpipe and suction is applied as the tube is pulled out. This might be repeated until the meconium is no longer seen in the suction tube. If the baby is not breathing or has a low heart rate, he or she may require help to start breathing. At delivery, oxygen and breaths given by face mask will help inflate the baby's lungs.

Your baby may be placed in a special care nursery or newborn intensive care unit (NICU) for close observation.

Other treatments may include

- antibiotics to treat possible infections
- breathing machine (ventilator) to keep infant's lungs open
- oxygen
- surfactant
- medicines to help keep their blood pressure stable (vasopressors)
- inhaled medicine to allow your baby's blood vessels to relax (nitric oxide)
- a chest tube to reinflate a collapsed lung.

This can be a scary time for parents. The special care nursery or NICU team will be there to support you and answer your questions. It may take a few weeks for your baby's lungs to heal so that they can begin to eat, grow, and go home. After you are able to go home, your baby may need frequent follow-up with specialized healthcare providers.



Necrotizing Enterocolitis

Necrotizing enterocolitis (NEC) is an inflammatory disease, or necrosis, of the bowel. NEC is a serious, life-threatening gastrointestinal emergency that primarily affects premature neonates; the more preterm a neonate is, the higher the incidence of NEC. Up to 10% of NICU admissions will develop NEC (incidence varies regionally and within individual units). Full-term infants also can develop NEC. It is estimated that 20%–40% of neonates with NEC will require surgical intervention. Surgical NEC fatality rates are as high as 50%. The onset of NEC most commonly appears within the first 6 weeks of life; in more premature infants, the age of inflammatory disease onset is earlier (days 3–30). The most common areas of intestinal damage are the distal ileum and proximal colon. Spontaneous intestinal perforation (SIP), or isolated intestinal perforation, generally occurs within the first week of life. Although infants with SIP will present similarly to those with NEC, SIP is distinctly different from NEC. SIP is a focal perforation without an inflammatory component.

The exact etiology of NEC is unknown, although it is characterized by intestinal injury, inflammation, and necrosis. Prematurity is the most common risk factor. Other factors that have been found to play a role in NEC include enteral feeding with formula, decreased bowel motility, and an immature immune system allowing for bacterial invasion. The premature neonate has an immature intestinal tract and therefore has decreased intestinal motility. The intestinal barrier isn't "tight" (or strong). As the intestinal wall's mucosal barrier breaks down from the invasion of abnormal bacteria (i.e., gas-producing bacteria), intestinal injury can become severe. Other risk factors include the following:

Feeding Practices. Feeding does provide a necessary medium for the multiplying of bacteria. Feeding hyperosmolar formula or medications can damage the intestinal mucosa. Examples of osmolality for different feeding types include

- breast milk: 257 mOsm/L

- preterm breast milk with fortifier: approximately 300 mOsm/L
- premature infant formulas (20 cal/oz): approximately 210 mOsm/L
- premature infant formulas (24 cal/oz): approximately 250 mOsm/L
- elemental formulas (20 cal/oz): approximately 250 mOsm/L–310 mOsm/L
- examples of medication osmolality include
 - Polyvisol: > 11,000 mOsm/L
 - NaCl: > 7,000 mOsm/L
 - Phenobarbital: > 7,000 mOsm/L (Jew, Owen, Kaufman, & Balmer, 1997).

Human milk has been identified to be protective against NEC, mostly due to immunologic factors. Mothers should be encouraged to provide their own breast milk. If the mother is unable to provide her own milk, use of donor milk should be considered, especially for the very-low-birthweight (< 1,500 g) population. Recent randomized, controlled trials comparing donor milk and formula demonstrated twice the incidence of NEC in the formula-fed groups (Ramani & Ambalavanan, 2013).

Gastric residuals do not necessarily indicate the presence of NEC. Gastric motility is slower in the preterm neonate. Because the motor complexes of the intestines are immature (thus slower motility), it can be normal to have light green-tinged or milky residuals in the absence of other clinical signs and symptoms. One must note the color of the residual, the amount of the residual in comparison with the amount of the feeding, and if there are any signs or symptoms.

Adopting a standardized feeding guideline may decrease the risk of NEC. There is some evidence to suggest this practice may decrease incidence of NEC, however, other studies do not show a significant difference. Some centers have noted a consistent decline in the incidence and severity of NEC following the institution of feeding guidelines.



Hypoxic/ischemic events. After a hypoxic event, intestinal ischemia may follow as blood is shunted away from the intestines. With reperfusion of the bowel, damage to the intestine may occur. Some examples of events that may impact gut perfusion include patent ductus arteriosus (diastolic steal), hypotension, hypovolemia, umbilical line(s) placement, exchange transfusion, packed red blood cell transfusion, and polycythemia. In addition, neonates with congenital heart disease have compromised bowel perfusion, which may make them susceptible to ischemic injury of the bowel.

Abnormal bacterial colonization. Abnormal bacterial colonization of the immature intestinal tract is a significant risk factor identified with NEC. Some studies have shown that neonates who were born via cesarean section, fed formula, or exposed to antibiotics have a decrease in diversity of intestinal microbiota and abnormal patterns of bacterial colonization. Probiotics are a potential mode of preventing severe NEC, but the specifics of timing and dosage are unclear (Niño, Sodhi, & Hackam, 2016).

H2 blockers. These medications (e.g., Pepcid, Zantac) alter the pH of the stomach. Histamine-2 blockers have been shown to increase the risk of sepsis and meningitis for neonates (Torrizza & Neu, 2013).

Presentation

Nonspecific symptoms of NEC may include apnea, bradycardia, temperature instability, lethargy, and hypotension. More specific symptoms may include discolored abdominal wall, visualization or palpation of bowel loops, abdominal distention, feeding residuals, bloody stools, and decreased or absent bowel sounds. Laboratory findings also can be nonspecific. These may include thrombocytopenia, neutropenia, and metabolic acidosis.

The Modified Bell's Staging Criteria chart is used to categorize NEC presentation using clinical symptoms and radiologic findings. There are three stages, and each stage is divided into two presentations.

Interventions

Lab work such as complete blood counts, blood cultures, inflammatory markers (e.g., C-reactive protein), blood gases, electrolytes, and glucose and coagulation studies should be evaluated and repeated as indicated. Frequent abdominal X rays may be taken in one or two views and may include left lateral decubitus or cross-table lateral views. Presence of the biomarker intestinal fatty acid-binding protein has been found to be an important predictor of NEC and the extent of intestinal damage (Niño et al., 2016).

Nonsurgical interventions include gastric decompression to low intermittent suction, intravenous fluids or parenteral nutrition, possible replacement of gastric output, monitoring of vital signs, antibiotics, pain management, ventilator support as needed, circulatory support as needed (e.g., for hypotension), strict intake and output, and laboratory studies (as mentioned above), including serum glucose, and frequent X rays. The pediatric surgeon should be called if Bell's Stage II or greater NEC is noted or if medical management is not successful.

Surgical intervention is necessitated if pneumoperitoneum is noted on the X ray. Other indications for surgery can include portal venous gas; fixed, dilated intestinal loops noted on the X ray; an abdominal mass; clinical deterioration; or presence of bowel necrosis on an ultrasound (Niño et al., 2016). Options for surgery include an exploratory laparotomy or placement of a peritoneal drain. The type of surgery performed will depend on the condition of the neonate as well as the progression of bowel necrosis. Peritoneal drain placement can be performed at the bedside and is a temporary measure for an unstable neonate. With an exploratory laparotomy, the bowel is examined and the necrotic segments removed. Most times, an ostomy is created with a mucus fistula. After the neonate has grown and is stable, with feedings re-established, a reanastomosis is performed, assuming there is enough viable bowel length to do so. Timing of reanastomosis may be weeks to months after the laparotomy.



Complications from NEC may include intestinal strictures, malabsorption with or without short bowel, cholestatic liver disease, recurrent NEC episode, and neurodevelopmental delay. Intestinal strictures are more often found in NEC patients managed medically, not requiring surgical intervention; infants with late onset NEC; and infants delivered via cesarean section (Zhang et al., 2017). Malabsorption is seen in infants having significant bowel length resected or those who lose their ileo-cecal valve. A general rule of thumb is that more than 30 cm of bowel with intact ileocecal valve or more than 50 cm of bowel without the ileocecal valve is required for an infant to survive on enteral nutrition (Kastenberg & Sylvester, 2013). Recurrent NEC occurs in about 5% of cases. Cholestatic liver disease may occur due to prolonged use of total parenteral nutrition and intralipids. Neurodevelopmental delay is related to the severity of NEC as well as the presence of circulating inflammatory mediators, which may contribute to a less than favorable neurodevelopmental outcome.

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Necrotizing Enterocolitis: Information for Parents

Necrotizing enterocolitis (NEC) is a disease that affects the intestines of sick babies. NEC occurs more often in premature babies—the earlier the baby is born, the greater the risk of NEC. Up to 10% of all babies admitted to the neonatal intensive care unit (NICU) can have NEC.

NEC is an inflammatory disease of the intestine (also known as the bowel). First, the intestinal wall lining becomes damaged. Then, bacteria attack the intestine to cause swelling and infection. This can lead to a rupture, or perforation, of the intestine. If the intestine ruptures, bacteria can get into the abdomen, which can be life threatening. The exact cause of NEC is unknown, but the most consistent risk factor is related to feeding. Babies who are fed formula are more likely to have NEC than those who are fed breast milk (human breast milk has a protective effect against NEC).

It can be difficult to identify NEC because the premature infant may have other issues that appear similar to NEC. Symptoms of NEC may include feeding intolerance, a round stomach or belly with “loops of bowel” noticeable, vomiting, bloody stools, not being active (lethargy), and times of not breathing and slowing of the heartbeat (apnea and bradycardia). Your baby may need assistance with breathing, such as the use of a ventilator. The best way to diagnose NEC is with an X ray of the stomach.

NEC treatment includes allowing the bowel to rest, so feedings will be stopped. This may be for as little as 3 days but may last for several days or weeks. A tube

from your baby’s mouth to the stomach will be placed to remove fluid and air from the stomach. Blood sampling will be done and intravenous fluids will be started for nutrition as well as antibiotics. Abdominal X rays will be frequent.

Many infants who have NEC do not need surgery, but there are some infants who will—if surgery is needed, a pediatric surgeon will be involved. During surgery, the sick part of the intestine will be removed, but sometimes, the healthy ends of the intestine can be sewn back together. Other times, the two ends of the intestine are brought to an opening in the skin called an ostomy. Your baby will stool through the ostomy into a bag. The ostomy may last a few weeks to months before the ends of the intestines are healed enough to be reconnected. After your baby has recovered from surgery and the antibiotics are done, he or she will be able to start feedings again.

Some babies experience narrowing of the intestines and poor digestion of feedings after having had NEC. When narrowing (also called *strictures*) happens, it can cause a blockage in the intestine. Poor digestion of feedings (called *malabsorption*) also may occur. If this happens, the use of human milk or another easy-to-digest formula may help.

During the initial diagnosis of NEC, you may not be able to hold your baby because he or she is so sick. Please ask questions of the NICU staff. The staff is here to support you together as a family.



Neonatal Abstinence Syndrome

Neonatal abstinence syndrome (NAS) is a group of problems a neonate experiences when withdrawing from narcotics (opioids) the neonate was exposed in utero. Finnegan and MacNew were the first to describe the characteristics of the infant born to the narcotic-dependent mother, using the term NAS to express the cluster of symptoms affecting the central nervous, autonomic nervous, gastrointestinal, and respiratory systems (Finnegan & MacNew, 1974). Although the presentation of NAS can be variable, withdrawal symptoms most commonly seen in neonates are tremors, irritability, decreased sleep intervals, high-pitched crying, increased muscle tone, hyperactive reflexes, poor feeding, abnormal/constant suck, diarrhea, dehydration, poor weight gain, fever, mottling, and temperature instability (Hudak & Tan, 2012). Hudak and Tan (2012) also note that onset of NAS symptoms vary depending on the drug(s) the mother abused during her pregnancy, the timing of the last dose, maternal metabolism, placental transport of the medication, and neonatal metabolism and excretion. The closer to the time of delivery the drug was consumed, the later the signs of withdrawal will occur. In general, withdrawal will occur from 24 hours after birth for heroin to up to 72 hours for methadone. There are cases in which withdrawal did not occur for up to 96 hours or more after birth. NAS symptoms can last up to 8–16 weeks of age for some neonates. It also is important to note that withdrawal symptoms are more severe for neonates whose mothers were chronic abusers and milder for premature infants.

Neonates diagnosed with NAS are not born addicted to medications but are dependent to the medications that they were exposed to in utero. The difference between addiction and dependence, according to the National Institute of Drug Abuse, is that addiction is the compulsive drug use despite the negative consequences on the person's family, social, and work life (National Institute of Drug Abuse, 2013). Dependence is when the body acclimates to the drug that is being taken, requiring

more to get a specific effect. When a drug is suddenly stopped, the body will show symptoms of withdrawal.

NAS has become a major health problem for neonates born in the United States. In 2012, Patrick and colleagues did a retrospective, cross-sectional analysis of neonates diagnosed with NAS from 2000–2009 in the United States to determine the incidence and healthcare costs associated with the diagnosis. They found that the number of neonates diagnosed with NAS almost tripled during that time from 1.2 per 1,000 live births to 3.39 per 1,000 live births. A follow-up study examined the incidence from 2009 to 2012 and found that the incidence doubled in this 3-year period. In 2012, the national average of babies being diagnosed with NAS was 5.8 per 1,000 live births, or one baby born every 25 minutes (Patrick, Davis, Lehmann, & Cooper, 2015). The authors also noted that there was great regional variation of NAS in the United States, ranging from of 3.0 per 1,000 live births in the Pacific Northwest to 16.2 per 1,000 live births in the East South Central (Patrick et al., 2015).

The costs associated with the increased length of stay for the NAS baby also have increased since 2009. In 2009 the average hospital cost was \$53,400; by 2012 that cost had increased to \$66,700, which is 19 times higher than the average hospital stay for a healthy term neonate of \$3,500 (Patrick et al., 2015). This translated into \$1.4 billion in total hospital expenses in 2012, which had doubled since 2009 and is mostly attributed to Medicaid dollars (Patrick et al., 2015).

The diagnosis of NAS begins with obtaining a history from the mother on her drug use during pregnancy. This history needs to include both prescription and over-the-counter medications, herbal use, illicit drug use, smoking habits, and alcohol usage. When obtaining the history from the mother, maintain a nonjudgmental attitude and conduct the interview in a private setting away from other family members or friends, using motivational interviewing techniques.



It is very important to do the interview away from family members, especially the significant other, as many times they are unaware of the drug usage. When interviewing the mother, it is of utmost importance to make clear to the mother that the objective behind asking the questions is to be able to determine the best way to care for the neonate, not to punish the mother. If the mother admits drug use, the following information needs to be documented: the drug use, amount of drug(s) used, the route of use, the duration of use, and any history of a drug treatment program. Questions about family member drug, alcohol, or smoking habits also are important to document. Many women will not admit their own drug use but will admit to their partner or husband's drug use.

Diagnosis of the infant can be done by testing the infant's urine, hair, meconium, or umbilical cord for drugs. Urine testing is the least accurate of the tests, as urine only detects recent use of a drug. Depending on the drug used and the timing of the last dose from when the urine is obtained, the infant's urine can be negative, even though the mother admitted to drug use. Hair, meconium, and the umbilical cord all show what drugs were taken during the last one to two trimesters of the pregnancy.

Hair is not used often because a 2 mg–5 mg of hair is needed to test for drug usage, and either the babies do not have enough hair or the healthcare providers do not like to remove hair for testing. The majority of hair grows in the last trimester so a hair sample will detect usage in the last trimester of pregnancy. If using hair for drug sampling, it is important to get the hair sample prior to discharge from the hospital as environmental contamination can affect the test results.

Meconium is relative easy to collect, but to get an accurate test, the entire meconium column needs to be collected from the first stool to the first transitional stool. The different meconium samples collected in one collection container need to be thoroughly mixed prior to sending them to the lab to be tested. Most labs will only take one or two samples at the most and depending on which sample they test, the test can come back negative even though the infant is positive.

The umbilical cord is the newest method for drug testing in a newborn. The umbilical cord can be collected at the time of birth and stored up to 7 days of age, if prepared properly. The cord sample needs to be 6 in. in length and is prepared by draining the blood from the cord and rinsing the specimen in the solution recommended by the drug testing company. The cord, like meconium, will give information on drug use during the last two trimesters of pregnancy.

Physical signs and symptoms of NAS were described earlier and will vary depending on the neonate, the drugs he or she was exposed to, the timing of the last dose, and the gestational age of the neonate. Assessment tools have been developed by several authors to assist with assessing the severity of the signs and symptoms and response to the NAS treatment. The Neonatal Abstinence Scoring System (NASS), developed by Dr. Loretta Finnegan in 1975, was the first scoring tool, and is commonly referred to as the Finnegan Scoring Tool (Finnegan, Connaughton, Kron, & Emich, 1975). This is the most widely used NAS tool in NICUs in the United States today, despite the tool only recently being validated for reliability. Other scoring tools available that are considered reliable and valid are the Lipsitz tool (Lipsitz, 1975), the Neonatal Narcotic Withdrawal Index (Green & Suffet, 1981), and the Neonatal Withdrawal Inventory (Zahorondy et al., 1998). All of the tools assess what the author of the tool believes to be the most common signs and symptoms of NAS and assign the symptom a score. The symptoms vary from 8 for the Neonatal Withdrawal Inventory to 21 for the Finnegan Scoring Tool.

For a neonate diagnosed with NAS, nonpharmacological interventions are instituted first; if they do not help to alleviate symptoms, pharmacotherapy will be ordered next. Nonpharmacological interventions such as decreased light and noise levels, skin-to-skin care, and swaddling have been shown to help the infant diagnosed with NAS. A complete list is described in Table 1. Many babies with NAS have difficulty with feeding. Nursing interventions such as offering small frequent feeds, not talking to the infant when feeding so the baby can focus on eating, occasional gavage feeds, offering a



higher caloric milk so a decreased volume can be given, and encouraging breastfeeding for those neonates whose mothers are in treatment programs have been shown to help with the NAS symptoms.

Table 1 – Nonpharmacologic Interventions

- Swaddling—in a flexed position with hands midline against chest and legs loosely swaddled in lumbar flexion—to decrease sensory stimulation
- Minimize environmental and physical stimulation—low lighting and noise level—do not use TV or mobiles
- Avoidance of abrupt changes in infant’s environment—handle gently and close to the body to increase sense of security
- Skin-to-skin care with the mother
- Gentle vertical rocking
- Soft voice and gentle touching to awaken baby and prepare for cares
- Limit all stimulation at first signs of distress
- Pacifiers for non-nutritive sucking
- Hand containment during cares
- Use of soft shushing, singing, or humming
- Offer firm input to feet for bracing during feeds, your hand on the infant’s chest to offer firm support and maintain flexion which will increase organization for sucking and firm pressure to palate to increase and improve quality of sucking
- Frequent, small feedings for infants with feeding difficulties or gavage feeds may be needed
- Avoid talking to the infant while feeding or rocking
- Clustering care with extended rest periods.

Breastfeeding babies with NAS is a controversial subject because many healthcare providers are uncomfortable with letting mothers who have a substance abuse disorder breastfeed, even those in treatment programs. Many are concerned with the amount of drug that may transfer into the milk, but studies on both methadone and buprenorphine have demonstrated that very little of the drug passes into the breast milk and even smaller amounts are measureable in the neonate’s blood or urine (Jansson et al., 2008; Ilett et al., 2012). The American Academy of Pediatrics (AAP) recommends breastfeeding for neonates experiencing withdrawal as long as the mother is in a supervised drug treatment program and the mother is HIV- and Hepatitis C–negative (Hudak and

Tan, 2012). Despite this recommendation, breastfeeding rates remain low, but it should be encouraged in this population of women and infants. Several studies show that infants with NAS who are breastfed or receive breast milk (breast or bottle) for more than 75% of their feeds have decreased severity of symptoms, lower use of pharmacologic agents, and decreased length of stay, as well as increased maternal attachment (Jansson et al., 2008; McQueen, Murphy-Oikonen, Gerlach, & Montelpare, 2011; Pritham, Paul, & Hayes, 2012; Hodgson & Abrahams, 2012; Welle-Strand et al., 2013; Crillo & Francis, 2016; Holmes, Schmidlin, & Kurzum, 2017).

Pharmacological treatment will be administered to neonates when the nonpharmacological interventions are insufficient to control the symptoms of NAS. There are no universal recommendations on which drug to treat the neonate with except that the AAP recommends therapy with the same class as the prenatal substance used, based on symptom severity (Hudak & Tan, 2012). Currently there is no standardized therapy; a high variability exists among practices in the United States and a best approach has not been determined. The most commonly used drugs to treat NAS are morphine, methadone, phenobarbital, and clonidine.

As with any neonate that requires care, the nurse also must care for the mother of the neonate. To give the best care to the neonate it is important to admit to yourself that these infants and their mother can be difficult and time consuming to deal with, and to confront your feelings regarding the issue of maternal substance abuse disorder and neonatal abstinence syndrome. Many times the mother-infant dyad requires a lot of energy and flexibility on the nurse’s part. Involving the social worker and other team members such as occupational/physical/music therapy and pastoral care for your unit often is helpful as they have many resources available to them to assist with the care of the mother-infant dyad.

When caring for this mother-infant dyad, it is important to remember that a substance use disorder is an illness. The mother was an addict prior to becoming pregnant; she did not become pregnant and then decide to become



an addict. Just as you would treat any parent who has a disease professionally and with compassion, you must treat the mothers of babies with NAS professionally and with compassion. By providing consistency in caregivers, the nurses will be able to develop a therapeutic relationship with the mothers. This will help with teaching the mother when the time comes for discharge. When working with the mother, give clear and specific guidelines of her expected behavior while in the mother-infant unit, special care, or intensive care unit. Many addicts struggle with long-term planning, so helping them to identify both daily goals (a one-day-at-a-time approach) as well as the longer-term goals that are required for discharge planning is useful.

Education of the mother to care for her neonate is essential to ensure the neonate will receive the proper care once discharged home. The educational material needs to be written at an appropriate level for the mother's educational level. Present material that is accurate and from a reliable source, such as the parent handout that accompanies this module, in a nonjudgmental manner. The parent education should be goal directed, with the goal of taking their neonate home with them. In addition to the normal newborn teaching, items that the nurses need to ensure are addressed during the hospitalization include the following:

- Assist the mother with attaching emotionally to her neonate. Skin-to-skin care and breastfeeding have been shown to increase maternal attachment (Pritham, Paul, & Hayes, 2012).
- Provide positive reinforcement and immediate feedback on all caretaking activities.
- Explain the neonate's behavior and sensitivity to the environment and that this behavior is not a rejection of her as a mother.
- Teach the mother to intervene early with her crying baby, as it is easier to settle a baby earlier than later.
- If the baby will go home with medication to control the symptoms of NAS, ensure the mother knows how to administer the medication as well as how to obtain the medication.

At the time of discharge the neonate needs to have a primary care provider identified with an appointment made, a referral for a home visit by a nurse, referral to Early Intervention/Help Me Grow Programs, and a referral to children's services if the neonate had a positive drug screen. The determination of whether to send the baby home with the mother is dependent on the city, county, and state the mother resides in as well as the substance used. Helping the mother find a drug rehabilitation program will assist with the mother's recovery from her addiction.

Long-term outcomes of neonates exposed to narcotics and other substances in utero are variable depending on the substance the neonate was exposed to. There are not many studies on this topic because this group of neonates is difficult to follow long-term. However, a 2017 study by Oei and colleagues looked at school performance of neonates diagnosed with NAS. The authors found that neonates diagnosed with NAS had lower mean test scores by third grade than their counterparts who did not have an NAS diagnosis and that the deficit was progressive (Oei et al., 2017). Other studies have reported delays in language, motor, cognition, growth, behavioral, and ophthalmic development; an increased incidence of sudden infant death syndrome; and increased rehospitalization rates due to maltreatment, trauma, and mental and behavioral disorders (Maguire et al., 2016; Uebel et al., 2015). With the developmental delays that have been reported, it is unclear whether the in utero exposure of the substances or the home environment of the neonate are the causes for the delays. More studies need to be done to determine what long-term complications are the result of exposure to drugs in utero.

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Neonatal Abstinence Syndrome: Information for Parents

During pregnancy the mother and her baby share their blood supply through the placenta. This means that substances a mother takes also may reach her developing baby. This is true for opioids (opium, morphine, codeine, hydrocodone, oxycodone, heroin, and fentanyl) and opioid replacement therapies (methadone, buprenorphine). (Opioid drugs sold under brand names include OxyContin®, Percocet®, Vicodin®, Percodan®, Tylox®, and Demerol®, among others.) When a baby has been exposed to drugs or medication while the mother is pregnant, the baby may experience signs of withdrawal after birth.

Neonatal abstinence syndrome (NAS) is a diagnosis given to a baby when he or she shows signs of withdrawal. Neonatal means “newborn.” Abstinence means “removed.” Babies whose mothers used drugs or medication during pregnancy can show withdrawal signs from 24 to 96 hours after birth. Babies will have discomfort (as do adults) when they go through withdrawal from a drug.

Signs of withdrawal depend on the drug or medication taken during the mother’s pregnancy—the amount, how long she was taking drugs, and her use of other substances like nicotine, alcohol, or marijuana. The most common signs are

- crying that can’t be easily comforted
- bad temper and/or stiffness
- trouble getting to sleep or staying asleep
- vomiting, loose stools (and diaper rash)
- skin scratches (from rubbing face, knees, and elbows)
- uncontrolled movements and shaking
- trouble eating; losing more weight than expected or not gaining weight
- sweating
- rapid breathing, nasal stuffiness, frequent yawning, frequent sneezing
- fever
- mottled skin.

Some babies may have mild signs of withdrawal and will not need medications. Others will have more severe signs that require a prolonged hospital stay in a special care nursery or a neonatal intensive care unit.

If your baby begins to show signs of withdrawal, the nurses may use a scoring and assessment tool to see how to teach your baby. These tools are used to help decide what sort of support, treatment, or medication your baby may need to help them feel better and recover comfortably. There are several tools available to describe NAS symptoms, with the most common one being the Finnegan tool. While the Finnegan is the most commonly used tool, other tools such as the Lipsitz, Neonatal Withdrawal Inventory, and Neonatal Narcotic Withdrawal Index are also reliable. Ask your nurse for a copy of the scoring tool and to explain it to you. This will help you recognize your baby’s withdrawal symptoms. Ask your nurse to show you the baby’s symptoms.

When your baby begins to show signs of withdrawal, the nurses and providers will work to create a care plan for you and your baby. It is important for you to help as much as possible with your baby’s care. You can help in many ways to ease your baby’s discomfort. The hospital staff is here to help.

Here are some things you can do:

- Hold your baby skin-to-skin.
- Talk to your baby in a soft voice. (Even though your baby can’t tell you, he or she knows your touch and your voice, which are very different from those of the staff.)
- Sing or hum softly to your baby.
- Learn how to swaddle your baby in a flexed position with their hands near their face/chin.
- Go slow and be gentle when picking your baby up.
- Keep the room quiet and the lights low.
- Offer your baby a pacifier to suck on.
- Rock your baby gently in a vertical (up and down) direction.



Your baby needs a lot of sleep. Ask the staff when you can come hold and feed your baby. Plan feeding, bathing, and diapering together so that you do them at one time.

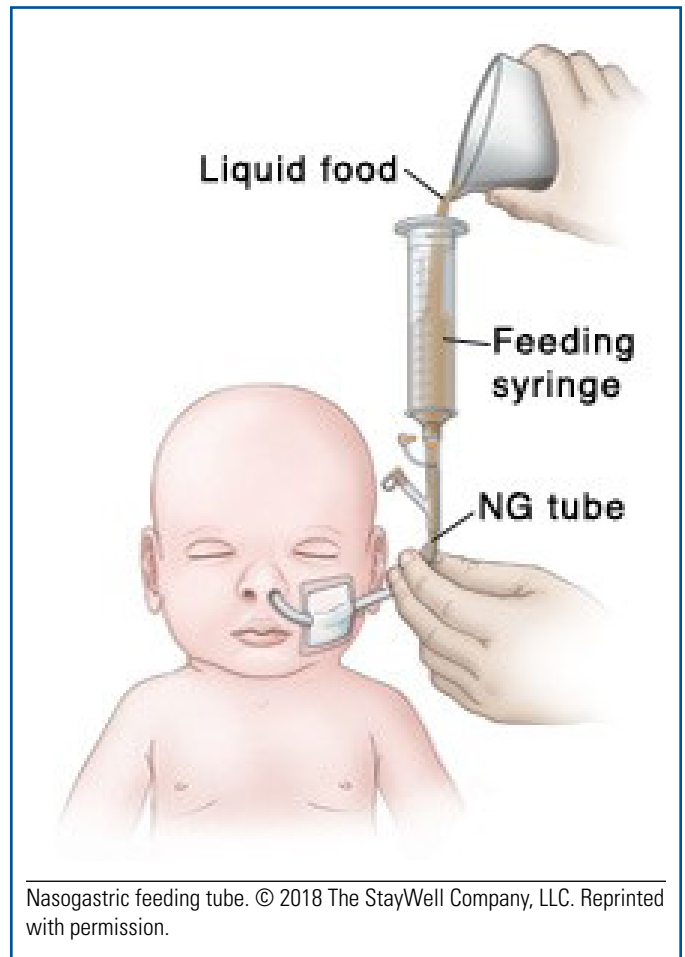
Another important part of caring for your baby right now is supporting his or her feeding. Babies who are experiencing NAS symptoms may need more calories (to support healthy growth) and more fluids than other newborns. Breastfeeding is recommended for all mothers who are HIV-negative and clean from street drugs. Even if a mother is on medication to treat their addiction, she can still breastfeed. Breastfeeding your baby is one of the best ways to decrease the withdrawal symptoms, decrease the amount of time he or she is in the hospital, and decrease the amount of medication your baby may need to ease the withdrawal symptoms. You and your medical team will work together to create a plan that is best for your baby. (This may include the use of formula, donor breast milk, or human milk fortifier for added calories and nutrients.)

Many times, babies with NAS have a hard time eating. There are things you can do to make feeding time better and less stressful for your baby. If your baby is extremely irritable or having a hard time eating, the lactation consultants and nurses can help you:

- Position your baby so that he or she is in a flexed, comfortable, swaddled position.
- Position the breast or bottle nipple in your baby's mouth to make sucking easier.
- Limit distractions that keep your baby from focusing on eating.

Remember, babies can use a lot of energy trying to eat. Sometimes, they can burn more calories eating than they take in. Sometimes calories need to be supplemented by feeding them with a tube that goes through their mouth or nose, directly to their stomach. This helps them get more calories and nutrition because it takes much less effort.

If your baby continues to show signs of withdrawal in spite of doing the above interventions, then your baby's



provider (nurse practitioner or physician) may start your baby on medicine to help decrease your baby's NAS symptoms. Morphine and methadone are the most common medications used but there are times when other medicines such as phenobarbital or clonidine need to be added to help. Depending on where your baby is being treated and the medication being used, your baby may go home on medication. If your baby goes home on medication, the nurses will teach you how to give the medicine and how often to give it. It is very important to give the exact amount of drug at the exact time.

You are a very important member of your baby's care team. The love and care you give to your baby during this time will help him or her recover more quickly. When you are in the neonatal intensive care unit, we encourage you to spend as much time as possible with your baby, holding and getting to know him or her. In most cases,



the more you participate in your baby's care when in the hospital, the greater the chance you will be able to take your baby home. If mom is unable to be there, you can invite your spouse, partner, friend, or other family member to help with holding and caring for your baby.

Once you and your baby are discharged home, it is very important to keep all appointments with your baby's pediatric providers (nurse practitioner or physician) so your baby can remain healthy by receiving immunizations on time and to monitor your baby's growth and development. It also is important that you continue in your treatment program and follow up with your physician. The postpartum period can be a difficult time in a parent's recovery. And your body is changing. Many mothers experience postpartum anxiety or depression. It's normal to feel tired and overwhelmed. Have a plan and ask for help. Work with your care providers and learn what you can do to limit the risks of relapse and overdose and be as healthy as you can be.

At this point no one knows what long-term problems babies exposed to drugs before birth can have. We

do know that babies exposed to opioids during pregnancy can do just as well as other babies who were not exposed. But every baby does better when they get regular medical care and developmental screenings to make sure they are meeting their milestones. Depending on where you live and what your unique circumstances are, your local children's services may become involved with you and your baby. It is important to remember that they are contacted to ensure your baby has the best possible situation to go home to, not to punish you.

Once your baby is home, you need to pay close attention and look for any withdrawal symptoms—some babies can have symptoms for up to 4 months. Your provider will not send your baby home until they have gotten through the worst of their withdrawal, but remember your baby may be fussier than a baby who was not exposed to drugs before birth. If your baby has signs of the withdrawal or will not eat, has diarrhea and/or vomiting, or cannot be calmed down, please call your nurse practitioner or pediatrician immediately. Call 911 if your baby has a seizure, stops breathing, or turns blue.



Neonatal Seizures

Neonatal seizures are defined as involuntary alterations in neurologic function, including motor behaviors, and can include autonomic functions such as heart rate, respiratory rate, and blood pressure. Neonatal seizures are age specific and occur in term infants less than 28 days of life and preterm infants less than 44 weeks adjusted age. Due to both relative excitability in the neonatal brain and the risk for brain injury in the perinatal period, the threat for seizures is highest in the first year of life, with the first 1 to 2 days being the most vulnerable time.

The incidence of neonatal seizures is difficult to determine and is related to gestational age and birth weight, but is estimated to occur in one to two of every 1,000 term infants, 57.5 of 1,000 infants less than 1,500 g, and 2.8 of 1,000 infants weighing 2,500 to 3,999 g (Crowell, 2017; Parsons, Seay, & Jacobson, 2016). Seizures are one of the most frequent—and sometimes the only—signs of neurological dysfunction and can signify an underlying brain injury or anomaly. Neonatal seizures require urgent diagnosis and management and are considered a neurological emergency.

Etiology

Determination of the etiology is crucial. Not only does it guide treatment strategies, but it is a determining factor of prognosis. Determining etiology can be a challenge for care providers. A detailed prenatal, perinatal, and family history can be helpful in narrowing down the differential diagnosis. Hypoxic ischemic encephalopathy (HIE) remains the most common etiology of neonatal seizures in the first 48 hours of life and accounts for approximately 80% of all neonatal seizures. Seizures caused by HIE are usually transient, and although they may be initially difficult to control, pharmacological therapy is usually short term.

Bacterial or viral exposure should be considered in all neonates with seizures. Meningitis is a common cause of neonatal seizures within the first few days of

life, with infections most commonly caused by *Group B Streptococcus* (GBS) and *Escherichia coli*. Other congenital infections include herpes simplex virus (HSV) type 2, rubella, toxoplasmosis and congenital cytomegalovirus (CMV). Congenital viral exposures caused by Zika, enteroviruses, and parvoviruses also should be considered.

Central nervous system malformations, trauma and cerebrovascular lesions (intraventricular, intracranial, or periventricular hemorrhages) are commonly associated with seizures and should be diagnosed by imaging studies.

Acute metabolic disorders such as hypoglycemia, hypocalcemia, hyponatremia, and hypernatremia constitute a large portion of neonatal seizures, and these indices should be part of the initial workup after seizures present. Although rare, persistent metabolic disorders or inborn errors of metabolism such as urea cycle defects, organic acidurias, and aminoacidopathies can cause seizures in the neonatal period.

An uncommon cause of neonatal seizures is drug withdrawal in infants born to mothers with barbiturates, alcohol, heroin, cocaine, or opiate/methadone abuse. Infants of mothers who were on selective serotonin reuptake inhibitors during pregnancy may exhibit tremors and jitteriness that can be mistaken for seizures. The infant can present with withdrawal symptoms in addition to seizures possibly occurring as long as 4–6 weeks after birth. Seizures caused by maternal drug use can occur due to substance withdrawal or may be associated with utero-placental insufficiency due to chronic substance abuse and poor health maintenance.

Genetic causes of seizures are rare and include epileptic encephalopathy and benign familial neonatal convulsions. These should be considered when other diagnoses have been ruled out or a concerning family history is present.



Clinical Presentation and Classification

Due to central nervous system immaturity and incomplete myelination patterns in the brain, neonatal seizures have characteristics that are unlike seizures in other age groups. Neonates may have minimal seizure expression, and only 10% of suspected seizures have ictal electroencephalography (EEG) activity. Subclinical seizures, or seizures identified by EEG without any motor or behavioral activity, are common in the neonatal period. Seizure-like clinical activity not associated with changes in EEG may be caused by excessive neuronal activity or generated from subcortical brain structures and are considered a type of primitive reflex. EEG is not only useful in identification of seizures, but it also can evaluate background brain activity, which is an important prognostic factor.

Management and Treatment

The dissociation between clinical and electrographic seizures makes monitoring and treating neonatal seizures a challenge. Neonatal seizures require immediate evaluation and treatment to prevent or reduce brain injury. In 2011, the World Health Organization (WHO) set treatment guidelines and recommendations for neonates with seizures. Management and treatment begins with recognizing seizures, ensuring ventilation and perfusion stability, monitoring neurological status, ruling out electrolyte abnormalities, and providing education and support to the family. Any electrolyte abnormalities should be corrected prior to starting antiepileptic medications.

Phenobarbital (see *Phenobarbital* in Diagnoses) is the first-line antiepileptic drug of choice. A common side effect of phenobarbital is sleepiness. If seizures are not controlled after the maximum dose, a benzodiazepine (Valium, Ativan), phenytoin (Dilantin), or Keppra (see *Keppra* in Step 9) can be used as a second-line treatment. Pharmacological treatment and duration of treatment remain a topic of discussion and debate due to the lack of data for long-term use in the neonatal and early infancy population.

Outcomes

Early recognition and prompt intervention may protect the brain and improve outcomes. Infants with a history

of neonatal seizures are at increased risk for adverse neurological outcomes such as cerebral palsy, epilepsy, behavior problems, and abnormal cognitive development. The etiology for neonatal seizures has the best predictive value for estimating outcomes. Neonatal seizures caused by HIE, meningitis, structural anomalies, and intracranial hemorrhages have more severe outcomes. Outcomes are also related to prematurity and birth weight. Fifty percent of neonates with seizures will have long-term neurological complications. Neonatal neurological exams are a good predictor of outcomes as is the severity of EEG abnormalities, such as burst suppression and severe low voltage and multifocal abnormal discharges. Infant with neonatal seizures should be followed at a high-risk clinic to monitor development and achievement of milestones.

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Neonatal Seizures: Information for Parents

The brain is made up of millions of nerve cells, all connected together, that create and receive signals. These signals control many functions of our body. A seizure can occur when there is a disruption in the communication between brain nerve cells, which alters the signals or causes them to not fire as they should.

Neonatal seizures are seizures in a baby who is less than 28 days old or in a preterm baby who is less than 44 weeks adjusted age. Neonatal seizures are different from seizures in older children and adults. Babies are at higher risk for having seizures because their brain is immature and still developing. Neonatal seizures can be caused by many different things, and just because your baby has seizures now does not mean that your baby will have seizures later in life.

Some causes of seizures in your baby include

- a decrease or lack in oxygen or blood flow to your baby's brain before or during birth
- an infection caused by certain bacteria or viruses, before or after birth, that can cause meningitis or encephalitis
- bleeding in or around the brain
- brain structure abnormalities
- abnormal metabolic or electrolyte levels, including low blood sugar, low calcium, and low or high sodium
- problems in the body's chemistry or metabolism
- family history of seizures or "fits"
- drug withdrawal, which may be seen in infants born to mothers using barbiturates, alcohol, heroin, cocaine, methadone, painkillers, or other substances.

Neonatal seizures do not usually last long and it may be hard to tell if your baby is actually having a seizure. Seizures in a newborn can include any of the following behaviors:

- change in facial movements (repeated movements of the eyes, lips or tongue)
- movements of the arms or legs that look like riding or pedaling a bike

- staring
- stopping breathing
- rhythmic jerking
- stiffening or tightening of arms or legs
- quick jerks involving legs, arms, or the whole body.

Newborn babies can have a variety of different movements that might look like seizures but are not. Some examples are simple things, like sucking and stretching, or jitteriness when they are crying or disturbed. The jitteriness should diminish over the first few weeks after birth and should be less frequent when the baby is quiet and awake. Other babies have single jerks of their arms or legs during sleep. This is called *benign neonatal sleep myoclonus* and should stop when the baby wakes up. Both of these examples are not concerning and do not need any treatment.

So how do you recognize seizures in your baby? Look for movements that the baby repeats over and over and are not provoked, or if your baby seems to be staring or not present during these movements. Many times these movements will occur in clusters for a short period of time. If you are unsure, try to video the movements to show your healthcare provider.

If seizures are suspected, it is important to monitor your baby's brain waves and function of the nerve cells using an electroencephalogram (EEG). An EEG can show how the brain cells are talking to each other and if there is a problem. Wires and gentle "paste" are used to hold electrodes to the baby's skin. It is not a painful procedure.

These electrodes then send wavy lines to a machine to graph the impulses, and the graphs tell the providers if something is abnormal and if there are seizures occurring. During an EEG recording, you may notice many different waves and changes on the screen—these do not always represent abnormal brain activity. Some changes may result from movement of the head or stimulation. Heart



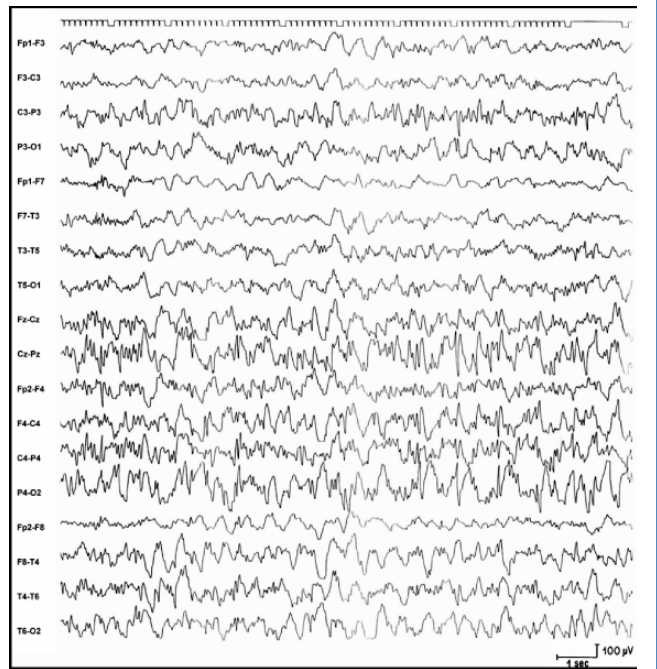
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rate and oxygen level changes will be monitored, as these may be associated with seizures.

If your baby is having seizures, it may be necessary to do other tests such as blood work, magnetic resonance imaging (MRI), or computed tomography (CT) scan to determine the cause of the seizures.

There is evidence that seizures may affect the brain function and development, so it is important to identify and control the seizures. Your baby's healthcare team will look for the cause of the seizures and treat them as needed. The healthcare team will first try to correct any abnormalities of blood sugar or electrolytes (other normal substances in our body). If the seizures continue, your baby may need an antiepileptic drug (a drug to treat and stop the seizures).

Phenobarbital is the first drug of choice to treat neonatal seizures. Sleepiness is one of the major side effects and may be observed, especially in the first days of treatment. If the seizures are not controlled with this medication, there are others that can be added. Often, newborns that have seizures only need medication for a



Neonatal EEG. © ASET - The Neurodiagnostic Society. Reprinted with permission.

short time. Many times, the medication is stopped before going home. If your baby still needs medication at home, your baby will need to be monitored by a neurologist (pediatrician who specializes in the brain and spinal cord) as an outpatient.

If your baby is diagnosed with neonatal seizures, the outcome may be different depending on the cause of the seizures. Talk to your baby's healthcare providers to find out what the future effects will be for your baby. If your baby's seizures are caused by an underlying brain injury or abnormality, his or her long-term outcome may be more serious. It is important to provide the healthcare team with as much information as possible regarding family history (especially of seizures or "fits"), birth history, and prenatal history. This may help the healthcare team identify a cause for the seizures and give more information to guide treatment and improve outcome expectations.



Neonatal Sepsis

Neonatal sepsis is a clinical syndrome of systemic illness or infection. Other definitions one may associate with sepsis include

- bacteremia—presence of bacteria in the blood
- septicemia—systemic illness due to bacteria in the blood stream
- meningitis—inflammation of the meninges of the brain and the spinal cord, most often caused by a bacterial or viral infection
- pneumonia—inflammation of the lungs caused by viruses, bacteria, or other microorganisms and sometimes by physical and chemical irritants
- early-onset sepsis—defined by the Vermont Oxford Networks (VON) as sepsis with onset within 72 hours of birth
- late onset sepsis—sepsis occurring after 3 days of age in a NICU patient and after 7 days of age in a term infant.

The incidence of early-onset sepsis is 0.77–1 per 1,000 live births. According to the National Institute of Child Health & Human Development (NICHD) Neonatal Research Network, the incidence of early-onset sepsis in infants with birth weight less than 1,000 g is 26 per 1,000 live births and incidence of early-onset sepsis in infants with birth weight 1,000g–15,00g is 8 per 1,000 live births and late-onset sepsis rates are approximately 21%.

Early-Onset Sepsis

The more common organisms that can cause early-onset sepsis are Group B streptococci (GBS), *Escheria coli* (E. coli), *Listeria monocytogenes*, *Haemophilus influenza*, *Enterobacter*, and *Streptococcus pneumonia*.

In early-onset sepsis, the infant will present with nonspecific symptoms. Premature infants may present with overwhelming systemic illness that can progress rapidly to shock and death.

There are risk factors for early-onset sepsis. These include preterm birth, maternal vaginal colonization with GBS, premature or prolonged rupture of membranes greater than 18 hours, and maternal urinary tract infection

or fever, which can be an indicator of maternal infection of inflammation. Early-onset sepsis is usually associated with *vertical transmission*, which is from mother to baby.

Late-Onset Sepsis

The more common organisms that can cause late-onset sepsis include coagulase-negative *Staphylococcus*, *Staphylococcus epidermis*, *Staphylococcus aureus*, *Pseudomonas*, GBS, and *Candida*. Late-onset sepsis is more often associated with *horizontal transmission*, which is from family, hospital personnel, and contaminated or inadequately disinfected equipment. It can also be known as *nosocomial*, or hospital-acquired infection (HAI).

In late-onset sepsis, the infant can present with systemic symptoms and illness that occur suddenly or with subtle symptoms. Risk factors for late-onset sepsis can include prematurity, low birth weight, and invasive lines or procedures. The infant can present with a wide spectrum of signs and symptoms for both early-onset and late-onset sepsis, which can range from subtle to life-threatening.

Signs and symptoms of sepsis can include

- temperature instability
- lethargy or irritability
- feeding difficulties
- gastrointestinal symptoms (e.g., hepatomegaly, abdominal distention, vomiting, diarrhea, and bloody stools)
- seizures
- grunting, flaring, retracting, tachypnea, and apnea
- cyanosis, pallor, mottling, apnea and bradycardia, hypotension, tachycardia, and poor perfusion
- hypoglycemia, hyperglycemia, and metabolic acidosis
- jaundice and petechiae
- decreased urine output (anuria).

These signs and symptoms can be seen in a multitude of disease states, such as meconium aspiration, necrotizing enterocolitis (NEC), respiratory distress syndrome, intraventricular hemorrhage, and drug withdrawal. Therefore, it can be difficult to diagnose sepsis based only on these signs and symptoms.



Laboratory studies may include

- blood tests, which may include a complete blood cell count with differential, acute phase reactants (i.e., C-reactive protein, procalcitonin, nonspecific inflammatory markers)
- blood culture, with 1 mL of blood volume placed in the single bottle
- urine culture, although not recommended for early-onset sepsis
- lumbar puncture (LP), also known as a *spinal tap*. Not all sepsis workups include an LP.
- X rays, especially for symptoms of respiratory distress or abdominal distention.

The management recommendation for early-onset sepsis is to perform the LP when (a) there is a positive blood culture, (b) the infant's clinical course has worsened, (c) lab data strongly suggest bacterial sepsis, or (d) infants worsen even after starting antibiotic therapy. In late-onset sepsis workups, LPs and urine cultures should be considered.

Treatment for sepsis is started before culture results are back from the lab, especially when there is a high suspicion of infection in a symptomatic infant. Providing supportive treatment for any of the symptoms the infant has is essential. For early-onset sepsis, a combination of ampicillin and an aminoglycoside (usually gentamicin) is used for synergy. The use of cefotaxime for initial therapy is not recommended (Clark, Bloom, Spitzer, & Gertsman, 2006). For late-onset sepsis, determining which antibiotics are selected may be based on the epidemiology data from that particular NICU or hospital. Vancomycin and either gentamicin or tobramycin are the antibiotic combinations most commonly initiated for late-onset sepsis. Length of treatment for early- and late-onset sepsis will vary. Antimicrobial therapy should be discontinued at 48 hours in clinical situations demonstrating low probability of sepsis (improved clinical course, negative blood culture). Confirmed bacteremia is generally treated for 10 days. Uncomplicated meningitis is generally treated for a minimum of 14 days. Gram negative meningitis is generally treated for 21 days or 14 days after the first negative

culture. Other focal infections (e.g., osteomyelitis) are treated for longer durations.

Controversy surrounds the duration of treatment for the infant with a negative blood culture. Consideration should be given to how the infant's clinical course is progressing and the risks and benefits of a longer course of antibiotics. Cotten and colleagues (2009) demonstrated a possible association between a prolonged duration of antibiotics (longer than 5 days) and NEC. Kuppala and colleagues (2011) found that a prolonged administration of empirical antibiotic therapy to preterm infants with sterile cultures in early-onset sepsis is associated with subsequent severe outcomes.

Sepsis prevention starts with early intervention. Intrapartum antibiotics are used in maternal treatment for possible infection. Penicillin, ampicillin, or cefazolin are considered first-line treatment options. Clindamycin or possibly vancomycin may be provided to the mother who has a penicillin allergy. Good handwashing is of the utmost importance. Encouraging mothers to provide breast milk is another way to decrease the risk of infection.

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Neonatal Sepsis: Information for Parents

Neonatal sepsis (you may hear it referred to simply as “sepsis”) is an infection of your baby’s bloodstream. The infection can spread throughout the body and can be very serious.

Sepsis can be caused from an infection by bacteria, viruses, and fungi. Your baby could have been infected during the pregnancy, delivery, or after the birth from being in contact with others.

During pregnancy or delivery, an infection from the mother may pass to the baby by way of the placenta or through the birth canal. If the sac around the baby starts to leak, the baby is no longer protected from infection. Once born, the baby also can get an infection from being around people who are sick or objects in the environment. Even normal “good” bacteria that live on the baby’s skin may make the baby sick. Remember that your baby is in the neonatal intensive care unit (NICU). Frequently, more procedures are required for NICU babies, so there can be more opportunities for an infection to happen, even while trying to prevent infection. In addition, if the baby is premature, his or her immune system, which fights bacteria, is immature and is not strong enough to fight off the bacteria, virus, or fungus. When the immune system is not strong enough to fight the infection, the baby can become quite sick.

There are many different ways a baby may show that he or she does not feel well, and each baby is different. Some signs that your baby is not feeling well may include

- acting sluggish or more sleepy than usual (also known as *lethargy*)

- decreased breathing or breathing too fast (apnea or tachypnea) or slowing of their heart rate (bradycardia)
- not feeding well (tolerating their tube feedings or not breast/bottle feeding well)
- pale, cool, clammy skin
- not being able to keep their temperature regulated.

The NICU team is observing your baby all of the time. If you notice your baby acting differently, please let one of the team members know (e.g., nurse, provider, respiratory therapist). Don’t be afraid to talk with the team if you are concerned.

To determine whether your baby has sepsis, the NICU team may do many different tests: blood tests, urine tests, a spinal tap (also called a lumbar puncture), or X rays. Your baby may stop eating and need an IV and fluids. Your baby may need some help to breathe (such as oxygen or a ventilator). Antibiotics, medications given to fight the infection, may be started. The medical team will watch your baby closely and follow the test results closely. Your baby may need to have some of the tests repeated to make sure the infection is going away.

Here are some ways to help your baby fight against getting an infection:

- Wash your hands every time you are with your baby and especially after changing his or her diaper.
- Stay home if you do not feel well. You can call the NICU staff to check in on your baby until you are feeling better.
- Breastfeeding may help prevent infections. If you are able to supply breast milk for your baby, that is great!



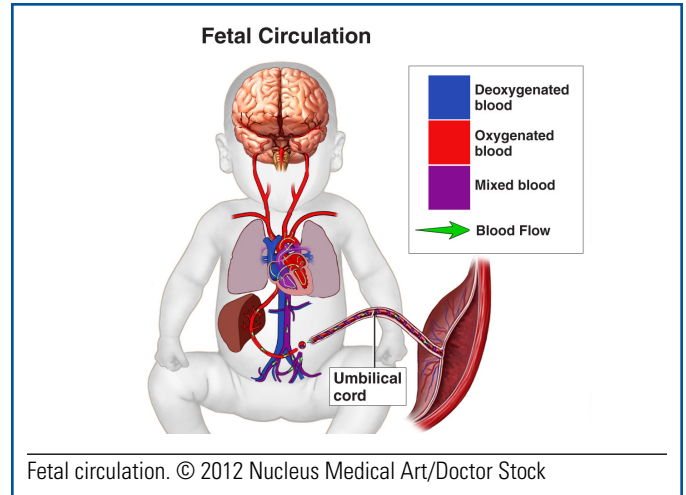
Persistent Pulmonary Hypertension in the Neonate

Persistent pulmonary hypertension in the neonate (PPHN) is a serious disorder of impaired transition to extrauterine circulation that primarily affects infants who are term or near term. PPHN is frequently associated with respiratory disease or failure from other causes such as meconium aspiration, sepsis, or congenital diaphragmatic hernia. Occasionally, PPHN occurs without any other conditions that can be identified.

During pregnancy, the infant's mother and the placenta provide the infant with oxygen, and very little of the infant's blood goes to the lungs. The blood vessels in the lung constrict (high pulmonary vascular pressure) to decrease blood flow to the lungs during this time. As a fetus, blood can bypass the lungs using the patent ductus arteriosus (PDA) and the foramen ovale. When an infant is born and takes his or her first breaths, the blood vessels in the lungs expand and allow blood to travel to the lungs to pick up oxygen and eliminate carbon dioxide. When these blood vessels fail to fully relax or fail to allow adequate blood to reach the lungs, it is called persistent pulmonary hypertension. The failure of these vessels to dilate may be related to underdevelopment of the vessels, hypertrophy of the muscle layer in the blood vessels, or a situation such as a difficult birth that interferes with the transition to extrauterine life. Because newborns still have the PDA and a foramen ovale, blood can bypass the lungs. This process is called shunting and can cause cyanosis. Oxygen is one of the molecules that helps vasodilate the newborn's pulmonary blood vessels. When an infant develops hypoxia or cyanosis, it acts as a pulmonary vasoconstrictor and tends to worsen the pulmonary hypertension. This cycle can be difficult to break.

The incidence of PPHN may be increased if the mother took certain medications during the last months of pregnancy, including nonsteroidal anti-inflammatory agents and serotonin reuptake inhibitors.

The diagnosis of PPHN should be considered in any infant with severe cyanosis or high oxygen requirements. PPHN



may be suspected due to an infant's clinical picture, but diagnosis should be confirmed with echocardiography (showing increased right atrial pressures, increased right ventricular pressures, or tricuspid insufficiency).

Treatment of PPHN includes support of oxygenation and ventilation, fluids and medications to maintain good cardiac output, and sedation. Surfactant may be given to improve lung function. Infants may require inhaled nitric oxide, a clear, odorless gas that when inhaled acts as a pulmonary vasodilator. In extreme cases, the infant may require extracorporeal membrane oxygenation, which is a form of heart lung bypass to avoid lung injury and allow the PPHN to resolve.

Persistent pulmonary hypertension puts the infant at risk for low blood oxygen levels, increased requirements for support, and long-term neurodevelopmental impairment such as developmental delays, motor delays, and hearing loss.

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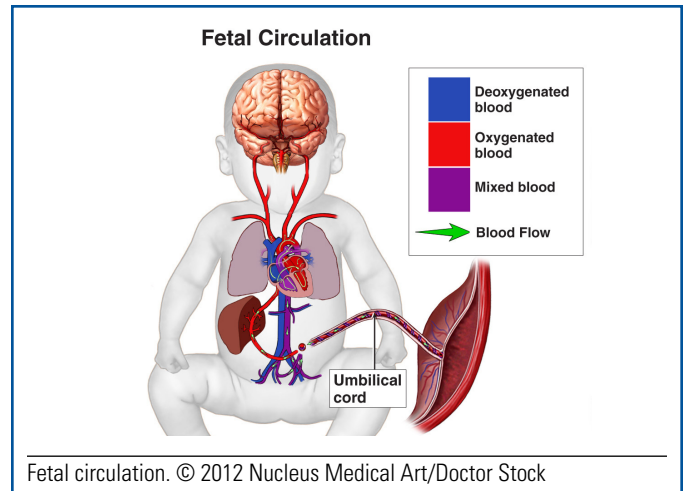


Persistent Pulmonary Hypertension in the Neonate: Information for Parents

Persistent pulmonary hypertension in the neonate (PPHN) is high blood pressure in the lungs and is a serious respiratory disorder that primarily affects infants who are born full term or near term (usually 34 weeks or more). PPHN is frequently associated with respiratory problems.

During pregnancy, the baby's mother and the placenta provide the baby with oxygen, and very little of the baby's blood goes to the lungs. The blood vessels in the lungs are mostly closed, because the lungs are not being used. When an infant is born and takes his or her first breaths, these blood vessels expand and allow blood to go to the lungs to pick up oxygen. When these blood vessels do not fully relax or do not allow enough blood to reach the lungs, it is called PPHN. PPHN is very dangerous because it can limit how much oxygen the baby can deliver to his or her brain and organs.

The treatment of PPHN may include the use of oxygen, special ventilators that breathe for the baby at a very fast rate, a gas called nitric oxide, or even temporary heart lung bypass.



After treatment for pulmonary hypertension, your baby's lungs will take weeks or even months to recover fully. It will be important to help protect your baby from catching colds or flus. Good handwashing and keeping your baby away from sick people and large crowds will help. It also will be especially important for your baby to see his or her pediatric provider and other specialists regularly to be screened for normal developmental milestones.



Pneumothorax and Air Leaks

An air leak occurs when the infant’s lung sacs, or alveoli, become overinflated and rupture, allowing air to escape. This can occasionally occur with an infant’s first breath, but it happens most frequently in infants who have lung disease, such as respiratory distress syndrome or meconium aspiration syndrome. The incidence of air leaks also increases when the infant is receiving some form of positive pressure ventilation, such as continuous positive

airway pressure, high-flow nasal cannula, or mechanical ventilation. The many different types of air leaks are identified by the location of the free air that escapes from the lungs (see table below). Pneumothorax occurs most frequently.

Air leaks are more likely to occur in the newborn period than at any other time of life. In the

Air Leak Types			
Name of Air Leak	Location of Free Air	Clinical Signs and Symptoms	Possible Treatments
Pneumothorax (most frequently occurring air leak)	Between the lung and the chest wall	If small, may be asymptomatic	None (if asymptomatic in the absence of positive pressure ventilation) Oxygen to promote nitrogen washout
Tension pneumothorax (can be life-threatening if there is a large enough pocket of air collected to increase pressure in the chest and decrease cardiac output)	Between the lung and the chest wall	Respiratory distress, decreased oxygen saturation, decreased breath sounds on affected side, movement of heart sounds away from affected side Bradycardia, hypotension, cyanosis	Increase oxygen high-frequency ventilation Needle aspiration for emergent evacuation, often followed by the placement of a chest tube
Pneumomediastium	In the mediastinal space	Most are asymptomatic. A large pneumomediastium may cause respiratory distress and cyanosis, distant heart sounds	Usually requires no treatment
Pulmonary interstitial emphysema	Air is trapped in the tissues that surround the air sacs and blood vessels in the lungs	Increasing oxygen and ventilation needs (may occur before and with other air leaks)	Supportive treatment, minimizing pressure to the lung (some use high-frequency ventilation)
Pneumopericardium	Area around the heart and inside the pericardial sac	Rapid development of tachycardia, hypotension, and narrowed pulse pressure. Heart sounds are distant.	Emergent needle aspiration, may require indwelling pericardial tube
Pneumoperitoneum (rare)	Peritoneal space	Abdominal distension	May require aspiration
Subcutaneous emphysema (rare)	Subcutaneous tissue	Crepitus (crackles) on palpation, usually in face, neck, or upper chest	Supportive treatment



extremely-low-birth-weight infant, air leaks are associated with an increased risk of intraventricular hemorrhage.

Transillumination with a high-intensity light source may demonstrate a halo or glow in the area of free air and give an initial clue to the diagnosis and location of the free air. A definitive diagnosis of all types of air leaks is made by X ray.

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Pneumothorax and Air Leaks: Information for Parents

A newborn's lungs are very fragile. Occasionally, some of the air sacs in the lungs will burst, allowing air to escape outside of the normal airways. This "free air" can collect outside of the normal airways and make it difficult for the lungs to properly inflate and for the infant to breathe. Air outside of the normal airways is called an *air leak*, and air leaks are named by where the free air is located. The most frequent air leak, called a *pneumothorax*, is when the air collects between the lung and the chest wall. Air also can become trapped in the mid-chest, in the tissue of the lung, around the heart, and in other spaces.

Babies who develop air leaks usually have other lung problems and frequently already require assistance to breathe. These air leaks can cause breathing problems to worsen and usually require medical treatment to resolve. Your baby may need increased oxygen, a special type of ventilator, and in some cases, the removal of the air. The free air is removed by placing a needle into the space of the air leak and removing the air. A tube may be placed temporarily in the chest to continuously remove the air, if needed (see *Chest Tubes* in Procedures).

Rarely, an air leak can occur with the baby's first big breath, but these are usually small and sometimes resolve without help.

Air leaks can range from minor to life threatening. Ask your medical team to discuss the severity of your baby's air leak. Babies with large, sudden air leaks are at risk for low oxygen and changes in blood pressure. In very premature babies, these sudden changes may put them at risk for bleeding in the brain. Babies who develop air leaks due to severe lung illness may be at risk for long-term breathing problems.



Respiratory Distress Syndrome

Respiratory distress syndrome (RDS), also known as *hyaline membrane disease* (HMD), is the dominant clinical problem and a major cause of morbidity and mortality in the premature neonate. Surfactant deficiency or dysfunction along with structurally and functionally immature lungs contribute to RDS.

Risk Factors

Premature and low-birth-weight infants are at the highest risk for developing RDS, and risk increases with younger gestational age and lower weight. At 23%–25% gestation, infants have approximately a 90% chance of developing RDS. Those delivered at 26–27 weeks gestation, 88%; 28–29 weeks gestation, 74%; and by 30–31 weeks gestation, the risk falls to approximately 50%. Other risk factors include

- male gender
- multiple gestation
- caucasian race
- previous infant with RDS
- perinatal asphyxia
- cesarean section without labor
- maternal diabetes
- antenatal infection such as chorioamnionitis (Newborns who develop RDS after exposure to chorioamnionitis tend to have a more severe course of RDS and more frequently develop bronchopulmonary dysplasia.)
- absence of antenatal steroid administration to the mother.

Factors Associated with Decreased Risk

The risk of neonatal RDS may be reduced in the presence of

- maternal chronic or pregnancy-induced hypertension
- maternal cocaine use
- maternal stress
- corticosteroids and thyroid hormones
- placental insufficiency (stress in the fetus may have the secondary effect of inducing accelerated lung maturation).

Normal Fetal and Neonatal Lung Development

A basic understanding of lung development and maturation will facilitate an understanding of how RDS occurs. Normal lung development can be divided into five stages:

- embryonic stage
- pseudoglandular stage
- canalicular stage
- saccular stage
- alveolar stage.

The Embryonic Stage (Embryonic Weeks 4–7)

The fetal lung bud—consisting of epithelium and surrounding mesenchyme, an endoderm-lined out-pouching of the primitive foregut—is first evident around embryonic day 24–26. During the next 3–5 weeks, the lung bud divides and branches dichotomously, giving rise to the conducting airways (trachea, right and left main bronchi, and segmental bronchi) and five primordial lung lobes (two left and three right). During the initial phase of development, the primitive airways are surrounded by loose mesenchyme supplied by primitive systemic arteries. Near the end of the embryonic period, the primitive systemic vessels are replaced by the pulmonary arteries.

The Pseudoglandular Stage (Embryonic Weeks 6–16)

During this stage, the airways grow to the level of the terminal bronchioles and primitive acini are formed. By the end of the pseudoglandular stage, branching of the large conducting airways is complete.

The Canalicular Stage (Embryonic Weeks 17–27)

During this stage, the blood-gas barrier begins to thin and an immature surfactant-producing system starts to develop, transforming the previable lung into a potentially viable lung. Distal airways develop into definitive primary acini, and the alveolar capillary barrier is formed. True acinus, the gas exchange unit of the lung encompassing a respiratory bronchiole and its associated alveolar ducts and alveoli, do not develop until around 36 weeks gestation. By 20–22 weeks gestation, epithelial differentiation into immature type I and II pneumocytes begins. Type I



pneumocytes are flat cells lining the alveoli and are necessary for gas exchange. Type II pneumocytes are cuboidal cells responsible for producing surfactant. At this stage, the surfactant components produced by type II cells are detectable in the form of lamellar inclusion bodies. Vascularization of the dense mesenchyme surrounding the airways begins.

The Saccular Stage (Embryonic Weeks 25–38)

During this stage of development, evolution of the relationships between the airspaces, capillaries, and mesenchyme acquire greater significance, and airway walls become increasingly thin, increasing the gas-exchanging surface area. Lamellar bodies containing surfactant and phospholipid in type II pneumocytes increase and mature, and further maturation of type II into type I cells continues. Alveolar ducts, mature cup-shaped alveoli, line the elongated saccules by around 34 weeks gestation.

The Alveolar Stage (Embryonic Week 36–3 Years of Age)

Alveolar formation and maturation continues through this phase of development. At the beginning of the alveolar stage, the walls of the alveoli are thicker than adult alveoli. The double capillary supply persists, as does mesenchymal tissue between the epithelial layers. Apoptosis enables development of a single capillary loop, and the number of type I and II pneumocytes lining alveolar walls increases. There is an overall increase in gas-exchanging surface area. The majority of alveolarization is believed to occur within the first 5–6 months of age, but it continues at a slower rate up to at least 2–3 years of age. Some evidence suggest this stage lasts through 7–8 years of age; others suggest it lasts even later into early adulthood.

Timing of the stages is not definitive, and the stages overlap.

Normal Anatomical and Physiological Features of Newborn Respiratory System

The respiratory system of the healthy term neonate is anatomically and physiologically different from the adult respiratory system. These differences are more profound

with younger gestational age. Some of the differences are outlined below.

The head of the neonate is larger in proportion to the body than the adult's head is to the body. The large head size predisposes the neonate to malposition and mechanical occlusion of the airway. Further, neuromuscular development is immature, which limits ability to correct by repositioning. The head is the largest body surface area in the neonate and where heat loss is most abundant. Hypothermia may induce and exacerbate respiratory compromise.

The tongue also is proportionately larger in the neonate, and combined with the large amount of lymphoid tissue in the pharynx, can contribute to airway obstruction.

Neonates prefer to breathe through the nose, but the diameter of the nares is smaller. The small nares can be easily occluded by secretions, inflammation, and devices, which may compromise the newborn respiratory status.

The ribs and sternum are primarily cartilage, the ribs are horizontally oriented, and the muscles are immature and shorter. These differences decrease the ability to lift the ribs during inspiration to increase intrathoracic volume. The diaphragms are inserted horizontally and are flatter than the adult, resulting in an inward movement of the lower ribs during inspiration. Muscle endurance is determined by muscle mass and oxidative capacity of the muscle fibers. Premature infants with respiratory compromise have both decreased muscle mass and are subjected to frequent periods of hypoxemia, which increases the risk of muscle fatigue and respiratory failure.

The airways are smaller both in length and diameter, and they have less smooth muscle than the adult. These features predispose the infant to having “floppy,” or more compliant, airways.

The upper airway is significantly different in the infant. The epiglottis is proportionately larger than in the adult, less flexible, and omega shaped. These differences increase the risk of trauma and obstruction. The larynx



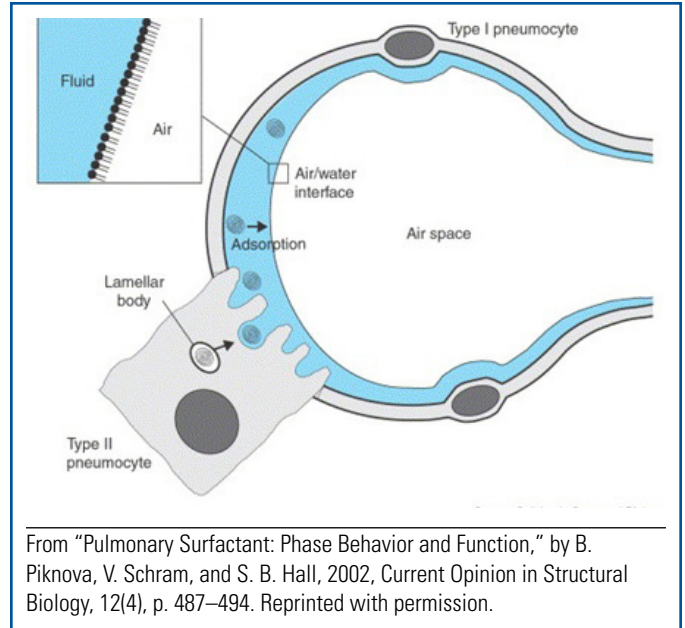
lies higher in the neck in relation to the cervical spine. The cricoid ring is the most narrow point in the trachea, forming the distinct funnel shape of the neonatal trachea. This natural narrowing allows the use of uncuffed endotracheal tubes in neonates.

The alveoli are the gas-exchange units in the lung and comprise the largest surface area of the lungs. The healthy full-term neonate is born with approximately 50 million alveoli with a well-developed microvasculature, whereas an adult has around 300 million alveoli. Premature infants born prior to 24 weeks gestation have just matured beyond the canalicular stage to the beginning of the saccular stage of development. This lung has undifferentiated distal air saccules and a poorly developed microvasculature. The potential gas-exchange surface area increases significantly after 29 weeks gestation.

Surfactant

Surfactant is produced and stored by type II pneumocytes in the distal airway epithelium. The first evidence of cellular differentiation occurs around 22 weeks gestation. Primitive type I and type II pneumocytes are evident at this stage, and primitive lamellar bodies are present. The 22-week fetal lung contains primitive structures and functions to survive outside of the womb, though this capability is limited and most often requires assisted ventilation.

Surfactant is a complex mixture of phospholipids, neutral lipids, and proteins and is a major determinant of alveolar wall surface tension. A thin film is spread at the air-liquid interface of the alveolar surface, thereby lowering the surface tension and preventing alveolar collapse, especially at low alveolar volumes reached at end-expiration. Surfactant produced by the 22- to 24-week fetal lung is functionally immature, and the volume is inadequate. It is not until around 30 weeks gestation that an adequate volume is produced and around 34 weeks before the produced surfactant shows functional maturity.



Surfactant synthesis is a dynamic process that depends on normal pH, temperature, and perfusion, and may be compromised by cold stress, hypovolemia, hypoxia, and acidosis. Exposure to high inspired-oxygen concentrations and the effects of barotrauma and volutrauma from assisted ventilation can trigger the release of proinflammatory cytokines and chemokines and further damage the alveolar epithelial lining, resulting in impaired surfactant synthesis and function. Furthermore, leakage of proteins such as fibrin into the intra-alveolar space aggravates surfactant deficiency by promoting surfactant inactivation.

Pathophysiology

RDS is a state of pulmonary insufficiency that manifests at or shortly after birth. Premature infants are born with underdeveloped, small alveoli that are difficult to inflate and larger, though still immature, alveoli that can easily become over distended. The alveoli that are available for gas exchange do not have the amount of surfactant necessary to maintain alveolar distention at end-expiration, resulting in atelectasis, and inspired air preferentially flows to the larger alveoli, resulting in further over distention. The premature infant is unable to achieve the significant negative inspiratory pressure required to open



the atelectatic regions, and the result is significantly increased work of breathing and hypoxemia.

Shear stress caused by repetitive attempts to reopen the collapsed alveoli results in significant damage to the lung epithelium. Increased work of breathing, hypoxia, and atelectasis leads to decreased tidal volumes causing alveolar hypoventilation and hypercapnia. Hypoxia and hypercapnia cause pulmonary vasoconstriction, which increases intrapulmonary resistance and intrapulmonary shunting. Intrapulmonary shunting results in the collapse of arterioles, thus receiving decreased blood flow and resulting in pulmonary hypertension. Prolonged hypoxemia activates anaerobic glycolysis, which produces lactic acid, resulting in lactic acidosis. Alveolar hypoventilation causes a worsening hypercapnia, which results in combined metabolic and respiratory acidosis. The acidosis causes further vasoconstriction, leading to more severe hypoventilation of the lung, intrapulmonary shunting, pulmonary hypertension, and intracardiac shunting through the foramen ovale and ductus arteriosus. Inadequate pulmonary perfusion causes worsening hypoxemia, acidosis, and decreased ability to produce surfactant. Capillary permeability increases, resulting in leakage of plasma proteins. Fibrin deposits accumulate in the air spaces, creating the appearance of hyaline membranes and further interfering with the function of available surfactant.

Clinical Manifestations

Signs and symptoms usually are apparent within minutes of birth, though manifestation may occur over the first few hours of life and can be exacerbated by cold stress or hypoglycemia. Infants presenting with severe respiratory distress or asphyxia require immediate resuscitation. The most striking clinical manifestations include tachypnea or apnea, expiratory grunting, intercostal and subcostal retractions, nasal flaring, poor color, decreased perfusion, and bradycardia. Progressive hypoxemia and dyspnea characterize the natural course. Within the first 6 hours of life, the chest X ray will reveal air-filled bronchi (air bronchograms) silhouetted against lung fields that have a “ground glass” appearance. Without intervention, RDS can progress to death. Uncomplicated or appropriately

managed RDS usually peaks within the first 3 days followed by a gradual improvement.

Management

Management optimally begins prenatally, with prevention of preterm birth being the most effective method to prevent RDS. Mothers presenting in preterm labor between 24 and 34 weeks gestation, when labor can be stopped or is not imminent, should receive antenatal glucocorticoids. Glucocorticoids are optimally administered in two doses over 48 hours; however, one dose administered at least 12 hours prior to delivery has been effective in reducing the severity of RDS. Multiple dosing has been associated with adverse effects, though the evidence is unclear, and dosing prior to 24 weeks gestation has not been well studied. Glucocorticoids induce significant and rapid acceleration of lung maturation and stimulation of surfactant production in the fetus. Some evidence shows that glucocorticoids not only reduce the severity of RDS but also may be valuable in reducing the incidence of central nervous system hemorrhage and neonatal mortality. Some research has suggested that although glucocorticoids are effective in accelerating early lung maturation, they may also be associated with abnormal lung development later in neonatal life.

Exogenous surfactant is another major advancement in the care and treatment of infants with RDS. Exogenous surfactant is available in synthetic or purified forms from animal sources, and it is instilled down the endotracheal tube. It is administered either prophylactically or as a rescue measure (there are new delivery methods being explored that include less invasive surfactant administration). Prophylactic surfactant is ideally administered to the infant in the delivery room or within the first 15–30 minutes of life. The criteria for prophylactic administration varies among institutions and is most often determined by the infant’s clinical status and most premature infants included in the selection criteria. Otherwise, for larger premature infants, prophylactic surfactant is administered based on clinical presentation. Repeat dosing is determined by the infant’s clinical status, and timing and frequency is based on the manufacturers’ guidelines. Immediate improvement in oxygenation and



ventilation is common and requires immediate intervention, such as decreasing inspired oxygen concentration, the peak inspiratory pressure (PIP; tidal volume, mean airway pressure), and possibly the positive-end expiratory pressure (PEEP) to avoid over distention and oxidative damage to the fragile lung tissue. Rescue surfactant is administered to infants who exhibit progressively worsening clinical symptoms, increasing oxygen requirements, or worsening blood gases.

Current evidence promotes treatment methods directed at protecting the fragile lung. Oxidative damage has been well researched, and studies show that administering high concentrations of oxygen in the delivery room induces oxidative lung damage that may be irreversible. Further, resuscitation provided via a T-piece device that allows control of PIP and delivering a constant PEEP improves lung volumes, facilitates functional residual capacity, and reduces the incidence of volutrauma and barotrauma. Stable premature infants who do not meet criteria for prophylactic surfactant administration may be placed on continuous positive airway pressure (CPAP) and monitored closely. Some infants who require surfactant (prophylaxis or rescue) are intubated, given surfactant, and immediately extubated to CPAP. Volume ventilation

provides a more physiologic method of ventilation and high-frequency ventilation provides a gentler method of ventilation.

Complications

Significant complications found in survivors of RDS include

- intracranial hemorrhage
- pulmonary hemorrhage
- sepsis
- necrotizing enterocolitis
- bronchopulmonary dysplasia.

It is unknown if the complications are the result of the underlying pathophysiology of RDS, administered treatments, or underlying prematurity.

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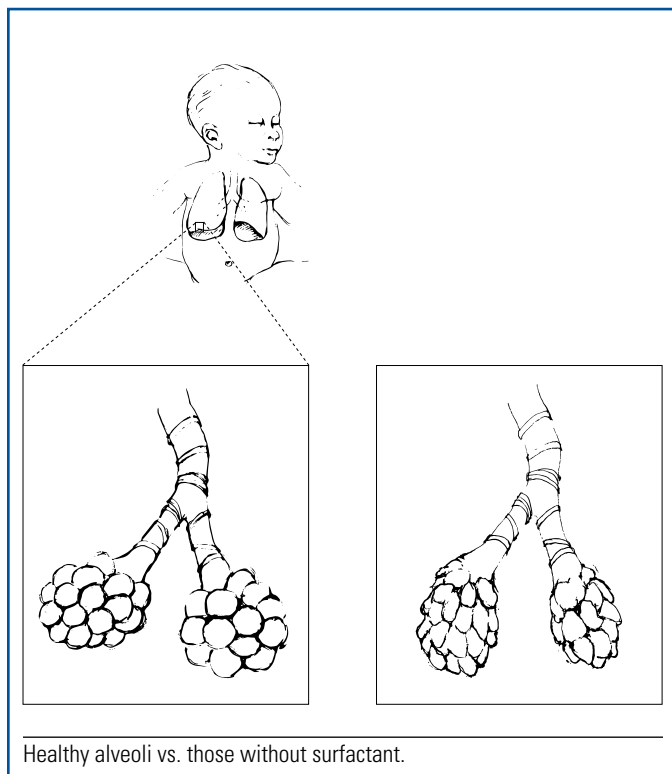


Respiratory Distress Syndrome: Information for Parents

Respiratory distress syndrome (RDS) also is known as hyaline membrane disease (HMD). This condition makes it difficult for the baby to breathe on his or her own.

RDS happens in babies whose lungs have not yet fully developed. It is caused when the baby does not have a slippery, protective substance called *surfactant* in the lungs. Surfactant helps the lungs inflate with air and then keeps them from collapsing when the baby exhales. Surfactant is a normal substance found in fully developed lungs.

The earlier the baby is born, the less developed the lungs are and the higher the chance of developing RDS. RDS is most commonly seen in premature infants born before 30 weeks gestation. It is very rare in full-term babies.



Other things can increase the risk of the baby developing respiratory distress syndrome:

- a brother or sister who had RDS
- when the mother has diabetes (high blood sugar levels) or an infection (chorioamnionitis)

- cesarean section, especially when mother has not experienced labor
- complications that decrease blood flow to the baby before he or she is born:
 - problems with the placenta
 - problems with the umbilical cord
 - a mother who smokes
- multiples in pregnancy (twins/triplets, etc.); the second and third babies are at higher risk
- quick labor (less than 3 hours).

The symptoms usually appear within minutes of birth, but sometimes they do not appear for several hours. Some of the symptoms include

- bluish color of the skin and mucus membranes (cyanosis)
- brief or prolonged periods where the baby stops breathing (apnea)
- a whining or grunting sound when the baby exhales
- nose “spreads out” when the baby inhales (nasal flaring)
- agitated or very weak and limp baby
- shallow and/or rapid breathing
- difficult breathing
- chest that appears to “sink in” with breathing (retractions).

Babies with the worst symptoms appearing in the delivery room will have a breathing tube placed; your baby may receive a form of surfactant (the slippery substance his or her lungs did not produce) down the breathing tube into the lungs to help him or her breathe more easily. Your baby may require more of the surfactant later. Some babies need only one dose, and other babies need as many as four doses. The breathing machine allows the baby to rest while the lungs have a chance to grow and recover.

Babies with less severe symptoms receive help breathing from nasal continuous positive airway pressure (CPAP). This type of support gives pressurized air through the



nose and helps the baby take a deep breath and keep the lungs inflated.



Baby on nasal CPAP. Courtesy of Hospital International.

The neonatal intensive care unit (NICU) staff will watch closely to make sure your baby rests and continues to breathe easily. If your baby needs more help breathing, he or she may need to have a breathing tube placed. Your baby may get a dose (or more) of surfactant.

Your baby's healthcare team usually knows within a few hours if more help to breathe is necessary. The signs and symptoms they look for are

- low blood oxygen levels (desaturations or blood gases)
 - requires more oxygen
- difficulty breathing (retractions, grunting, nasal flaring)
 - requires more pressure from the nasal CPAP or ventilator
- worsening apnea (more episodes, longer episodes, or more effort to stimulate the baby to breathe again).

Other treatments that may be used include

- high-frequency ventilation
 - a breathing machine that breathes very fast but may be less harmful to the fragile lungs
- medications to help the baby breathe easier
 - caffeine or theophylline stimulates the baby to breathe

- lasix (furosemide) or other diuretics to help get rid of extra fluid
- blood pressure support medications.

Babies with RDS have to be monitored very closely. Your baby may need X rays and small amounts of blood drawn to test his or her oxygen levels.

It is very important that all babies with RDS receive excellent supportive care. The following will help to decrease how much oxygen your baby needs:

- dim lighting, quiet room, and few disturbances
- gentle handling
- maintaining ideal body temperature.

Babies with RDS are too sick to eat from a bottle, so they receive nutrition through the IV fluids we give. We may try to feed your baby through a tube inserted into the nose or mouth that goes down into the stomach. At first the amount of food will be very small. Breast milk has the best nutrients and antibodies for your baby. Breast milk will help your baby recover better.

When RDS is the only problem and your baby responds well to the treatments, he or she will start to recover within about 3 days. The full recovery usually takes about 7–10 days, but sometimes a little longer.

Some of the complications associated with RDS, prematurity, or the treatments are

- chronic lung disease, also called bronchopulmonary dysplasia
- bleeding in the lungs, head, or brain
- higher risk of developing an infection
- pneumothorax or other air leaks
 - *Pneumothorax* is when air is found in the chest but outside of the lung.
- necrotizing enterocolitis
 - an infection in the bowel
- patent ductus arteriosus
 - A blood vessel in the heart that is normally open before the baby is born but closes after birth either stays open or reopens after birth.



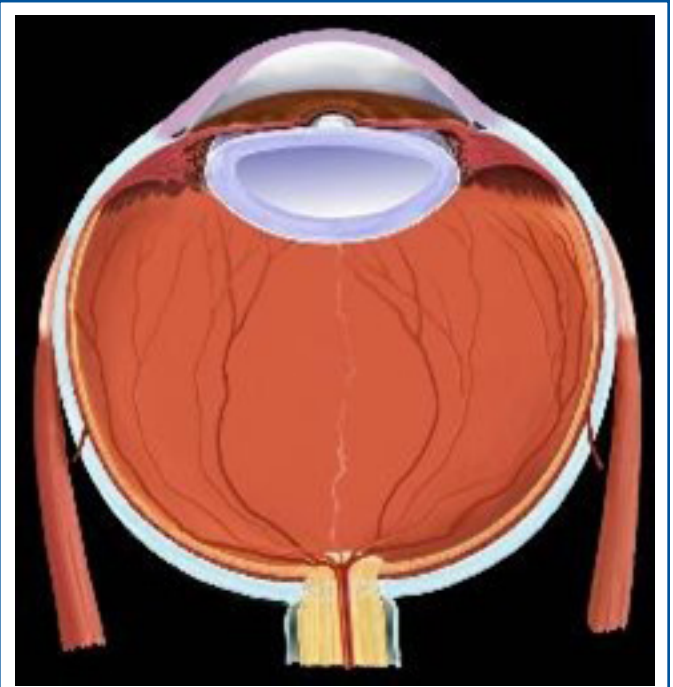
Retinopathy of Prematurity

Retinopathy of prematurity (ROP) is a potentially blinding eye disorder, caused by an abnormal development of retinal blood vessels. ROP primarily affects premature infants, with risk and incidence increasing as gestational age and birth weight decrease. Infants at highest risk are those born before 31 weeks gestation and weighing less than 1,250 g, those who experience intrauterine growth restriction, males, and those who experience prolonged exposure to supplemental oxygen.

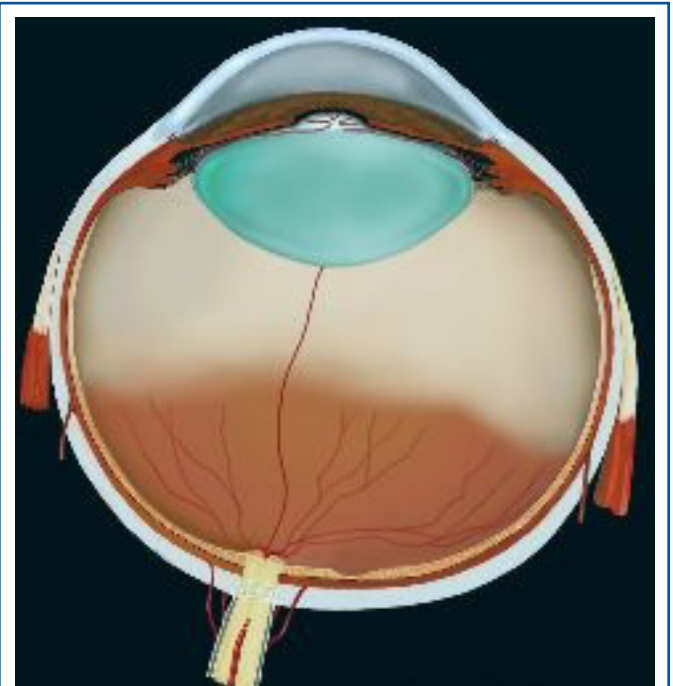
Several complex factors impact the development of ROP. The eye starts to develop at about 16 weeks of pregnancy, when the blood vessels of the retina begin to form the macula at the optic nerve in the back of the eye. The blood vessels grow gradually toward the edges of the developing retina, supplying oxygen and nutrients. During the last 12 weeks of a pregnancy, the eye develops rapidly. At term gestation, the retinal vessel growth is near complete. (The retina is usually fully vascularized within a few months after birth.) When an infant is born prematurely, the normal pattern of vascularization is disrupted and may be halted. The peripheral edges of the retina are at risk for oxygen deprivation.

As these abnormal blood vessels grow, they become fragile and can leak, scarring the retina and pulling it away from its position on the back of the orbit, causing retinal detachment. Retinal detachment is the main cause of visual impairment and blindness in ROP. Infants with ROP are considered to be at a higher risk for developing certain eye problems later in life, such as retinal detachment, myopia (nearsightedness), strabismus (crossed eyes), amblyopia (lazy eye), and glaucoma.

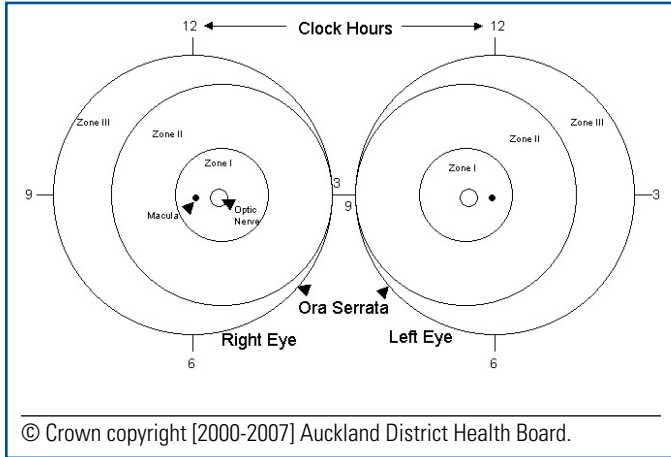
For premature infants, titrating oxygen saturations within acceptable targets can be challenging at best. There have been differing opinions as to maintaining saturations lower (85%–89%) or higher (91%–95%). In the SUPPORT trial, the rates of severe retinopathy or death did not differ significantly between the groups. Death before discharge was higher in the lower-oxygen-saturation



Normal blood vessels in the eye. Courtesy of the Vision Research ROPARD Foundation.



Abnormal blood vessels in the eye with a ridge of scar tissue from ROP. Courtesy of the Vision Research ROPARD Foundation.



group even though this lower saturation group had a lower occurrence of severe retinopathy.

Eye exams for infants at risk should be performed at 31 weeks postconceptual age or 4 weeks chronological age, whichever is later. Remember, ROP disease is diagnosed based on the zone of the eye where it is identified and assigned a stage based on severity of the disease (see figure).

Treatment

The most common treatments for ROP are laser therapy or Avastin®. Laser therapy burns away the periphery of the retina, which has no normal blood vessels. With cryotherapy, the surface of the eye that overlies the periphery of the retina is “frozen” to stop the abnormal growth of blood vessels. Both laser treatment and cryotherapy destroy the peripheral areas of the retina, slowing or reversing the abnormal growth of blood vessels. The side effect of these therapies is that the peripheral vision is lost in an effort to preserve the most important part of vision near the macula. A relatively new therapy for ROP is Avastin (bevacizumab). Avastin is an

angiogenesis inhibitor, slowing the growth of new blood vessels. First used in cancer patients, this antivasular endothelial growth factor drug is injected into the posterior chamber of the eye into the vitreous. In the BEAT-ROP clinical trial, Avastin was found to be superior to laser treatment in Zone 1, Stage III plus disease, but not in Zone 2. The role of anti-VEGF medications is still unclear but initial research is promising. Both therapies are performed on infants with advanced ROP, usually Stage III with “plus disease.”

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Retinopathy of Prematurity: Information for Parents

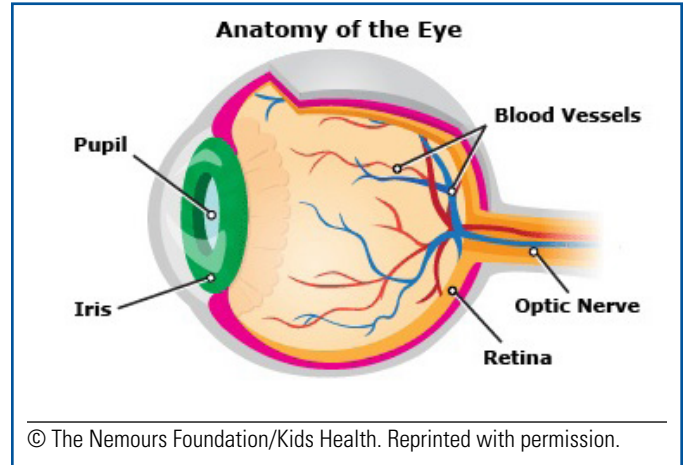
Retinopathy of prematurity (ROP) is an eye disease found in some premature babies. When a baby is born early, the blood vessels in the retina (the inner lining of the back of the eye) may not be fully developed. After birth, the blood vessels begin to grow abnormally. This is called ROP. Researchers do not know all of the reasons why ROP happens, but premature birth and exposure to high amounts of oxygen are two risk factors. Many times, this is a balancing act because sick babies may die without oxygen. It is very difficult to tightly control oxygen levels in sick babies.

Although most babies with ROP will heal over time, in some babies, the blood vessels continue to grow abnormally. This can cause the retina to separate from the back of the eye. Severe ROP can lead to loss of vision and even blindness.

ROP can be treated with a laser or medicine injected into the eye. Both treatments can slow down or even reverse the abnormal growth of the blood vessels in the eye.

While in the hospital, an eye doctor will check your baby's eyes on a regular basis until the retina is fully developed. When your baby goes home, you will have an appointment with an outside eye doctor for your baby.

Please be sure you know the time and location of this appointment.



Because ROP is a serious disease that can get worse very quickly, you should not change or reschedule this appointment unless it is absolutely necessary. Waiting too long for ROP check-ups and treatment can lead to blindness for your baby. An eye doctor (called an ophthalmologist) must do the exam, because ROP can only be seen using special equipment. Your baby's eyes may look normal to you even when there is severe ROP.

Resources



Resources

Retinopathy of Prematurity

InfantSEE

www.infantsee.org

InfantSEE is a public health program, managed by Optometry's Charity. The American Optometric Association (AOA) Foundation is designed to ensure that eye and vision care becomes an integral part of infant wellness care to improve a child's quality of life. Under this program, AOA optometrists provide comprehensive eye and vision assessments for infants within the first year of life regardless of a family's income or access to insurance coverage. Their website has helpful information for families on babies' developing eyes. It also explains vision screenings and what they detect. To find an optometrist who participates in the InfantSEE program call 1.888.396.EYES(3937).

The Association for Retinopathy of Prematurity and Related Diseases (ROPARD)

www.ropard.org

Founded in 1990 by a concerned group of physicians and volunteers, ROPARD is the first organization in the country dedicated to eliminating the problems of low vision and blindness in children caused by premature birth and retinal disease. They offer practical information for parents and physicians about understanding ROP and caring for children who have it. To contact them, e-mail ropard@yahoo.com, call 800.788.2020, or visit their website at www.ropard.org.

Hearing Screening

Centers for Disease Control and Prevention

www.cdc.gov/ncbddd/hearingloss/

Visit the CDC website for contact information for hearing specialists organized by state and territory.

National Institute on Deafness and Other Communication Disorders

www.nidcd.nih.gov/health/hearing/pages/baby_screening.aspx

If your baby's screening reveals a possible hearing problem, visit this website for information about next steps.

Parenting

NICU Journal: A Parent's Journey

A parent-focused diary, from the American Academy of Pediatrics, is available at <http://ebooks.aappublications.org/content/nicu-journal-a-parents-journey>

Bonding with Your Medically Fragile Baby in the Neonatal Intensive Care Unit

<http://handtohold.org/wp-content/uploads/2012/06/Bonding-with-Your-Medically-Fragile-Baby.pdf>
Written by Dawn K. Gibson, LCSW, this printable PDF discusses bonding with your baby during the NICU stay and beyond.

Psychosocial Support

National Perinatal Association. (2015). Interdisciplinary recommendations for the psychosocial support of NICU parents. *Journal of Perinatology*, 35, 59–513.

Immunizations

Centers for Disease Control and Prevention

<https://www.cdc.gov/vaccines/parents/tools/parents-guide/downloads/parents-guide-part3.pdf>

Bronchopulmonary Dysplasia (Electronic) **American Lung Association**

www.lung.org/lung-disease/bronchopulmonary-dysplasia

National Heart, Lung, and Blood Institute, National Institutes of Health

www.nhlbi.nih.gov/health/health-topics/topics/bpd

Books

Newborn Intensive Care: What Every Parent Needs to Know, 3rd Ed. (2010), by Jeanette Zaichkin. Available from American Academy of Pediatrics Publications. <http://ebooks.aappublications.org/content/newborn-intensive-care-3rd-edition>

Preemies: The essential guide for parents of premature babies, 2nd ed. (2010), by Dana Wechsler Linden, Mia



Wechsler Doron, and Emma Trenti Paroli. Available from Gallery Books, a division of Simon and Schuster, New York.

The Premie Primer: A Complete Guide for Parents of Premature Babies-From Birth Through the Toddler Years and Beyond (2010), by Jennifer Gunter. Available from Da Capo Press, a division of The Perseus Books Group, Jackson, TN.

Breastfeeding

Hand to Hold

Pumping and Breastfeeding

<http://handtohold.org/wp-content/uploads/2018/03/Pumping-and-Breastfeeding-FINAL.pdf>

Early Childhood Intervention

Hand to Hold

Your Guide to Early Intervention

<http://handtohold.org/wp-content/uploads/2018/03/eci.pdf>

General Information

Eli's Hope

www.elishope.org

Graham's Foundation

www.grahamsfoundation.org

Hand to Hold

www.handtohold.org

KidsHealth

www.kidshealth.org

Parent Premie Alliance

www.premieparentalliance.org

Premie World, LLC

www.premieworld.com