

Extremely Preterm Birth

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Extremely Preterm Birth



A normal pregnancy with one baby lasts about 40 weeks. Babies born before 37 completed weeks of pregnancy are called “*preterm*” or “premature.” Babies born before 28 completed weeks of pregnancy are considered extremely preterm. The earlier a baby is born, the less likely he or she is to survive. Those who do survive often have serious, sometimes long-term health problems and disabilities.

This pamphlet explains

- *gestational age* and survival
- research on preterm birth
- health problems that affect preterm babies
- specialized care for extremely preterm birth
- management and treatment options

- making decisions
- caring for a preterm baby

Gestational Age and Survival

Gestational age is the “age” of the pregnancy. It often is counted in weeks and days. For example, “24 and 2/7 weeks of pregnancy” refers to 24 weeks and 2 days of pregnancy. In this pamphlet, “24 weeks of pregnancy” refers to 24 completed weeks and the next 6 days.

Although less than 1% of babies are born extremely preterm, they make up the majority of newborn deaths. Medical advances have helped some preterm babies survive and overcome health challenges, but the chances that a baby born extremely early will survive without disability are still small.

With very rare exceptions, babies born before 23 weeks of pregnancy do not survive. While survival rates increase for babies born between 23 weeks and 25 weeks of pregnancy, most survivors face serious, often lifelong disabilities. As gestational age increases, the outlook for preterm babies improves. A recent study found that more than one half of babies born at 28 weeks survive without major disability.

Research on Preterm Birth

Research groups such as the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) collect information about preterm infants from hospitals all across the country. Researchers note that more infants born between 23 weeks and 24 weeks of pregnancy are surviving. They also note that the survival rates without major disability of babies born between 25 weeks and 28 weeks of pregnancy have steadily increased over the past few decades.

Despite this overall trend, it is hard to predict the outcome for an individual baby. Some babies develop faster, while other babies develop more slowly. Gestational age itself is only an estimate. Additional factors can affect the outcome for an extremely preterm infant, including birth weight, sex of the baby, and whether certain medications are given during pregnancy. Survival and complication rates also change over time as more research is completed and new treatments are developed.

Health Problems in Preterm Infants

Most babies who are born very early have serious health problems. They may need immediate and often ongoing medical care. Almost all of a baby’s organs and body functions are affected by being born preterm:

- Lungs—**Surfactant** is a substance that helps the air sacs of the lungs stay inflated. The lung’s ability to make surfactant increases with gestational age. By about 36 weeks of pregnancy, most babies have enough surfactant to keep the air sacs inflated. Lack of surfactant is the main cause of a serious breathing disorder called **respiratory distress syndrome (RDS)**. Babies with RDS are treated with surfactant replacement therapy and may need help breathing. Another common condition in preterm babies is **apnea of prematurity**, which causes the baby to stop breathing for 15–20 seconds or longer. This condition has been traced to underdevelopment in the area of the brain that controls breathing.
- Blood flow—All developing babies have an extra blood vessel called the **ductus arteriosus** that allows blood to bypass the lungs before birth. Normally, this blood vessel closes at birth or shortly afterward. In preterm babies, the ductus arteriosus may stay open. It may close on its own later, but some babies need treatment, including surgery, to close it. Another common problem in preterm infants is low blood pressure. Low blood pressure can reduce the flow of **oxygen** to organs.
- Brain—A baby’s brain is still developing in the last weeks of pregnancy. Even in babies born just a little bit early, the brain may not be fully developed. In extremely preterm babies, bleeding in the brain may occur because its blood vessels are fragile and easily injured. Parts of the brain may not grow normally, or the brain may be damaged by lack of oxygen. Brain damage in extremely preterm infants may cause **cerebral palsy**, a

lifelong condition that affects muscle movement. Developmental disabilities, learning problems, and behavioral disorders also may occur but may not be noticed until later in a child's life.

- Vision and hearing—A condition called *retinopathy of prematurity* may cause poor vision or blindness. Hearing disorders are common in preterm babies. Some hearing problems are caused by the brain not being able to process sounds.
- **Immune system**—Because their immune systems are not finished developing, extremely preterm infants run the risk of serious infections that can be life threatening.
- Digestion—Preterm infants are at risk of a digestive condition called *necrotizing enterocolitis (NEC)*. NEC damages the tissues of the digestive tract. Treatment, which may include surgery, is needed to help the tissues heal and to prevent infection. Babies who have had NEC may have lifelong digestive problems requiring medical care.
- Body temperature—In the last weeks of pregnancy, babies develop a layer of fat that helps them stay warm after birth. The skin thickens to adapt to cooler temperatures outside the mother's body. Extremely preterm babies may not be able to stay at a normal body temperature and will need help keeping warm.

Specialized Health Care

Extremely preterm birth usually is managed by a team of specialized health care professionals. In addition to your obstetrician or other pregnancy care professional, the team may include a *maternal-fetal medicine subspecialist* (an obstetrician with additional training and experience in caring for women with high-risk pregnancies) and a *neonatologist* (a pediatrician with additional training in treating sick newborns). Pediatric subspecialists in heart and lung problems, eye problems, or other areas also may form part of the health care team.

Because of the possible need for urgent medical care for you and your preterm infant at birth, you may be transferred to a hospital that offers specialized care. If time allows, this transfer may take place before delivery. High-level *neonatal intensive care units (NICUs)* provide care for infants with serious health problems. High-level maternal care facilities care for women with high-risk pregnancies. These units are specially equipped and have staff with advanced training in managing preterm birth.

Management of Extremely Preterm Birth

If your baby is expected to be born very early, you and your health care team will work together to form a plan about the care you and your baby will receive. This involves weighing the risks and benefits of the available treatment options for both you and your baby. You also will need to think about your personal beliefs and values and what your wishes are for your baby.

Assessment

Your medical team will evaluate your condition and the likely condition of the baby. The team will assess your baby's chances of survival, how sick the baby is likely to be after birth, and the baby's risk of long-term health problems. Information from the NICHD and other organizations for babies the same gestational age as yours may be used to estimate the range of outcomes that are likely.

Treatment Options

The team will provide guidance about the medical care that is likely to help your baby. They also will discuss whether any laws need to be followed about providing life-saving care for the baby. These laws vary from state to state. Some hospitals also have policies that are followed in these situations. The benefits and risks of each option will be discussed. Your health, including the risk of complications for future pregnancies, also should be considered.

Resuscitation. Extremely preterm infants will not survive without *resuscitation*. Often this means helping the baby breathe by inserting a tube into his or her airway. Steps may be taken to start the baby's heart. Even with resuscitation efforts, some babies will not survive. Those who do may have severe disabilities. It is not

possible to predict before delivery which infants will respond to resuscitation and which will not. However, babies born before 23 weeks of pregnancy typically do not survive even with resuscitation.

In some cases, after discussion with the health care team, a family may decide that resuscitation is not the best option for their baby. For example, a family may make this choice if resuscitation is not likely to help the baby survive or if the risks of severe disability are very high. In situations like this, medical care will focus on keeping the baby warm and comfortable and ensuring that the baby is free from pain.

Medications. If resuscitation of the baby is planned or being considered, medications given to the pregnant woman may improve the baby's chances of survival and reduce the risk of disability. These medications include the following:

1. **Corticosteroids** to help the baby's lungs and other organs mature
2. **Magnesium sulfate** to decrease the risk of cerebral palsy
3. **Tocolytic** medications to help prolong pregnancy for a few hours or days to give time for the first two drugs to work
4. **Antibiotics** to prevent infection

Recommendations for giving these medications are made on a case-by-case basis. For example, corticosteroids are not recommended when delivery is expected at 22 weeks of pregnancy or earlier because they have not been found to be helpful. At 23 weeks of pregnancy, corticosteroids may be considered, but whether they will help is uncertain.

Cesarean Delivery. Babies at risk of extremely preterm birth may not be in a good position in the *uterus* to allow for a safe vaginal delivery. In these cases, a **cesarean delivery** may be recommended depending on gestational age. Cesarean delivery is rarely recommended before 23–24 weeks of pregnancy because it is unlikely to affect the outcome.

Forming a Treatment Plan

With support from family members and others you choose, you will need to think about what your wishes are for your baby and for your own care. Although the decisions about your baby's care after delivery can be shared between you and the baby's other parent, decisions about your care during pregnancy rest only with you.

Together, you and your health care team will decide on a plan of care. This care plan may change as circumstances change. For instance, care plans may be adjusted after the baby is born when more information is known about the baby's condition. Care decisions also may change depending on how the baby responds to treatment.

Making Decisions

Making decisions about your and your baby's care can be very difficult. Your health care team is trained to give medical guidance and to include your and your family's wishes and preferences in the decision-making process. Your culture, values, and religious beliefs all are important to consider when making these decisions. You may want to seek support from family, trusted friends, and clergy. The hospital may offer counseling services for you and your family. Many hospitals have programs that put you in touch with parents who have been through the same situation and who can listen to your concerns.

Extremely premature delivery can affect your own health as well. A cesarean delivery can increase the risk of complications in future pregnancies. Prolonging pregnancy may worsen some medical conditions, such as **preeclampsia**, or put you at risk of infection. These health consequences also should be considered in care decisions.

Given the risks to both your health and the baby's health, if delivery is likely to occur before 24 weeks of pregnancy, another option is to end the pregnancy. Your health care team can provide information and counseling about this option.

Ideally, there will be enough time to process all of this information and make an informed decision. But delivery may happen suddenly. You may need to make decisions quickly. Your health care team will do its best to make sure that you are given all of the information about the baby's condition as soon as possible after birth.

If you decide to withdraw or withhold life-saving care, measures will be taken to make sure the baby is kept warm and comfortable. You will be able to spend as much time as you want with your baby. Nurses and other staff can help you create keepsakes, such as taking pictures and making footprints. Your health care team will make sure that you get the help and support you need.

Caring for a Preterm Baby

If Your Baby Does Not Survive

Parents who lose a newborn experience pain, guilt, and depression and need support. When dealing with your grief, remember you are not alone. A number of people have the knowledge and skills to help you. Ask members of your medical team to direct you to support systems in your community. These can include childbirth educators, self-help groups, social workers, and clergy. Take time to find the type of support that suits you best.

Many grieving parents find it helpful to get involved with groups of parents who have gone through the same loss. Members of such groups respect your feelings, understand your stresses and fears, and have a good sense of the type of support you need.

Professional counseling also can help. Talking with a trained counselor can help you understand and accept what has happened. You may wish to get counseling for yourself only, for you and your partner, or for your entire family. You also can find online support groups for parents who just want to read about how others have coped with this difficult situation.

Most extremely preterm babies spend months in the hospital. After they are discharged, many will need ongoing, specialized medical care. There are pediatricians who specialize in the care of preterm babies from birth through childhood. Some clinics focus on follow-up care for preterm babies. The doctor will closely watch how your baby grows and check to see if any other problems develop during childhood.

Many agencies provide help for parents caring for preterm babies. It is a good idea to become as informed as you can so you can give your baby the best care. As your child reaches school age, you may need to find a special school or teachers to help with any learning problems.

Finally...

If you give birth to an extremely preterm baby, you will be faced with many decisions. You will need medical guidance and emotional support. In addition to your family members, other individuals who offer support, and your medical team, you may want to talk to counselors, social workers, or other health professionals who can assist you during this difficult time.

Glossary

Antibiotics: Drugs that treat certain types of infections.

Apnea of Prematurity: A condition affecting preterm babies in which breathing stops for periods of 15–20 seconds or longer.

Cerebral Palsy: A long-term disability of the nervous system that affects young children in which control of movement or posture is abnormal and is not the result of a recognized disease.

Cesarean Delivery: Delivery of a baby through surgical incisions made in the mother's abdomen and uterus.

Corticosteroids: Medications given to help fetal lungs mature, for arthritis, or for other medical conditions.

Ductus Arteriosus: A fetal blood vessel that allows blood to bypass the fetal lungs. It usually closes soon after birth.

Gestational Age: The age of a pregnancy, usually calculated from the number of weeks that have elapsed from the first day of the last normal menstrual period and often using findings from an ultrasound examination performed in the first or second trimester of pregnancy.

Immune System: The body's natural defense system against foreign substances and invading organisms, such as bacteria that cause disease.

Magnesium Sulfate: A drug that may help prevent cerebral palsy when it is given to women in preterm labor who are at risk of delivery before 32 weeks of pregnancy.

Maternal-Fetal Medicine Subspecialist: An obstetrician-gynecologist with additional training in caring for women with high-risk pregnancies; also called a perinatologist.

Necrotizing Enterocolitis (NEC): Severe inflammation affecting the digestive tract that is most commonly found in preterm babies.

Neonatal Intensive Care Units (NICUs): Specialized area of a hospital in which ill newborns receive complex medical care.

Neonatologist: A pediatrician who specializes in the diagnosis and treatment of disorders that affect newborn infants.

Oxygen: A gas that is necessary to sustain life.

Preeclampsia: A disorder that can occur during pregnancy or after childbirth in which there is high blood pressure and other signs of organ injury, such as an abnormal amount of protein in the urine, a low number of platelets, abnormal kidney or liver function, pain over the upper abdomen, fluid in the lungs, or a severe headache or changes in vision.

Preterm: Born before 37 completed weeks of pregnancy.

Respiratory Distress Syndrome (RDS): A condition of some babies which causes breathing difficulties because the lungs are not mature.

Resuscitation: Medical procedures that restore life to someone who appears to be dead.

Retinopathy of Prematurity: A condition affecting the blood vessels in the part of the eye that sends images to the brain; it can cause permanent visual problems and blindness in preterm infants.

Surfactant: A substance produced by cells in the respiratory system that contributes to the elasticity of the lungs and keeps them from collapsing.

Tocolytic: A drug used to slow contractions of the uterus.

Uterus: A muscular organ located in the female pelvis that contains and nourishes the developing fetus during pregnancy.

This Patient Education Pamphlet was developed by the American College of Obstetricians and Gynecologists. Designed as an aid to patients, it sets forth current information and opinions on subjects related to women's

