

Early Infant/Neonatal Death

(Courtesy of March of Dimes Resource Center)

When a baby dies in the first 28 days of life, it is called neonatal death. In the United States in 2006, about 19,000 babies died in their first month (1).

As parents attempt to cope with a loss, they may have many questions about what happened to their baby. The following may help parents discuss the loss of their baby with their health care providers.

What are the most common causes of neonatal death?

Premature birth (before 37 completed weeks of pregnancy) is the most common cause of neonatal death. Prematurity and its complications cause about 25 percent of neonatal deaths (2). The later a baby is born, the more likely he is to survive. Almost 30 percent of babies born at 23 weeks of pregnancy survive, while about 50 to 60 percent of babies born at 24 weeks, about 75 percent born at 25 weeks, and more than 90 percent born at 27 to 28 weeks, survive (3,4,5).

More than 12 percent of babies born in the United States each year are premature (6). The causes of premature birth are not thoroughly understood. Three groups of women are at greatest risk for premature birth:

- Women who have had a previous premature birth
- Women who are pregnant with twins, triplets or more
- Women with certain uterine or cervical problems

In some cases, a pregnant woman may have health problems (such as high blood pressure), pregnancy complications (such as placental problems) or lifestyle factors (such as smoking) that increase her risk of delivering prematurely. More often, preterm labor develops unexpectedly in a pregnancy that had been problem-free.

Premature babies, especially those born at less than 32 weeks of pregnancy and weighing less than 3 1/3 pounds, may

develop serious complications that can sometimes cause neonatal death. Some of these complications include:

- **Respiratory distress syndrome (RDS):** About 16,000 babies develop this breathing problem each year (7). Babies with RDS have immature lungs that lack a protein called surfactant that keeps small air sacs in the lungs from collapsing. Treatment with surfactant has greatly reduced the number of babies who die from RDS. However, about 825 babies a year die in the neonatal period due to RDS (1).
- **Intraventricular hemorrhage (IVH):** Premature babies sometimes develop bleeding in the brain. While mild brain bleeds usually resolve themselves with no or few lasting problems, severe bleeds often result in brain damage or even death.
- **Necrotizing enterocolitis (NEC):** Some premature babies may develop this intestinal problem, a serious inflammation of the bowel. It often resolves after treatment with antibiotics and, sometimes, surgery. However, some babies develop severe bowel damage and die.
- **Infections:** Premature babies have immature immune systems and sometimes develop serious infections, such as pneumonia (lung infection), sepsis (blood infection) and meningitis (infection of membranes surrounding the brain and spinal cord). In spite of treatment with antibiotics and antiviral drugs, some babies die.

While deaths due to prematurity are still too common, the outlook for premature babies is improving. Surfactant and other treatments are saving more premature babies after birth. And treatment before birth can sometimes prevent or lessen the complications of prematurity. Women who are likely to deliver between 24 and 34 weeks of pregnancy can be treated at least

several days before delivery with drugs called corticosteroids, which speed maturation of fetal lungs (8). Studies show this treatment reduces RDS, brain bleeds and infant deaths (8).

Birth defects cause about 20 percent of neonatal deaths (2). Babies with birth defects may be premature or full term. Sometimes parents learn about their baby's birth defects before birth from prenatal tests, such as ultrasound, amniocentesis and chorionic villus sampling (CVS).

Ultrasound uses sound waves to take a picture of the fetus. It can help diagnose structural birth defects, such as spina bifida (open spine), anencephaly (brain and skull defect), and heart or kidney defects. In amniocentesis, the doctor inserts a thin needle through the abdomen to obtain a small sample of amniotic fluid for testing. In CVS, the doctor takes a tiny sample of tissue from the developing placenta, either using a thin tube that is inserted through the vagina or a needle that is inserted through the abdomen. Amniocentesis and CVS are used to diagnose chromosomal abnormalities, such as Down syndrome, and many genetic birth defects.

Other causes of neonatal death include problems related to:

- Complications of pregnancy (such as preeclampsia, a pregnancy-related form of high blood pressure)
- Complications involving the placenta, umbilical cord and membranes (bag of waters)
- Infections
- Asphyxia (lack of oxygen before or during birth)

Which birth defects most commonly cause neonatal death?

Leading causes of birth defect-related neonatal death include:

- **Heart defects:** These are the most common birth defect-related causes of infant death (deaths that occur in the first year of life) (1). Heart defects cause about 25 percent of infant deaths (1). About 1 in every 125 babies is born with a heart defect (9). Because of

improvements in the surgical treatment and medical management of heart defects, most affected babies survive and do well. However, some babies with severe heart defects may not survive until surgery or may not survive the surgery. Many babies who die of heart defects in the first month of life have a specific heart defect called hypoplastic left heart syndrome. In this heart defect, the main pumping chamber of the heart is too small to supply blood to the body. New surgical procedures and heart transplantation are saving more babies with this heart defect, but many still die. In most cases, doctors do not know why a baby is born with a heart defect, although both genetic and environmental factors are believed to play a role.

- **Lung defects:** A baby may be born with malformations or underdevelopment of one or both lungs. In most cases, lung defects occur because other birth defects (such as congenital diaphragmatic hernia) or pregnancy complications (such as lack of amniotic fluid) interfered with lung development. Many babies die due to complications that occur in immature lungs as a result of premature birth.
- **Chromosomal abnormalities:** Humans normally have 46 chromosomes. Chromosomes are tiny, thread-like structures in our cells that carry our genes. Sometimes a baby is born with too many or too few chromosomes. In most cases, an embryo with a chromosomal abnormality does not survive, and the pregnancy ends in miscarriage. In other cases, the baby survives until birth but dies in the early weeks of life. For example, babies with an extra copy of chromosome 18 or chromosome 13 (called trisomy 18 or trisomy 13) have multiple birth defects and generally die in the first weeks or months of life. Babies with less severe chromosomal abnormalities, such as Down syndrome (trisomy 21), often survive, although affected children have

intellectual disabilities and, often, heart defects and other health problems.

- **Brain and central nervous system defects:** One example is anencephaly, in which most of the brain and skull are missing. Affected babies may be stillborn (the fetus dies before birth) or die in the first days of life. This birth defect often can be detected before birth with a blood test, ultrasound or amniocentesis. Anencephaly may be prevented in later pregnancies when a woman takes the B vitamin folic acid before and in the early months of pregnancy. A woman who has had a baby with anencephaly, or a related birth defect called spina bifida, should consult her health care provider before getting pregnant again to find out how much folic acid to take. Generally, a higher-than-normal dose is recommended (usually 4 milligrams) (10).

What happens after a baby dies?

Grieving parents can see or hold their baby after death. Some parents may find this comforting, but others may feel this is too upsetting. Parents should do what feels right to them. Providers may ask if the parents want certain mementos of their baby, such as a lock of hair, footprints, photos or a receiving blanket. Even if looking at these things around the time of death is painful, parents may eventually treasure these remembrances. Hospital staff also may provide information on options for burial or memorial services.

The baby's doctors can tell parents what is known about the cause of the baby's death. They may suggest an autopsy (internal examination after death) to find out more. An autopsy reveals new information about why the baby died in more than one-third of all cases (11). This information can be helpful for parents when they are planning another pregnancy and could possibly improve care in a future pregnancy.

Some parents are not comfortable with an autopsy and may choose not to have one. In these cases, other tests can help determine

why the baby died. These tests include X-rays, an examination of the placenta and umbilical cord, and genetic tests. Some of these tests also are done along with an autopsy.

The doctors who cared for the newborn usually meet with the parents about 4 to 6 weeks after the baby's death to discuss test results. At this time, they can answer the parents' questions in detail. Doctors also can refer the family to counselors or support groups.

Parents whose baby had a birth defect should consider consulting a genetic counselor. These health professionals help families understand what is known about the causes of a birth defect and the chances that future babies could have the same birth defect. Genetic counselors can provide referrals to medical experts, as well as to appropriate support groups in the community. Genetic counseling is available at most large medical centers and teaching hospitals. To find a genetic counselor in their area, individuals can ask their health care provider or go to the Web site of the [National Society of Genetic Counselors](#).

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