

IMPORTANT UPDATES + NOTICE OF VENDOR DATA EVENT

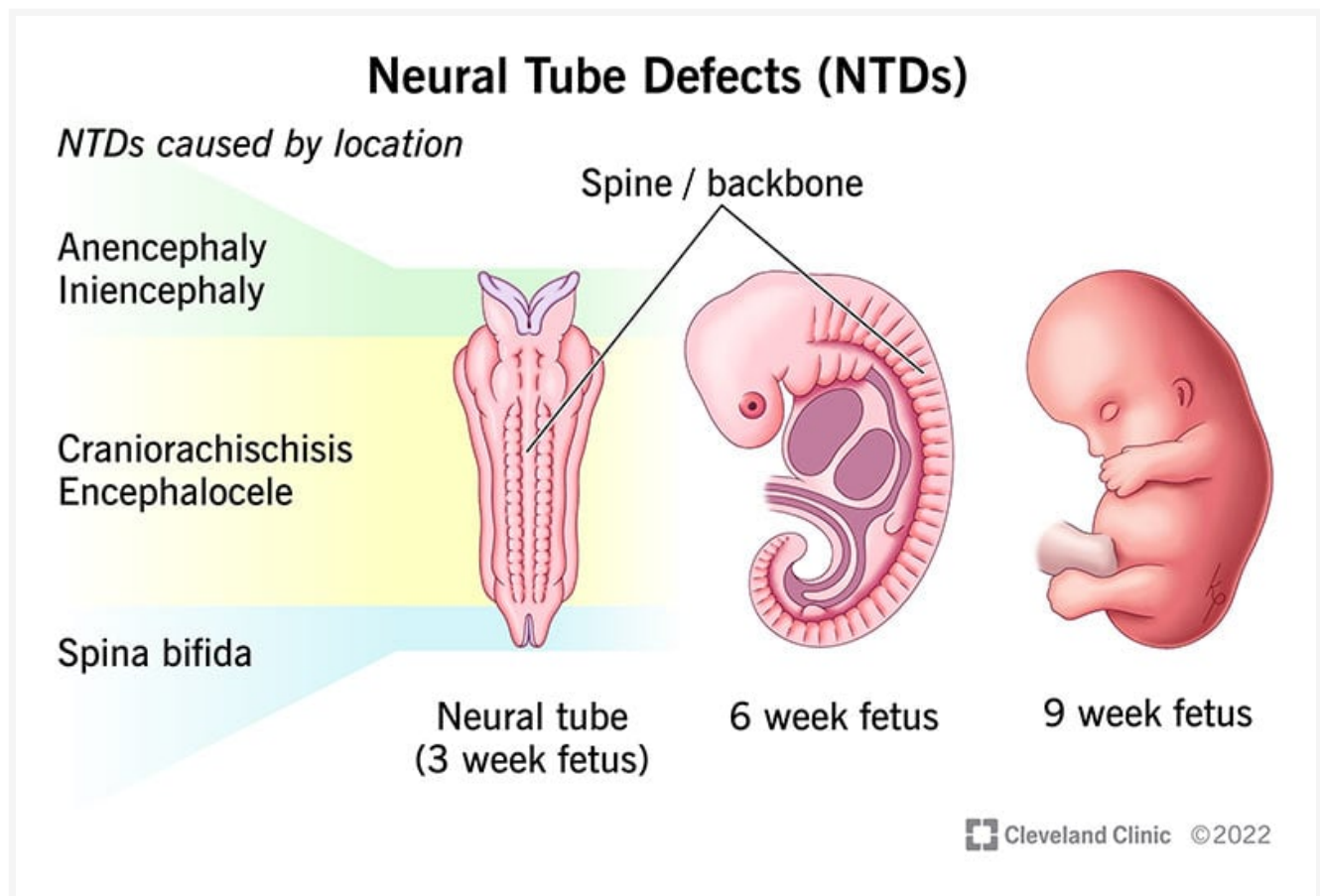


Neural Tube Defects (NTD)

Neural tube defects (NTDs) are birth defects of the brain, spine or spinal cord that happen in fetuses within the first month of pregnancy. NTDs are linked to folate (folic acid) deficiency before and during pregnancy, so it's important to make sure you're getting enough folate through supplements and in your diet before and during pregnancy.

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OVERVIEW



Neural tube defects (NTDs) happen to developing fetuses within the first month of pregnancy. An NTD happens when the neural tube doesn't close completely somewhere along its length.

What is a neural tube defect?

Neural tube defects (NTDs) are [birth defects](#) (congenital conditions) of the brain, spine or [spinal cord](#). They happen to developing fetuses within the first month of pregnancy – often before you even know you're [pregnant](#). The two most common neural tube defects are [spina bifida](#) and [anencephaly](#).

Normally, during your first month of pregnancy, the two sides of the fetus's spine (backbone) join together to cover and protect the spinal cord, spinal nerves and meninges (the tissues covering the spinal cord). At this point, the developing brain and spine are called the neural tube.

As development progresses, the top of the neural tube becomes the brain, and the rest of the tube becomes the spinal cord. An NTD happens when this tube doesn't close completely somewhere along its length.

What are the types of neural tube defects (NTDs)?

There are several types of neural tube defects, including:

- Spina bifida.
- Anencephaly.
- Encephalocele.
- Iniencephaly.

Spina bifida

Spina bifida is the most common type of neural tube defect (NTD). It happens when the neural tube doesn't close completely somewhere along the spine during fetal development.

There are a few different types of spina bifida, including:

- **Myelomeningocele (open spina bifida):** This NTD is characterized by incomplete neural tube closure and a fluid-filled sac that protrudes (sticks out) from your baby's back. The sac contains part of their spinal cord, meninges, nerves and cerebrospinal fluid (CSF). Myelomeningocele is the most severe and the most common form of spina bifida.
- **Meningocele:** This NTD is characterized by a sac of fluid that protrudes through an opening in your baby's back, but their spinal cord is not involved or damaged.
- **Spina bifida occulta:** This NTD is characterized by a small gap in your baby's spine, but there isn't an opening or sac on their back. Their nerves and spinal cord aren't damaged, and the condition usually doesn't cause any disability. This is the mildest form of spina bifida.

Anencephaly

Anencephaly happens when the fetus's neural tube doesn't close at the top during fetal development. This causes the skull, scalp and brain not to develop properly, and portions of the brain and skull are missing. The brain tissue that does form is

usually exposed because there isn't enough skin and bone to cover it. Infants with anencephaly are either [stillborn](#) or die soon after birth.

Encephalocele

Encephalocele happens when the neural tube doesn't close near the brain, and there's an opening in the skull. The fetus's brain and the membranes that cover it can protrude through the skull, forming a sac-like bulge. In some cases, there's only a small opening in the nasal cavity or forehead area that's not noticeable.

Iniencephaly

Iniencephaly happens when the spine is severely malformed (misshapen). It often causes a lack of a neck, and your baby's head is bent severely backward. The skin of your baby's face is connected to their chest, and their scalp is connected to their back. Babies with iniencephaly are usually stillborn.

Who do neural tube defects affect?

Neural tube defects (NTDs) are birth defects (congenital conditions), so they develop in fetuses. NTDs develop within the first month of pregnancy.

How common are neural tube defects?

Neural tube defects (NTDs) occur in about **3,000 pregnancies** each year in the United States. To put that into perspective, there were approximately **3,605,000 births** in the U.S. in 2020.

The two most common NTDs are spina bifida and anencephaly. Spina bifida affects about 1,500 babies a year in the U.S., with myelomeningocele being the most common form. Anencephaly affects about 1,000 babies each year in the U.S.

Encephalocele and iniencephaly are both rare NTDs.

SYMPTOMS AND CAUSES

What causes neural tube defects (NTDs)?

Healthcare providers and scientists don't yet know the exact cause of neural tube defects (NTDs), but they believe it's a complex combination of genetic, nutritional and environmental factors.

In particular, low levels of folic acid in a person's body before and during early pregnancy appear to play a part in this type of congenital condition. Folic acid (or folate) is important for the fetal development of the brain and spinal cord.

What are the symptoms of neural tube defects (NTDs)?

Each type of neural tube defect (NTD) has different symptoms.

Some babies with NTDs have no symptoms, while others experience serious disabilities. Babies with iniencephaly and anencephaly are typically stillborn or die shortly after birth due to complications from the defect.

General symptoms of NTDs can include:

- Physical problems, such as [paralysis](#) and urinary and bowel control issues.
- Blindness.
- [Deafness](#).
- [Intellectual disability](#).
- Lack of consciousness and, in some cases, death.

If your healthcare provider suspects that the fetus you're carrying has a neural tube defect, your medical team will be able to provide more information about what to expect. NTDs affect each baby differently.

What are the signs of neural tube defects (NTDs) during pregnancy?

If you're pregnant with a fetus that has a neural tube defect (NTD), you won't experience any symptoms directly related to it.

When you undergo a fetal ultrasound, your healthcare provider will look for certain signs of the fetus's health and development depending on its fetal age, including looking for signs of NTDs in the spine and head. Healthcare providers can usually diagnose NTDs with an ultrasound.

DIAGNOSIS AND TESTS

How are neural tube defects (NTDs) diagnosed?

Healthcare providers typically diagnose neural tube defects (NTDs) during pregnancy through prenatal tests, such as ultrasound.

What tests will be done to diagnose neural tube defects (NTDs)?

Healthcare providers use the following tests to help diagnose neural tube defects (NTDs) before birth:

- **Blood test:** Your healthcare provider will order a screening test that measures the amount of alpha-fetoprotein (AFP) in your blood during the 16th to 18th week of pregnancy. The amount is higher than normal in about 75% to 80% of pregnant people who are carrying a fetus with an NTD. If your level is elevated, your healthcare provider will order other tests, such as an ultrasound, to better evaluate the growing fetus.
- **Fetal (prenatal) ultrasound:** An ultrasound during pregnancy is the most accurate method to diagnose several NTDs. Healthcare providers typically recommend ultrasounds during the [first trimester](#) (11 to 14 weeks of pregnancy) and [second trimester](#) (18 to 22 weeks of pregnancy).
- **Amniocentesis:** Healthcare providers use this test to check for NTDs and other birth defects. During amniocentesis, they use a needle to remove a sample of

fluid from the amniotic sac that surrounds the fetus. You can get this test at 15 to 20 weeks of pregnancy. This test carries certain risks. Be sure to talk to your healthcare provider about the process.

Healthcare providers also use imaging tests, such as an [MRI \(magnetic resonance imaging\)](#) or [CT \(computed tomography\) scan](#), to diagnose some NTDs after birth.

MANAGEMENT AND TREATMENT

How are neural tube defects (NTDs) treated?

There are several treatment options for spina bifida and encephalocele depending on the severity of the condition.

There isn't a treatment for anencephaly or iniencephaly. Infants with these conditions are typically stillborn or die shortly after birth.

Treatment for spina bifida and encephalocele

Treatment for both spina bifida and encephalocele depends on the severity of the condition and if your baby has other complications. Surgery is a common option for both conditions.

Healthcare providers typically treat encephalocele with surgery to place the protruding part of your baby's brain and the membranes covering it back into their skull. They then close the opening in your baby's skull.

Treatment for myelomeningocele, the most common form of spina bifida, typically involves surgery to repair the opening in your baby's spine. Healthcare providers can perform surgery before birth ([fetal surgery](#)) or shortly after birth (postnatal surgery).

Long-term treatment for both conditions depends on your child's condition. They may need multiple surgeries over time and other treatments related to

complications, such as a shunt to treat [hydrocephalus](#) (excess fluid surrounding their brain).

PREVENTION

What are the risk factors for developing a neural tube defect (NTD)?

Any person can have a baby with a neural tube defect (NTD). But certain factors make you more likely to have a baby with an NTD, including:

- **[Folate \(folic acid\) deficiency](#):** Folate, the natural form of vitamin B-9, is important for healthy fetal development. A folate deficiency before and during pregnancy increases the risk of having a baby with spina bifida and other NTDs. If you're pregnant or thinking of becoming pregnant, it's important to take prenatal vitamins to ensure you're getting enough folate (folic acid) and other nutrients to support a healthy pregnancy. The Centers for Disease Control and Prevention (CDC) recommends all people who can become pregnant take 400 micrograms (mcg) of folic acid every day, in addition to eating food with folate, to help prevent NTDs.
- **Family history of neural tube defects:** People who've had one baby with an NTD have a 2% to 3% increased risk of having a second baby with an NTD. To learn more about your risk of having a baby with an NTD, consider seeing a genetic counselor.
- **Certain antiseizure medications:** These medications are linked to neural tube defects when taken during pregnancy. If you take medicine to prevent seizures, talk to your healthcare provider before you get pregnant about how the medicine may affect your pregnancy.
- **[Diabetes](#):** People with poorly managed diabetes who are pregnant have a higher risk of having a baby with an NTD.
- **[Obesity](#):** People who have obesity before pregnancy have an increased risk of having a baby with an NTD.

- **Increased body temperature in early pregnancy:** Increases in core body temperature ([hyperthermia](#)) in the early weeks of pregnancy due to a prolonged [fever](#) or use of a sauna or hot tub have been associated with a slightly increased risk of NTDs.
- **[Opioid](#) use in early pregnancy:** Opioids are a class of very powerful and highly addictive drugs that reduce pain. People who are pregnant and who've taken opioids in the first two months of pregnancy have an increased chance of having a baby with an NTD, in addition to other complications. If you're pregnant and taking any drugs or medications that may be an opioid, tell your healthcare provider right away.

OUTLOOK / PROGNOSIS

Can a baby live with a neural tube defect?

Yes, your baby can live with certain neural tube defects, including spina bifida and encephalocele.

Babies with anencephaly and iniencephaly are typically stillborn or die shortly after birth, however.

What is the prognosis (outlook) for neural tube defects (NTDs)?

For babies with spina bifida, especially myelomeningocele, or encephalocele, there's a high likelihood of nerve damage, which can cause paralysis and other issues. The nerve damage and loss of function that are present at birth are usually permanent. But there are a number of treatments that can sometimes prevent further damage and help with complications.

Some babies with spina bifida have no or minimal complications.

LIVING WITH

How do I take care of my baby with a neural tube defect?

It's important to remember that no two people with a neural tube defect (NTD), especially spina bifida and encephalocele, are affected in the same way. It's impossible to predict how your baby will be affected. The best way you can prepare is to talk to healthcare providers who specialize in researching and treating your baby's condition.

As they grow, your child may benefit from a team of healthcare providers who can care for their needs. It's important to advocate for your child and to arrange the best medical care possible.

When should I see my healthcare provider about neural tube defects (NTDs)?

If your child was born with a neural tube defect (NTD), they'll likely need to see their healthcare provider — or team of healthcare providers — regularly throughout their life.

If you take antiseizure medication or opioids, it's important to talk to your healthcare provider before becoming pregnant about how these medications could affect your pregnancy and the likelihood of having a child with an NTD.

A note from Cleveland Clinic

Learning that the fetus you're carrying has a neural tube defect (NTD) is scary and overwhelming. But know that you're not alone — many resources are available to help you and your family. It's important that you speak with a healthcare provider who's very familiar with neural tube defects so you can learn more about how your baby will be affected and how to prepare.



Medically Reviewed

Last reviewed by a Cleveland Clinic medical professional on 03/30/2022.

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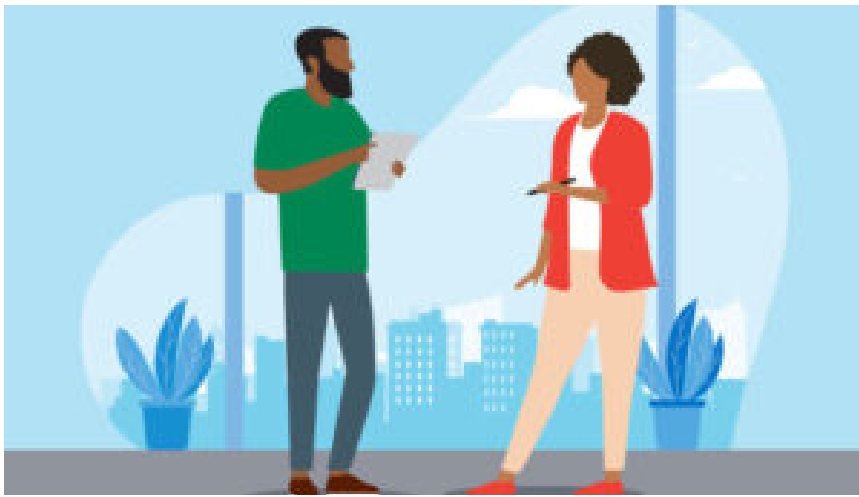
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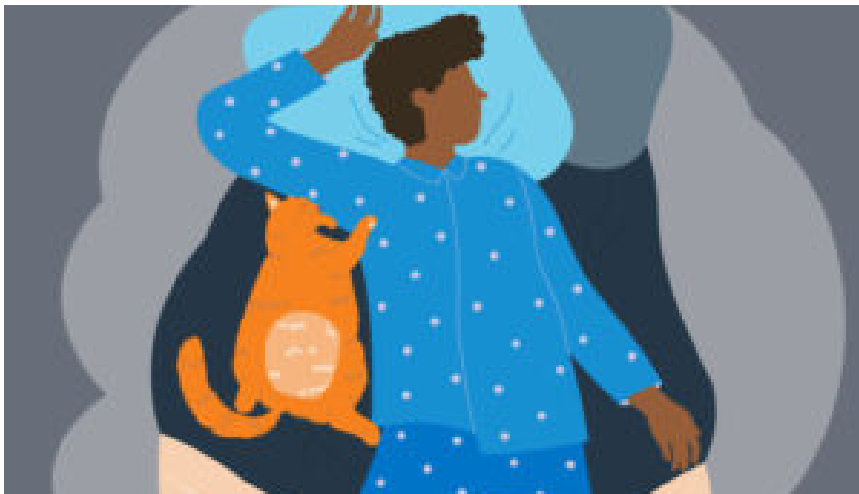
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