

ANENCEPHALY

March of Dimes • University of South Florida • Florida Department of Health

We are so saddened to hear that your baby has anencephaly. We know this is not easy for you and you may not know how to feel. That's okay. Parents of babies with anencephaly feel shock, denial, grief, and even anger. It is all right to feel this way and no one will blame you. It will get better. You are not alone. Soon you will find lots of people and programs to help you. You may want to join a support group. We hope this information is helpful for you. We wish you all the best.

What is anencephaly?

- Anencephaly (say: an-en-seh-fuh-lee) is when the tube that makes the brain and spine does not close at the top part by the head. This means a baby is born without a brain that is fully formed.
- Babies with anencephaly may be lost early or late in pregnancy or die shortly after birth (a few hours, sometimes a few days at most).
- The problem that causes anencephaly happens in the first month of pregnancy, before many women know they are pregnant.

What caused this to happen?

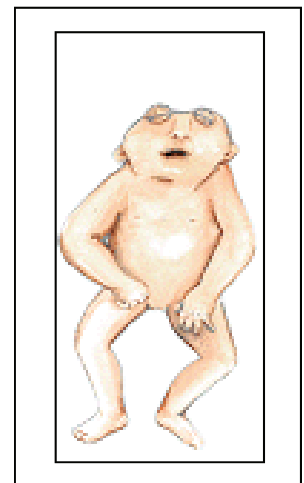
We do not know the cause of anencephaly. Most likely it is caused by a combination of how you live and something that may run in the family.

Is there a cure for anencephaly?

There is no cure or treatment for anencephaly.

How can I create memories of my baby?

- Ask the nurse how you can help care for your baby.
- Give your baby a name.
- Keep your baby's armband.
- Keep baby's cap and blanket.
- Take pictures of your baby.
- Make plaster hands and footprints of your baby.
- Plant a tree in his/her memory.
- Keep a special houseplant in his/her memory.



How will I cope?

- Try not to feel alone. You and your partner should support one another.
- Take one day at a time.
- Take care of yourself.
- Ask your clergy for support or help.
- Join a support group.

Should we try again?

- Give yourself time to make the right decision for you.
- Talk to your partner.
- Be positive. Every pregnancy is different.
- Talk to your doctor about how long you should wait. Your doctor can tell you if your body is ready to try again.
- Ask your doctor about talking to a genetic counselor before you become pregnant. A genetic counselor can:
 - help you understand what we know about anencephaly
 - explain about your chance of having another baby with anencephaly, and
 - tell you about support groups where you live

Will it happen again?

- Now that you have had a baby with anencephaly, your chances of having a baby with anencephaly or with spina bifida are high (refer to spina bifida fact sheet for more information).
- Folic acid, taken before you become pregnant and through the first trimester of pregnancy, may help prevent anencephaly. Folic acid is a B vitamin. It helps your body make new cells.
- Ask your doctor about the right amount of folic acid you will need before you become pregnant. He or she will give you a prescription for the dose of folic acid you will need.
- Take folic acid every day. It is important to take it before and during pregnancy.

Where can I go for help?

- AMEND: Aiding a Mother & Father Experiencing Neonatal Death-www.amendgroup.com
- A Place to Remember: www.aplacetoremember.com
- March of Dimes: visit marchofdimes.com
- National SIDS/Infant Death Resource Center 1-866-866-7437
- Talk to the hospital social worker about counseling services and support groups in your area.

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