

You have been told that your baby has anencephaly. This leaflet has been designed by parents who received that same heartbreaking news and who want to be of help in this troubled time.

### **What is anencephaly ?**

Anencephaly is a congenital birth defect. While the word anencephaly means « without a brain », it does not accurately describe a child with such a defect. Children with anencephaly do have a brain, but it is not fully developed.

A baby with anencephaly is admittedly born with little scalp, cranium vault, or brain, but he or she does usually have part of the cerebral trunk. Your baby's facial features will be complete; however, there will be an opening in the skull. The size varies from child to child. If you look into the opening, you will see some brain tissue. Your baby's head can be covered with a cap if you do not want to see this.

There may be other problems with your baby's body (folded ears, cleft palate, open spine), but usually your baby's body will develop normally.

### **Can a baby with anencephaly live?**

During your pregnancy, your baby will receive everything needed through the mother and so grows well, just like any healthy baby. After birth, however, vital functions cannot be sustained for long. Though breathing is often spontaneous, it is not stable enough.

Many babies with anencephaly live throughout the pregnancy to birth. Still, some die prematurely while others die during the delivery. This is called stillbirth. Those who survive may live a few seconds, minutes, hours, or even days. Sadly, the condition is not correctable or reversible. Anencephaly is always fatal.

### **Why does my baby have anencephaly?**

First, it is not your fault. From the beginning of your baby's development, before you even knew you were pregnant, the nervous system (brain, spinal cord) did not develop normally. It is thought that this is due to a combination of genetic and environmental factors.

### **Where do you go from here?**

Your pregnancy can continue normally because your health is no more at risk than it is during a normal pregnancy. In a few cases, the baby is not able to swallow the fluid in the bag of waters so too much amniotic liquid (hydramnion) is produced. Doctors can remove some of this excess fluid.

Although some parents choose to end their pregnancies early and thus end their babies' lives as well, babies with anencephaly can be born normally.

### **More information:**

Please consider looking at the website <http://www.anencephalie-info.org>.

This site contains much information as well as photos of babies with anencephaly, personal stories, and the opportunity to be in touch with other parents who have had a baby with anencephaly.

### **A carefully considered farewell**

Anencephaly! To be told that your baby has this birth defect is heartbreaking and shocking. There is no other way to describe this terrible news.

Everything you wanted for your baby--your hopes and wishes--are gone with the news of this fatal defect. Nothing will ever be the same again. Your pain and grief are very real and very normal. You will not grieve more if your baby lives longer or less if your baby dies very soon. Grief is intense and can't be avoided or lessened. It may, however, be increased. In our experience, we have never heard of any parents who carried their babies as long as they could who regretted that decision, but we have heard of parents who ended the pregnancy early and did regret that decision very much.

A carefully planned farewell to your child is the first step you can take to deal with that grief.

Take the time to prepare for the birth and death of your baby. Your baby deserves to be welcomed in love and to be given a dignified farewell. Your child is a small human being even if he or she cannot live long.

You can give your baby a name and hold and cradle your baby in your arms when born even if your baby is stillborn. You can admire and cherish your baby. If you cover the opening on the head with a cap or hat, you can focus fully on your child.

Don't forget to take photos and footprints; these will be priceless memories.

Unfortunately, burial or cremation costs are not covered expenses in the USA for our babies. But having even a simple memorial ceremony is an opportunity to say a farewell to your baby. The pain felt at the time is very intense, but you will feel that pain no matter what. For closure or relief of grief, it can be important to have this ceremony and some place to feel your sadness. This can be a burial place, a memorial garden, even a small memory box in your home where you put photos or other things that remind you of your baby. This is an official testimony to your child's reality because your baby is a real human being despite the deformity. If your baby is cremated, you may wish to pick a special place to scatter the ashes, a place of comfort and meaning for you.

### **Will my next baby have a risk of anencephaly?**

In most cases anencephaly is an isolated anomaly. It is very unlikely that it should occur again in the same family. Statistically, the rate of recurrence for a woman who has already had a child with anencephaly is 4%.

It has been shown that the vitamin folic acid can prevent up to 70% of potential cases. So, women who have had one baby diagnosed with

anencephaly should take 4 mg. of folic acid every day before trying to have another baby. It is important to take this daily because many pregnancies are unplanned.

See [www.cdc.gov/ncbddd/folicacid](http://www.cdc.gov/ncbddd/folicacid)

*"It is the time you have wasted on your rose that makes your rose so important.*

...

*You are responsible for your rose."*

Antoine de Saint Exupéry

### **Help and Information:**

The Anencephaly Information website, available in many other languages:

[www.anencephalie-info.org](http://www.anencephalie-info.org)

### **Support groups for families affected by anencephaly:**

Anencephaly Support

[http://groups.yahoo.com/group/Anencephaly\\_Support](http://groups.yahoo.com/group/Anencephaly_Support)

Anencephaly Blessings From Above

<http://groups.yahoo.com/group/AnencephalyBlessingsFromAbove/>

### **Support after the loss of a baby:**

MISS Mothers In Sympathy and Support

<http://www.misschildren.org>

SHARE

<http://www.shareatlanta.org/>

This pamphlet can be downloaded at :

<http://www.anencephalie-info.org/e/download.php>

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## Information on babies with anencephaly



Anouk's footprints  
Baby with anencephaly

*"Hope is not the expectation that things will turn out well, but the conviction that something is worth working for, however it turns out."*

Vaclav Havel