

Getting Help

A midwife can be a good point of contact and companion on your journey. More information about the clinical diagnosis of anencephaly, photos of babies with anencephaly, personal stories of parents who had a baby with anencephaly, points of contact and other helpful links can be found at: www.anencephaly.info

You have received the heartbreaking news that your child has anencephaly. Receiving this diagnosis for your baby is devastating. Your wishes, hopes and expectations for life with your child are suddenly destroyed, replaced by questions and uncertainty. Nothing is as it was before.



Cody, a baby with anencephaly

“Hope is not the expectation that something will turn out well, but the certainty that something is worth working for, regardless of how it turns out.”

VACLAV HAVEL

ANENCEPHALY NETWORK

anencephaly.info

Monika Jaquier
info@anencephaly.info
www.anencephaly.info



Scientific Supervision

Prof. Dr. Harald Goll
Prof. Dr. Josef Römelt

This flyer was designed by parents of babies affected by anencephaly. Photos by Amy McDaniel (Dewdrops Photography) und Michelle Kathrin Weber (Sternenregen Photographie).

Children with Anencephaly



Footprints of Anouk, a baby with anencephaly
Feet of Nahum, a baby with anencephaly

Cody, a baby with anencephaly



What is anencephaly?

The word anencephaly literally means “without a brain,” though this does not accurately describe the condition of babies with anencephaly. A baby affected by anencephaly is missing parts of the skullcap and brain, but the cerebral trunk still exists. The bony part of the forehead typically stops at or just above the eyebrows. The baby’s skull is not fully closed and the size of the opening varies from child to child. The rest of the baby’s body usually develops normally without other defects.

During the pregnancy the baby grows like any other baby and receives all the needed nutrition for growth from the mother. The pregnancy can be continued to term and the health of the mother is generally no more at risk than when carrying a healthy baby. In some cases, there is an excess of amniotic fluid (polyhydramnios) that builds during the pregnancy, which typically carries minimal risk.

Babies with anencephaly can be born alive. However, life-sustaining bodily and vital functions cannot be sustained for long after the birth. About a quarter of affected babies pass away before or during birth. Those that survive have a life expectancy ranging from a few minutes to a few days, and in very rare cases, a few weeks. Unfortunately, there is no cure.

Why does my baby have anencephaly?

In about one of every 1,000 babies, the central nervous system does not develop correctly between the third and fourth week of gestation. Different hypotheses have been developed as to why anencephaly occurs, but a satisfying answer has not yet been found. However, you are not at fault! You did not do, or fail to do, anything that caused your baby to have anencephaly.

Where do you go from here?

You may still be in a state of shock. It can feel impossible to make important decisions about your pregnancy and your baby. At the same time, you are asked to make decisions as soon as possible.

The dilemma is that no matter what you decide, the time with your baby will be short. Please know that you have the right to keep your options open and to take as long as you want to make a decision.

In the case of anencephaly, you are legally permitted to end the pregnancy at any time. Or, you can continue the pregnancy. We (the authors of this flyer) are parents who have found that carrying the baby to term is the right decision for us, and we would like to share it with you because we have found it to be healing and “good” despite the unthinkable awful situation. For some of us, continuing the pregnancy was not our initial intention immediately following the diagnosis. Rather, it was the choice that came slowly as we realized that we could not imagine terminating the pregnancy.

Making your time together meaningful

You may be feeling fearful or uncertain about bonding with your unborn baby. Many of us found it helpful to try and live

each day to the fullest and do things with our babies during our pregnancies that we had hoped to do with them after they were born. Some examples include reading to him/her, singing, traveling, and eating favorite foods. This approach allowed us to make special memories and develop deep relationships with our babies even before they were born.

The months during your pregnancy can be a wonderful time filled with memorable experiences with your child. Your baby is living and growing in your belly and you can parent him/her even before birth.

Birth and farewell

Mixed emotions, like grief, pain and joy often characterize this challenging journey. It is completely normal to feel grief even when you are only in the first or second trimester of your pregnancy. Regardless of how long your baby lives, or does not live, you are going to experience deep grief. This grief cannot be avoided, and it is very important to process these feelings.

We hope you will be encouraged by knowing this: despite the grief, many parents truly treasure the moments with their baby after birth. It is a very special and valuable time.

It is best to prepare for the birth and death of your baby in advance so you can live in the moment when he/she is born. Your baby deserves a loving welcome and a special farewell.

Your baby can be loved and respected despite his/her different appearance. Your child is a human being with dignity even though his/her disability won’t allow for a long life. You can hold your baby in your arms and cradle him – even if your baby has already passed away. You can snuggle and admire your baby, and give him/her kisses. If you want, the opening on your baby’s head can be covered with a small hat, so that you can focus completely on your little baby. If you like, you can take photos as well as hand-prints and footprints of your baby. These will be unforgettable, priceless memories of your baby to keep forever.

A dignified, loving, and special farewell is also possible if the pregnancy is ended prematurely.