

# WHAT A DIAGNOSIS OF ANENCEPHALY MEANS FOR YOUR BABY



## *What is anencephaly?*

**ANENCEPHALY** is a condition that prevents the normal development of the brain and the bones of the skull.

At early stages of development, the neural tube forms and closes, and helps form the baby's brain and skull. Anencephaly happens if the upper part of the neural tube does not close all the way.

As a result, babies with anencephaly are missing large parts of the brain called the cerebrum and cerebellum. The bones of the skull are also missing or incompletely formed.



## WHAT DOES THIS MEAN?

- ♥ Sadly, anencephaly is a life-limiting condition for which there is, at this time, no treatment or therapy.
- ♥ Most babies with anencephaly do live after birth, even for a short time. Recent research found that 72% of babies lived beyond birth although their lives were usually brief. However, research shows that a 25% of babies born alive lived for up to 5 days, while 7% lived for up to 28 days. (*British Journal of Obstetrics & Gynaecology*)
- ♥ There are few things worse than losing a child, and this is a terribly difficult situation for a mother and a family. Parents say that the time they had with their baby, however short, was precious and full of love, and was a pathway to healing.



*"I held her in my tummy, my heart and my arms. Her name was Anouk. She was worth everything."*

**Monika, mother to Anouk,  
born with anencephaly**

# SOME THOUGHTS FOR PARENTS WHO HAVE RECEIVED A DIAGNOSIS OF ANENCEPHALY FOR THEIR CHILD

## **1 A BABY WITH ANENCEPHALY IS A CHILD WITH A DISABILITY**

Babies with anencephaly have a profound disability and have special needs. Like all human beings, they are alive and kicking in the womb where they have protection, warmth, shelter, food and water. There is no form of care that is more intimate or more suited to a child whose life is going to be very short than the safety of a mother's womb.

## **2 A BABY WITH ANENCEPHALY IS NOT BRAIN DEAD**

Babies with anencephaly are not brain dead. Their brainstems are functioning at least in part which is why they can breathe without ventilators, and often survive for several days.

## **3 PERINATAL CARE**

Perinatal care helps parents to make the most of their time with baby before and after birth. It ensures that parents see the same medical team, that a separate room is provided at birth, and that medics, counsellors and photographers help families to make memories with baby. It ensures that a lifetime of love can be poured into hours or days.

## **4 PALLIATIVE CARE IS THE BEST RESPONSE TO TERMINAL ILLNESS**

Babies with anencephaly are human beings with a terminal condition. They are dying babies for whom no curative treatment is possible, but they suffer no pain while in the womb. After birth, the appropriate management of any discomfort is palliative care – food, water, warmth, human company and symptom relief.

## **5 SUPPORT AND HELP IS AVAILABLE FOR FAMILIES**

Support and help is available for mothers and families at this difficult time, including counselling and assistance in making every moment with baby count. Please contact us to ensure you know where to go for the best support and advice possible, or to talk to other mothers who have faced similar difficulties.

## **6 YOU SHOULD FEEL SUPPORTED**

The Bruce Inquiry in Britain revealed that there was sometimes a strong presumption that parents whose babies were diagnosed with a disability would not wish to continue with their pregnancy. This led to subtle or direct pressure being placed on parents who were repeatedly asked to reconsider their decisions. Parents have a right to know that their child's life is valued.

SEE BEAUTIFUL STORIES AT  
[www.everylifecounts.ie](http://www.everylifecounts.ie)



## 7 SAYING GOODBYE PROPERLY IS IMPORTANT FOR RESOLVING GRIEF AND ACHIEVING CLOSURE

Achieving effective closure after the loss of a baby is best achieved if parents are able to spend time with their baby, saying what they would have wanted to say and treasuring the precious moments. See [www.everylifecounts.ie](http://www.everylifecounts.ie) for beautiful testimonies of love and loss.

## 8 ABORTION FOR ANENCEPHALY CAN BE DAMAGING TO A MOTHER'S MENTAL HEALTH

Women who undergo abortion because the baby has a life-limiting condition are more likely to suffer mental health problems afterwards. Recent research from Duke University has found that women who aborted after a diagnosis of anencephaly were significantly more likely to suffer depression and despair than women who carried to term. In these circumstances, these are often late-term abortions: the baby was not unexpected; at this stage, a bond with baby has been established, and there has been no opportunity to say goodbye. There is a better answer than abortion.

*"She was so loved by everyone. People said they were coming to hold an angel."*  
Aileen, mother of Lilly Ann

*"My beautiful little son taught me that imperfection in human beings is something beautiful to be valued. I wouldn't swap that for the world."*

Cliona, mother to John Paul

*"Lillie fought for 35 weeks to say hello and goodbye to us. That was her life, we had that time together. I was able to tell her I loved her; now she is my beautiful angel".*

Tanya, mother to Lillie

# AN EXPERIENCE WHICH CHANGED AN ATTITUDE

Dr Peter Saunders tells of an **EXPERIENCE** he had as a junior doctor which opened his eyes to the value of every child's life. "The administrative clerk on the medical ward where I was working was heavily pregnant and I asked her when she was due. She gave me the date and before I could say anything else said, 'my baby has anencephaly'. While I was inwardly asking why she had not had an abortion, she added, 'I could not bring myself to end the life of my own baby'.

The baby was born a few weeks later and survived about a week. She held it, nursed and cared for it and said her goodbyes before its inevitable death. Up until that point I had not contemplated that such an approach was even possible. She not only demonstrated that it was but **TAUGHT ME A HUGE LESSON ABOUT COURAGE**, compassion and how to face and handle tragedy, grief and bereavement. I have never forgotten it and resolved then that if I was ever in the same situation, I would want to do the same.

I have heard many similar testimonies since from women in similar situations who have made similar decisions and have become even more convinced that this is the best way to handle it (see below). Having a baby with a severe disability changes one's life forever, whatever choice one makes. But choosing to offer a mother's care and compassion to your dependent and severely disabled child, and to be willing to shoulder the inevitable pain of separation and bereavement, is, I believe, **THE BEST WAY THROUGH THIS TRAGIC SITUATION.**"



- Jaquier M, Klein A, Boltshauser E. 'Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly'. BJOG 2006
- <http://perinatalhospice.org/>
- <http://pjsaunders.blogspot.co.uk/2013/02/women-who-seek-to-keep-their-disabled.html>
- <http://thegiftofrachelslife.blogspot.co.uk/2012/07/the-truth-about-anencephaly.html>
- Korenromp, Christiaens, van den Bout, et al, 'Longterm psychological consequences of pregnancy termination for fetal abnormality: across-sectional study', Prenatal Diagnosis, 2005 March 25(3), 253-60, <http://www.ncbi.nlm.nih.gov/pubmed/15791682>
- Kersting, A. 'Grief After Termination of Pregnancy Due to Fetal Malformation', Journal of Psychosomatic Obstetrics and Gynaecology, <http://www.ncbi.nlm.nih.gov/pubmed/15715039>
- Cope, H., Garrett, M. E., Gregory, S., and Ashley-Koch, A. (2015) Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome. Prenat Diagn, 35: 761-768. doi:10.1002/pd.4603 <http://dx.doi.org/10.1002/pd.4603>
- **Personal testimonies and support:** <http://www.anencephalie-info.org>

## REFERENCES



[www.everylifecounts.ie](http://www.everylifecounts.ie)

Dominick Court, 41 Dominick Street Lower, Dublin 1 T: 01 879 2382



/EveryLifeCountsIreland



/EveryLifeCounts



@EveryLifeCount