WHAT A DIAGNOSIS OF ANENCEPHALY MEANS FOR YOUR BABY

Baby Faith Hope

Baby Anouk Jaquier
**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.

“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
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 very brief. The research showed that 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 any 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.
A BABY WITH ANENCEPHALY IS A CHILD WITH A DISABILITY

Babies with anencephaly have a profound disability. They are alive and kicking in the womb where they have protection, warmth, shelter and nourishment. 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.

A BABY WITH ANENCEPHALY IS NOT BRAIN DEAD

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

PERINATAL HOSPICE CARE WILL HELP

Perinatal hospice 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 medical staff, counsellors and photographers help families to make memories with baby. It ensures that a lifetime of love can be poured into hours or days.
PALLIATIVE CARE IS AVAILABLE
Babies with anencephaly are human beings with a terminal condition. They are babies for whom no curative treatment is possible, but there is no evidence that they will suffer any pain while in the womb. After birth, the appropriate management of any discomfort is palliative care – food, water, warmth, human contact and company and symptom relief.

SUPPORT AND HELP IS AVAILABLE FOR FAMILIES
Support and help is available for mothers and families at this difficult time, and the HSE’s Standards on Bereavement Care (2016) offer counselling and support so that you can make every moment with the 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 situations.

YOU SHOULD FEEL SUPPORTED
The Bruce Inquiry in Britain revealed that there was sometimes a presumption that parents whose babies were diagnosed with a disability would not wish to continue with their pregnancy. This could lead to subtle or direct pressure being placed on parents, who have a right to know that their child’s life is valued.

SEE BEAUTIFUL STORIES AT www.everylifecounts.ie
A BRIDGE TO HEALING
Parents have found that spending time with their baby and having their baby’s life valued can help them to cope with grief and be a bridge to healing. Holding, cuddling and talking to baby, and treasuring the precious moments, are vitally important. See more at www.everylifecounts.ie for beautiful testimonies of love and loss.

WHERE ANENCEPHALY HAS BEEN DIAGNOSED, CARRYING THE BABY TO TERM BRINGS BETTER OUTCOMES FOR MOTHERS
Recent research by H. Cope et al. found that there was a psychological benefit for women who continued their pregnancy after a diagnosis of anencephaly. These mothers were significantly less likely to suffer despair, avoidance, depression and distress.

“...that she would be held and loved by everyone. People said they were coming to hold an angel.”
Aileen, mother to Lilly Ann
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’.

The baby was born a few weeks later and survived about a week. She held her baby, nursed and cared for her child, and said her goodbyes. 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.”

“A HUGE LESSON ABOUT COURAGE’

“Lillie fought for 35 weeks to say hello and goodbye to us. That was her life, I was able to tell her I loved her.”

Tanya, mother to Lillie

http://perinatalhospice.org/

HSE, National Standards for Bereavement Care following pregnancy loss and perinatal death (2016)

Parliamentary Inquiry into Abortion on the Grounds of Disability (2013)


Personal testimonies and support: http://www.anencephaly.info/

www.everylifecounts.ie

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Shane Michael: “He taught us a love we had never known before he entered this world”

Lillie: “Her imperfections are beautiful to me. I am blessed to have seen her beautiful face and touched her tiny hand.”

(Baby Lillie was diagnosed with iniencephaly, a neural tube defect similar to anencephaly)