

WHAT A DIAGNOSIS OF **ANENCEPHALY** MEANS FOR YOUR BABY



Baby Faith Hope



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**

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 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.

SOME THOUGHTS FOR PARENTS WHO HAVE RECEIVED THIS DIAGNOSIS

1 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.

2 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.

3 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.

4

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.

5

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.

6

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. Parents have a right to know that their child's life is valued and to the support they need around the time of diagnosis, pregnancy and birth.

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www.everylifecounts.ie



7 **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.

8 **RESEARCH SHOWS TIME WITH BABY CAN HELP WOMEN**

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 women were significantly less likely to suffer despair, avoidance, depression and distress, and the authors noted that "continuing the pregnancy also allows more opportunities to find meaning and for memory making, such as opportunities to hold and care for the baby, take photographs, create other keepsakes and perhaps participate in research, tissue or organ donation, all of which can contribute positively to the grieving process".

"...People said they were coming to hold an angel."

Aileen, mother to Lilly Ann

SHARE YOUR LOVE

RaeAnne Fredrickson's son Samuel lived for four hours after his birth. She shares how to make the most of your time before birth.

While Samuel was with us, we wanted to make the **MOST OF EVERY DAY** we had with him. It's not always easy to share your life with a person you can't hold in your arms, but we found the following things helpful as we bonded with our precious boy.

PLEASE NOTE: Obviously, there is a large range of emotions when carrying a baby that won't live past pregnancy/ birth. You love them endlessly but you are also afraid because your time is short.

Be kind to yourself. Do what feels right to you and don't push it. There were plenty of times I would sob during/after trying to do things with him, because I wanted to keep him so badly. Take it **ONE DAY AT A TIME** and do what is best for you and your baby.

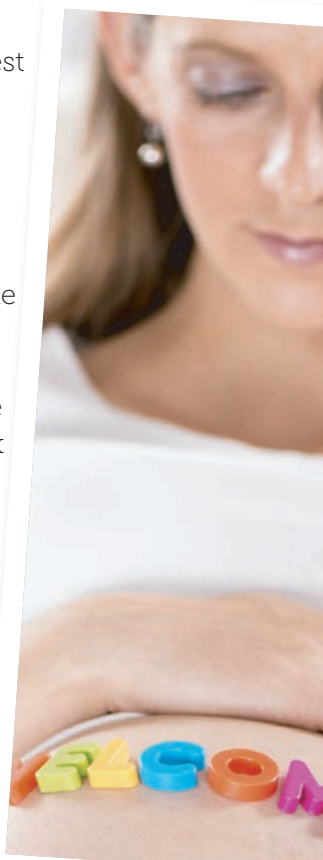
♥ NAME YOUR BABY

♥ READING

Take time to read to your baby every day. They love to hear your voices. We read to Samuel all the time. We had one book in particular we read so often that we memorized it. Then, after he was born and the doctors were working with him, we recited it to him again. I know it helped him relax and know we were close.

♥ SINGING

My husband sang lullabies to Samuel. Singing helps to calm the baby and it will give you a special memory to last forever. (I even made up a few special songs for him. Now that he's gone, I can sing them to myself when I'm really missing him and it helps me feel him with me.)



♥ LOVING WORDS

Take every moment you can to tell your baby just how special they are to you. I love you! I love you! I love you! It can't be over-said. One thing that helps me now that he's gone, (as much as anything can help) is the knowledge that Samuel was loved more in the few months we had with him, than some babies are loved at all. We made sure he knew our love.

♥ MASSAGING / CARESSING

As long as it won't hurt them or aggravate any problems, you can rub your hands along your tummy and gently caress your baby. It's the closest thing you may have to holding them and snuggling, so use this "tummy time" to connect with your little one(s). My husband found that he could give a light "love tap" and then get a kick back from Samuel. This was one of their favourite games.

♥ INTRODUCING

Let siblings, grandparents and other family members talk to your little one. They can be the ones to read a story. They can share their own life stories/experiences with baby. If you're comfortable, you can also allow friends to do the same. Always do what feels comfortable to you. It's perfectly ok for your baby to just know mama and daddy.

♥ NIGHT TIME RITUALS

Every night, Samuel and I would go into his room. I would turn on a CD of soft, instrumental lullabies and dim the lights. Then, after lots of "I love you" and "goodnight, my love" from me, I would snuggle my tummy up in a blankie and rock him to sleep in the rocking chair. (He may not have actually gone to sleep, but it was a special time for us).

Thank you to RaeAnne Fredrickson from "All that love can do".

'A HUGE LESSON ABOUT COURAGE'

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 it."

"We had nine months together, and we had sing-songs, and we went to the park, and we smelled the grass.. and he knew he was with his Mammy and he was loved and snug and warm"

Fiona, mother to Baby Andrew

SAYING **HELLO** & SAYING **GOODBYE** TO YOUR BABY

Making every moment count

Inevitably, the day comes when you say hello and then goodbye. It's such a beautiful and wonderful moment when you say "**HELLO MY LOVE**" When that hello is followed by **GOODBYE**, the pain can seem overwhelming.

The following are suggestions. Do what's best for you and your baby.



♥ **PREPARE FOR LABOUR**

Take classes, there are many options. Find the one that will work best for you.

♥ **MAKE OR BUY A SPECIAL BLANKET FOR YOUR BABY**

You will cherish it forever and, because you hold your baby in it, it may smell like him or her and provide a small comfort as you grieve later.

♥ **BUY A SPECIAL OUTFIT**

Buy a few different sizes, just in case, including preemie. If it's early in your pregnancy, there are lots of websites with very tiny outfit sizes

♥ **BRING ANY SPECIAL BOOKS, OR OTHER ITEMS YOU'LL WANT, FOR PHOTOS WITH YOUR BABY**

♥ **BE SURE TO BRING A CAMERA AND VIDEO CAMERA**

Have someone specific (family, friend, nurse, etc) whose only job is to record your time with the baby. Make sure a video camera is set up to record your time with your baby. You'll want it later, believe me.



- ♥ Bring a **SPECIAL LOTION OR ESSENTIAL OIL FOR YOUR BABY**. It'll be a special time to massage their precious little body and the scent will remind you of them forever.
- ♥ Give your baby a **BATH** and dress him / her.
- ♥ Sleep with them.
- ♥ **TAKE ALL THE TIME YOU NEED**. Don't let anyone rush you.
- ♥ If you have other children, allow them to hold, kiss, see their sibling. Let them see your emotions and talk openly with them about what is happening.
- ♥ Take time to focus on every part of your little one.
- ♥ Rock them, sing to them, read a special story to them, kiss them, and love on them for as long as you'd like.
- ♥ If possible, take a hair clipping, make hand and feet molds (many hospitals will provide them, or you can buy them at craft stores), and make hand and foot prints.
- ♥ Allow all emotions. It's okay to smile and laugh, it's okay to cry and hurt. Allow them as they come. You may even just feel numb.
- ♥ If you would like friends and family to visit, give them time to meet your little one, but also have someone whose job is to get people out of the room if you're feeling overwhelmed, or if you just want some alone time with the baby.
- ♥ Depending on your faith, have the baby baptized, or anything else spiritually important to you.
- ♥ As you prepare to leave the hospital, ask for any/all items your baby had or used that you can keep.
- ♥ Have something to hold when you leave the hospital. A teddy bear or blanket can help as you leave without your baby.

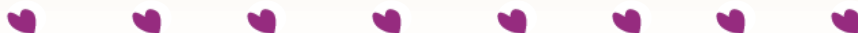


Shane Michael: *"He taught us a love we had never known before he entered this world"*



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)



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- **Personal testimonies and support:** <http://www.anencephaly.info/>



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