WHEN UNBORN CHILDREN HAVE A LIFE-LIMITING CONDITION

Why Every Life Counts

"I was told that she wouldn't live after birth, but she did for 6 days. When you're told you're going to get nothing, to get 6 days is just a miracle......People said they were coming to hold an angel."

Aileen, mother to Lilly Ann, born with anencephaly

There are **several conditions** diagnosed during pregnancy which can mean that a baby **may not live for long after birth,** or that he or she might not make it to birth at all. But those children, until such time as nature takes its course, are alive and kicking, and have the **SAME RIGHT TO LIFE** as every other child.

THE IRISH SITUATION

Recently huge media attention has been given to legalising abortion for unborn babies who have life-limiting conditions. Here's what you need to know:

- Research shows that most Irish parents DO NOT abort their baby following a life-limiting diagnosis when support and best care is made available. A study looking at all Trisomy 18 and Trisomy 13 pregnancies in the region serviced by Cork University Hospital from 2001 to 2012 found that between 94% and 96% of parents continued with the pregnancy.(1) Another 2010 study found that the 'predominant parental choice' after diagnosis of anencephaly was continuation of pregnancy. Figures from the British Department of Health show just 36 abortions were carried out on Irish women because of life-limiting abnormalities in 2011.(2)
- Many of those parents have then been able to spend precious time with their children - both while the baby was in the womb, and then for hours, days and sometimes weeks and months and even years after birth.
- The experience of many parents is that abortion is often suggested for their unborn children. This is unacceptable and contrary to what is best for mother and baby.
- Parents also point out that children with life-limiting disorders have a right to their life, however short it may be, and however severe their disability.
- In contrast to Ireland, up to 95% of children with a disability are aborted in countries where it is legal.(3)

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THE RARE DISORDERS - AND OUTCOMES FOR BABY

These diagnoses are RARE but can ARISE FOR 700 BABIES every year in Ireland - or about 1% of pregnancies. Everyone would feel enormous sympathy for parents faced with a terminal diagnosis for their baby. What many parents are not told, however, is that while their children will have a short life, the time they have with them can be hugely joyful and rewarding.

ANENCEPHALY is a condition that prevents the normal development of the brain and the bones of the skull. 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.4) Clíona Johnson's baby boy, **JOHN PAUL**, lived for just 17 minutes after birth. She says her time with her baby, in the womb and after birth, was used to lay down precious memories which helped her to heal. "He taught me that imperfection in human beings is something beautiful to be valued."

TRISOMY 18 OR EDWARDS SYNDROME arises because of the presence of an extra chromosome. There is a significant risk of miscarriage before birth, but studies have found that children who lived until birth with Trisomy 18 lived an average of 14.5 days; with 39% of babies surviving for more than a month, while 8.4% survived for more than a year.(5) (6)

Here in Ireland, **ELAINE FAGAN**, given just days to live after birth, spent **25 YEARS** with her loving family before her death in 2011. "She has touched so many people. I now know happiness comes from caring and sharing with others. I wouldn't have found that out if I didn't have Elaine. It's thanks to her that I am seeing a lovely side of human nature," said her father Michael.

TRISOMY 13 OR PATAU SYNDROME also arises when the baby has an additional chromosome. There is a significant risk of miscarriage, but research shows that children with Trisomy 13 live an average of 7 days after birth, some 31% live for more than a month, and almost 10% live for more than a year.(5) (6)

KATHLEEN ROSE HARKIN, has now reached her **tenth** birthday living with Trisomy 13, despite being described as 'incompatible with life.' Her mother Tracey says Kathleen Rose "is not incompatible with life - she is the love of our lives".

POTTER'S SYNDROME / RENAL AGENESIS arises when the baby's kidneys fail to develop correctly and a dramatic decrease in amniotic fluid occurs. It has been associated with a very poor outcome but data shows the outlook may be improving. Doctors predicted that infant **ABIGAIL ROSE BEUTLER**, like other babies with Potter's Syndrome, would never breathe on her own and live for, at most, just a few minutes. Doctors used a new treatment of amnioinfusion every week for five weeks, and Baby Abigail is now defying the odds, living and thriving. Her mother, Jamie, says she is a 'miracle baby'.

SUPPORT FOR PARENTS

It's clear that parents in this situation deserve much more than sympathy; they need support systems to be put in place. Every Life Counts is urging the Minister for Health to **ESTABLISH PERINATAL HOSPICE SERVICES** across Ireland as soon as possible. These services would prepare and assist parents facing a diagnosis of severe foetal anomaly, ensure that babies would not suffer pain after birth, and provide counselling and support for parents who have lost their child.

The good news is that perinatal hospice services are not difficult to establish or maintain. Perinatal Hospice Pioneer Dr Byron Calhoun explains that "all the typical hospital needs is a few extra rooms for these families", with nurses, chaplains, neonatologists, social workers, bereavement counselors and a photographer to capture precious moments. **"TIME WITH THE BABY IS EXTREMELY IMPORTANT TO THESE MOMS,"** he said. "Families want a live birth, a chance to hold the baby; to give as much love a child can have in their brief life."

As Dr Calhoun pointed out, "the only alternative parents are given is termination of pregnancy or they're told they are on their own." This should simply not be acceptable for a society which cares for its most vulnerable citizens.

PSYCHOLOGICAL DISTRESS FOR MOTHERS

- Research has shown that aborting a baby with birth defects can be a "**TRAUMATIC EVENT**...which entails the risk of severe and complicated grieving." (7)
- One long-term study found that, for mothers who had aborted babies with life-limiting conditions, "a substantial number...showed pathological scores for post-traumatic stress."(8)
- In contrast, research has found that parent's responses to the support of perinatal hospice are "overwhelmingly positive" (9) .
- As the perinatal hospice movement says: "**TERMINATION IS NOT A SHORTCUT THROUGH GRIEF**"

PROTECT SICK BABIES: LOVE THEM BOTH

Those calling for a change in Irish law want the practices available in Britain to be made legal here. Those practices include what is known as **FETICIDE**, where the baby, alive and kicking in the womb, receives a lethal injection into the heart.

Whether by feticide then, or by some other method of late-term abortion, the lives of babies with profound disabilities are ended, not by allowing nature to take her course, but by the intervention of an abortionist or other medical practitioner. And parents who are already distraught and in shock find themselves involved in the decision to end the life of their child.

Research has shown that some parents do not feel fully informed, many are confused by information given at a traumatic time, and parents can be upset by suggestions that they should abort their baby (10). Misinformation is certainly a real problem, since many parents are led to believe their baby will suffer if they continue with the pregnancy.

This is UNTRUE. If pain is a possibility, it will be treated effectively, and pain can be absolutely minimised by palliative care, while baby is wrapped in comfort and love.

It comes down to this: we can find a better answer than abortion.
It is disturbing to see abortion campaigners attempt to use these sad situations to push their own agenda of abortion on demand. These are **OUR MOST SPECIAL CHILDREN** and we are resolved to work instead towards a solution that **LOVES AND PROTECTS BOTH MOTHER AND BABY.**

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