

# TERMINALLY ILL CHILDREN

/why they have a right to life.

“ She was the most amazing little person I could ever put my eyes on. I kissed her and cried .... but most of all I just loved her and held her. I had the 3 greatest days of my life with this little girl and I could not imagine life without knowing her. ”

*Dawn, whose baby girl Amanda, was born with anencephaly and lived for three days. (Benotafraid.net)*



Baby Faith: born with anencephaly

There are several conditions which, if diagnosed during pregnancy, can mean that the 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.

This factsheet discusses the Irish situation, some of these rare disorders, the outcomes for baby, what support should be provided for parents, and why abortion is not the answer.

## ► The Irish Situation:

Recently huge media attention has been given to legalising abortion in Ireland for babies who have received fatal diagnoses. **While the phrase ‘incompatible with life’ has been used, it’s important to recognise that the phrase does not constitute a medical diagnosis.** It is simply an opinion, often expressed in a manner which is both negative and insensitive to both parents and baby.

- According to the Irish Times, research shows that **90% of Irish parents** do not abort their baby following a fatal diagnosis.<sup>1</sup> 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 after birth.
- On some occasions babies who were not expected to live at all **defied the odds** and continue to amaze their families and doctors.
- The experience of parents that have spoken to the Life Institute is that the Irish medical system encourages abortion for children with a fatal diagnosis. This is unacceptable and contrary to what is best for mother and baby.
- Those parents also pointed out that children with life-limiting disorders have a right to their life, however short it may be, and however severe their disability.
- In stark contrast to the Irish experience, in countries where abortion is legal up to 95% of children with a fatal diagnosis are aborted.<sup>2</sup>

***90% of Irish parents do not abort their baby following a fatal diagnosis.***

## The most common of these rare disorders - and outcomes for baby:

These diagnoses are rare but they can arise for up to 700 babies - about 1% of pregnancies - every year in Ireland. Everyone would feel enormous sympathy for parents faced with a fatal 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.



Baby Faith and Myah

► **Anencephaly** is a serious neural tube defect which causes the baby's brain not to develop properly. A recent study found that 72% of babies with anencephaly lived for a short time after birth. Of those children, 25% lived up to 5 days, while up to 7% lived up to 28 days after birth.<sup>3</sup> Two children - Stephanie Keene and Nicholas - lived in excess of two years. In one recent case, Baby Faith Hope lived for a wonderful 93 days. Her mother, Myah wrote: **"I chose to carry my baby to term for one simple reason: love. Then to everyone's surprise, we were blessed with 3 months and 4 days with Faith before she went to Heaven. She was the sweetest little girl... so beautiful and so full of life. I feel so blessed to be her mother."** (<http://babyfaithhope.blogspot.com/>)



Elaine Fagan

► **Trisomy 18 or Edwards Syndrome** arises because of the presence of an extra chromosome. Quite contrary to recent reporting, studies have found that the average duration of survival for children with Trisomy 18 was 14.5 days; with 38.6% of babies surviving for more than a month, while 8.4% survived for more than a year.<sup>4</sup> Here in Ireland, Elaine Fagan, given just days to live after birth, spent 25 years with her loving family before her death in 2011, confounding all medical expectations.

**"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 Micheal.


► **Trisomy 13 or Patau Syndrome** also arises when the baby has an additional chromosome. Research has found that children with Trisomy 13 live on average for 7 days after birth, while almost 31% live for more than a month, and almost one in 10 live for more than a year.<sup>5</sup> Anthony Arritola lived for twelve months after birth, and his mother Janina said his life had inspired many others to realise **"how incredibly precious each and every little life is"**.



Baby Anthony

► **Potter's Syndrome, Potter's Sequence and Renal Agenesis** are conditions in which the kidneys either do not form or do not function, and where an absence or reduced volume of amniotic fluid also arises. It has tended to be associated with a very poor outcome but this is not invariably so, and data shows the outlook may be improving. Doctors predicted that infant Sarah Elizabeth Kaster, like other Potter's Syndrome babies, would never open her eyes, never utter a sound, and never breathe on her own. Her life expectancy was two or three minutes. Instead, she lived 22 and a half glorious hours. During that time, little Sarah opened her beautiful eyes, cried like any baby, and responded to her parents' loving touch. Her mother, Holly Kaster, said that: **"Sarah brought me so much joy in the short time she was with me, I look at her life as a total blessing. And I feel honoured to have been her mother."**





***“Termination is not a shortcut through grief. In contrast, parental responses to perinatal hospice are overwhelmingly positive.”***

## ► Support for parents:

What is crystal clear is that all parents in this situation deserve much more than our sympathy - they need us to put professional support systems in place. That’s why the Life Institute has written to the Minister for Health urging him to establish perinatal hospice services as expeditiously as possible. **Many parents facing a fatal diagnosis believe that their children would suffer unbearably following birth - and are not made aware that perinatal hospice care would eliminate that suffering.**

The good news is that, according to leading experts in the field, centres offering this essential care are not difficult to establish or maintain. In a recent article in the Washington Times, Dr Byron Calhoun of West Virginia University explained that **“all the typical hospital needs is a few extra rooms for these families”**. Dr Calhoun explained that the perinatal hospice movement supports parents of children expected to die soon after birth. It offers nurses, chaplains, neonatologists, social workers, bereavement counselors and even a photographer to capture brief moments. **“Time with the baby is extremely important to these moms,”** he said. **“Families want a live birth, a baptism, 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.”** <sup>6</sup>

One long-term study found that, for mothers who had aborted babies with fatal diagnoses, **“a substantial number...showed pathological scores for post-traumatic stress.”** <sup>7</sup>

As the perinatal hospice movement says: **“Termination is not a shortcut through grief. In contrast, parental responses to perinatal hospice are overwhelmingly positive.”**



## ► Methods of abortion for these babies:

Those calling for a change in Irish law want the practises available in Britain to be made legal here. Those practises 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, the lives of babies with fatal disabilities would be 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 would be involved in the decision to end the life of their child.

**Can this really be the best answer for parents and for baby in these very upsetting circumstances?**

## A Better Answer

**It comes down to this: whatever the crisis, we can find a better answer than abortion.**

It is disturbing to see abortion campaigners like the Irish Family Planning Association attempt to use these sad situations to further their own agenda - which is to see abortion on demand legalised in Ireland. Their only answer to the trauma facing parents is to offer the medieval solution of abortion.

**We are resolved to work instead towards a solution that loves and protects both mother and baby.**



**For more information please go to [www.thelifeinstitute.net](http://www.thelifeinstitute.net)**

## lifefacts/backup

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