

EVERY LIFE COUNTS



Every Life Counts is a beautiful initiative which seeks to offer forums where parents can share their memories, their stories, their love and their pain; where their children are remembered and cherished, and where we acknowledge that every life counts.

ELC also reaches out to parents in similar situations, campaigns for better services for families who receive this very sad and distressing news, and seeks to ensure that the lives of children with life-limiting conditions are protected.

Parents in ELC have ensured that their children knew nothing but love for their brief time on this earth, and that is an extraordinary achievement.

At this very difficult time, with the loss and the sorrow can also come joy and love and comfort. We hope to improve the services available for families so that they can have time with their babies and take photos and make memories.

The Situation In Ireland



Those services have certainly improved in Ireland - great work is being done in the Coombe for example - but the improvement is patchy. Right now, getting the right kind of support and understanding from the medical system is really the luck of the draw; it can depend on where you live and who you meet, and that is not acceptable.

More worryingly, some attitudes have changed, not for the better but for worse, in that parents are being pressured to go for abortion once a diagnosis of a life-limiting condition has been made.

This is hugely distressing for parents, yet we are not hearing from those parents at the moment - instead we are repeatedly being told that the law in Ireland must change to allow children with a profound disability to be aborted here.

You may have read that most Irish women who are told their baby has been diagnosed with a serious or life-limiting condition go to the UK for an abortion. Figures as high as 80% have been suggested repeatedly - on *RTE's Prime Time* for example. The Waterford TD, John Halligan claimed that 1,200 Irish women were travelling for abortions to Britain each year because their baby had a 'fatal foetal abnormality'.

Official records from the British Department of Health show that estimation to be **wildly incorrect**.

The reality is that only **an estimated 10% of Irish parents - in only 34 cases in 2011** for example - go to Britain for an abortion because their baby had a serious or life-limiting anomaly.

At least 90% of Irish parents choose to continue with the pregnancy and to spend every moment they can with their child.

We know this because the records kept by the British Department of Health not only record all Ground E abortions (abortion on disability grounds) on Irish women, but also record the condition diagnosed, and separate out conditions such as anencephaly, Trisomy 18 (Edwards Syndrome), Trisomy 13 (Patau Syndrome) etc.

As you can see from the Table released by the British Department of Health below, in 2011 a total of 51 abortions were carried out on Irish women for reasons of disability - including Down Syndrome and Spina Bifida, which are not life-limiting abnormalities at all.

When we narrow it down to life-limiting disorders then we see that the total is **34 abortions**.

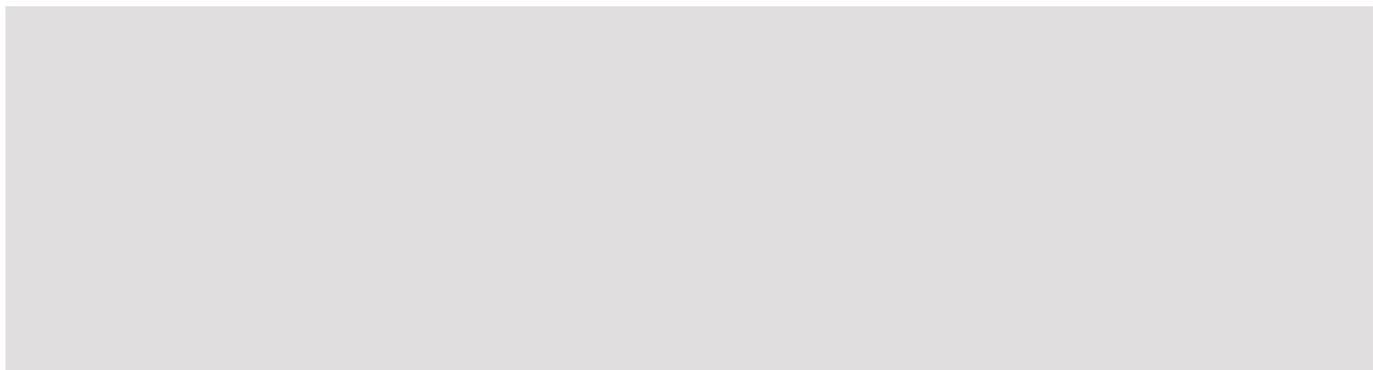
In 2011, for example, 8 babies with anencephaly were aborted, 7 babies with Edwards Syndrome were aborted, while 7 babies with Patau's Syndrome also had their lives ended. In 2010, the numbers were slightly higher; in 2009, they were slightly lower.

We've now obtained the 2012 figures and the number of babies with life-limiting disorders who were aborted under Ground E is at 42 for 2012 - so the figure flexes from 41 in 2010 to 34 in 2011 to 42 in 2012.

The increase in the total numbers of Ground E abortions (ie all abortions carried out on Irish women in Britain for reasons of disability) are largely being driven by an increase in abortion of babies with Down Syndrome - 28 in 2012 - a shocking and very sad increase of 460% since 2008. This may be due to the increasingly negative reporting in the media on disabilities detected in pregnancy.

NOTE: *These British DoH figures record all Ground E abortions in all hospitals and clinics in England and Wales.*

See Table in Appendix 1



The experience of families

So we know that most Irish parents do not abort despite being pushed to do so. What has their experience been?

Mothers who have joined the Every Life Counts initiative have told us that they've experienced some or all of the following during their pregnancy:

- *Negative attitudes from medical staff towards their pregnancy*
- *Repeated suggestions of abortion*
- *Surprise expressed that they had continued with their pregnancy*
- *A lack of empathy and respect for the dignity of their child*
- *Use of terms and words that are incorrect, unsympathetic and cause hurt for parents involved, including the phrase 'incompatible with life'.*

This reflects the experience of parents in other jurisdictions, although, since abortion ends the life of up to 95% of children with a range of disabilities in other countries, that experience is likely to have been even more negative.

A 2013 paper published in the *American Journal of Medical Genetics* found that 94% of parents given a diagnosis of Trisomy 13 or 18 were told their baby would not live after birth, although, as we will see, that is not the case with these conditions. 61% of parents said they came under pressure to abort, 55% were told that their child would be a vegetable, 28% that their baby would destroy their family or their marriage. Others had more positive experiences, but, and this must have been enormously upsetting, some parents were told that their obstetrician would refuse to continue seeing them if they did not abort.

It should be pointed out that these attitudes often arise because of a lack of understanding, and the adoption of phrases which are medically meaningless such as "incompatible with life".

A 2012 paper entitled '*Fatally Flawed?*' published in the *British Journal of Obstetrics and Gynaecology (BJOG)* similarly found that the term 'lethal anomaly' is not a medical prognosis and should not be used in counselling parents facing a diagnosis of severe malformation for their unborn child.

The authors, who work in the field of newborn intensive care and in counselling, said that the term hindered clear communication, and should be avoided in counselling.

Crucially, they pointed out that "prenatally diagnosed abnormalities that are associated with death in the newborn period are often referred to as 'lethal malformations'. Yet, for many of the commonly described lethal malformations long-term survival is possible if supportive interventions are provided."

In an interesting discussion entitled '*The Language Of Lethality*', the authors examine the use of the term 'lethal', and consider the published literature, accounts of parents, and their own experience, and conclude that "a significant proportion of practitioners do use this or related terminology."

They then ask why the term is used, and identify several reasons:

1. Practitioners may mistakenly believe that conditions [such as Trisomy 18] are not compatible with survival beyond the newborn period.

2. A second potential reason is a discomfort with uncertainty, or a desire to make decision-making simpler. The authors write that "It is potentially easier for women to come to terms with termination of pregnancy or with palliative care if they are told that survival is impossible, and it may be easier for professionals to make and rationalise such decisions".
3. A third possibility is that doctors make a judgment call on the 'quality of life' of another person – has certainly been the experience relayed to us by parents who have faced a diagnosis of a severe abnormality. Parents and their babies deserve better than judgment and a nudge towards abortion.

The authors of '*Fatally Flawed?*' also found that, having searched the published literature, no agreed definition of a 'lethal fetal or congenital malformation' existed, nor could they 'identify an agreed list of conditions that fit into this category'.

It is certain that language matters then, and that language that misinforms is a barrier to counselling and good communication.

A recent Parliamentary inquiry in Britain, the Bruce Inquiry, showed that parents came under pressure to abort if the baby had a disability and that parents felt they did not receive adequate information about other options, including palliative care after birth.

The *Fatally Flawed* paper was published just weeks after new research by Dr Anne Janvier of the University of Montreal found that almost all families of children with Trisomy 13 and 18 reported that their time together was happy and rewarding overall. The research, published in the peer-reviewed journal, *Pediatrics*, found that over 97% of the parents interviewed considered that their child was happy and their presence enriched the life of their family and their life as a couple, regardless of longevity. This finding is hugely significant to the current debate on perinatal care in Ireland and elsewhere.

Janvier et al also found that 93% of the families of children with Trisomy 13 and Trisomy 18 had been told their baby's condition was 'lethal' or 'incompatible with life' and more than two-thirds felt under pressure to abort.

A survey of 1000 obstetricians in the UK, Australia and New Zealand by Wilkinson et al found that 85% regarded Trisomy 18 as lethal and 80% said that children with Trisomy 18 would not have a 'meaningful life'. This was in sharp contrast to a recent study in the *American Journal of Medical Genetics* (2013) which found that many parents met with negative reactions from healthcare providers regarding their children. 91% of parents who continued with the pregnancy said they would do that again - and for most of these parents, perinatal hospice care was not available.

That's why we're working to have perinatal hospice care made available right throughout the country.



What is perinatal hospice care?

Perinatal hospice and palliative care is a new and compassionate model of support that can be offered to parents who find out during pregnancy that their baby has a life-limiting condition. As prenatal testing continues to advance, more families are finding themselves in this heartbreaking situation.

Perinatal means around the time of birth, and hospice incorporates the philosophy and expertise of hospice and palliative care into the care of patients.

Sometimes we can think that the word hospice means that we have given up hope - but that's not the case. Hospice is a special concept of care designed to provide comfort and support to patients and their families, and staff offer a specialised knowledge of medical care, including pain management.

When we hear the word hospice we think of a building, but, as author and mother **Amy Kuebelbeck** notes, perinatal hospice is not a place. It is more a frame of mind. It's about providing support to families and can easily be incorporated into standard pregnancy and birth care, and be made available in maternity hospitals and units in Ireland.

Indeed, in some centres in Ireland, this kind of care is made available but, as we previously noted, that provision is patchy.

In practical terms, perinatal hospice care requires that obstetricians, nurses, chaplains, neonatologists, social workers, bereavement counsellors and even photographers work together to ensure that parents are given the gift of time with their children. This ensures:

- *Continuity of care, so that the family has a dedicated team who are aware of the baby's diagnosis and they do not have to explain their situation at every appointment. It also ensures that parents are properly informed about their baby's condition, and are not misinformed either by medical staff, or by being told to look things up on google.*
- *That a special, separate room is made available for the family when their baby is born.*
- *That counselling is available for families throughout the pregnancy and bereavement counselling is available afterwards.*
- *That palliative care ensures that any pain or discomfort the baby may feel is managed and minimised*
- *That a specialised photographer helps to make memories for families.*
- *That a chaplain is available to baptise the baby if that is desired.*

All of this ensures that parents have the gift of time - that they can focus on spending every precious moment with their child, before and after birth.

So we can see that the support begins at the time of diagnosis, not just after the baby is born. This approach supports families through the rest of the pregnancy, through decision-making before and after birth, and through their grief. Perinatal hospice also enables families to make meaningful plans for the baby's life, birth, and death, honoring the baby as well as the baby's family.

For a baby who is expected to die, parents' original wishes and dreams for their child's long life are shattered. But their hopes can change direction; for the baby to be treated with dignity, for the baby to be protected until death comes naturally, for the baby's life to be filled with love.

Parents who have chosen perinatal hospice have said that this kind of care helped their hopes be fulfilled.

We know that in Ireland some 700 cases of life-limiting conditions such as anencephaly or Trisomy 13 arise each year. As previously noted, we also know from figures released by the British Department of Health that more than 90% of Irish parents continue with the pregnancy. It's a matter of urgency then, that the Minister makes proper care and support available to families.

We can see too from the experience of other countries, that when parents are offered perinatal hospice care the percentage that continue their pregnancies increases dramatically. In a U.S. study, when parents were given the option of perinatal hospice, the number rose to 75 percent. (D'Almeida et al, 2006) And in another U.S. study, the number who chose perinatal hospice was 85 percent (Calhoun 2003).

Giving parents real information

So we can see that making this best-standard care available is not expensive, does not require capital expenditure or huge investment, but, rather, requires training and the commitment and goodwill of the HSE. We've written to the Minister of Health previously on this, and we're now making a full submission to the Minister and we will be requesting a meeting with him to discuss this in full. Your experiences and your contribution would be hugely important to us in compiling that submission.

We also need to deal with the dreadful mis-information that is currently being given to parents and to the public regarding life-limiting conditions and the dignity and worth of each and every child.

These are our most sick and vulnerable children: they are babies with a serious and life-limiting disability. We need to wrap our arms around these families and lift some of the burden of what is otherwise an almost unbearable sadness.

For example, parents are told their baby is 'incompatible with life' - which is a judgment and not a medical opinion. They are told that abortion is a better option because the baby will not make it until birth, and will suffer after birth. The medical literature contradicts those assertions.

The most common conditions

A recent study published in the *British Journal of Obstetrics and Gynaecology* 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. Two children - Stephanie Keene and Nicholas - lived in excess of two years.

Kildare mother Aileen Behan's little girl Lilly Ann lived for 6 days. She says: *"I was told that she wouldn't live after birth; she did for 6 days. When you're told you're going to get nothing, to get 6 days is just*



Baby Lilly Ann

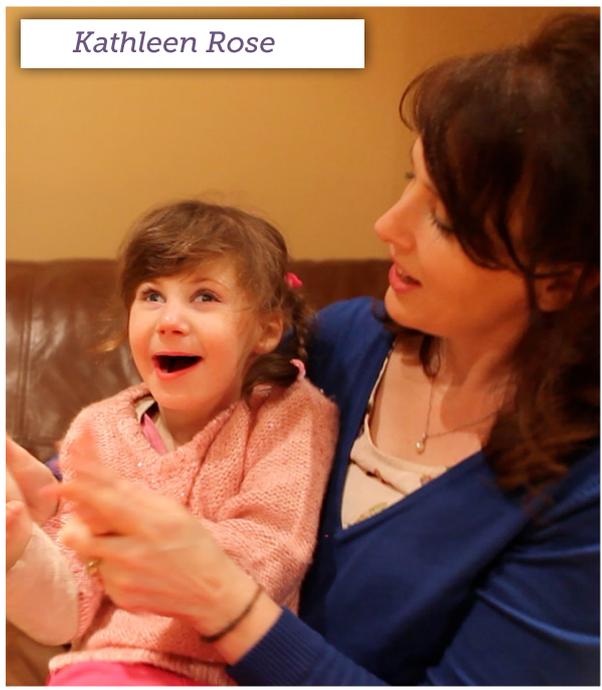
a miracle. There were two wishes I had for her, one that she would feel the air in her face, and one that she would be held and loved by everyone. And she was."

Trisomy 18 or Edward's Syndrome

arises because of the presence of an extra chromosome. There is a significant risk of miscarriage before birth, but, quite contrary to recent reporting, studies have found that the average duration of survival for children who lived until birth with Trisomy 18 was 14.5 days, with 39% of babies surviving for more than a



Elaine Fagan



Kathleen Rose

month, while 8.4% survived for more than a year. 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.

Research has also found that children with **Trisomy 13 or Patau's Syndrome** 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. Kathleen Rose Harkin, who lives in Cavan, has defied all doctors predictions to celebrate her 8th birthday despite having Trisomy 13.

Some conditions, including Potter's Syndrome, Potter's Sequence and Renal Agenesis, mean that a lack of kidneys or kidney development causes a decreased amount of amniotic fluid - which

can also mean that the baby's lungs fail to develop. It has tended to be associated with a very poor outcome but this is not invariably so, and a new treatment means the outlook may dramatically improve.

US Congresswoman Jamie Herrera Beutler was told that her daughter had **Potter's Syndrome** and that "It's 100 per cent fatal. She will either be stillborn, you'll miscarry, or she will suffocate in your arms after she's born". But the Beutlers urged doctors to try an experimental treatment - injecting a small amount of saline into the womb to act as a substitute amniotic fluid.

Abigail Beutler was born in July 2011, and is thriving, sitting up, chattering and playing with her adoring parents. She is awaiting a kidney transplant and her Dad, Dan Beutler, is a match. Abigail's story may now change the treatment protocol for Potter Syndrome.



Herrera Family

What is best for mothers?

Whatever the condition, the time parents can have with their children is hugely rewarding and tremendously important for healing.

In contrast, research suggests that substantial numbers of women who undergo abortion in these circumstances suffer post-traumatic stress. (Korenromp et al, 2005),

A longitudinal study in 2009 in the Netherlands looked at 147 women who had a termination of pregnancy for anomalies and reviewed psychological outcomes at 4, 8, & 16 months.

- At 4 months 46% women revealed pathological levels of post-traumatic stress symptoms
- At 16 months, 21% still have symptoms

Abortion is not a shortcut through grief, and in contrast, parents responses to perinatal hospice are "overwhelmingly positive" (Calhoun & Hoeldtke 2000), and parents report being emotionally and spiritually prepared for their baby's death and feeling "a sense of gratitude and peace surrounding the brief life of their child" (Sumner 2001).

Let's work together to make the case for perinatal hospice services in Ireland, and work to give parents the gift of time with their precious babies, because every life counts.

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Appendix 1

Total abortions to women resident in Irish Republic, having abortions under Ground E, in England and Wales, by principal medical condition, 2007-2012

ICD-10 code	Condition	2007	2008	2009	2010	2011	2012
	Total	27	29	42	68	51	93
Q00	anencephaly	2	5	3	10	8	5
Q01	encephalocele	0	0	0	1	0	2
Q02	microcephaly	0	0	0	0	0	0
Q03	hydrocephalus	0	0	1	1	0	2
Q04	other malformations of the brain	0	1	2	6	1	2
Q05	spina bifida	4	1	2	2	3	4
Q06-Q07	other	2	1	0	4	0	2
Q10-Q18	the eye, ear, face and neck	0	0	0	0	0	0
Q20-Q28	the cardiovascular system	0	1	2	1	2	2
Q30-Q34	the respiratory system	0	0	0	0	0	0
Q35-Q37	cleft lip and cleft palate	0	0	0	0	0	0
Q38-Q45	other malformations of the digestive system	0	0	0	0	0	0
Q60-Q64	the urinary system	3	1	2	2	1	5
Q65-Q79	the musculoskeletal system	0	3	2	7	0	3
Q80-Q85	the skin, breast integument phakomatoses	0	0	0	0	0	0
Q86-Q89	other	1	2	0	4	3	2
Q90-Q99	Chromosomal abnormalities total						
Q90	Down's syndrome	9	5	7	16	11	28
Q910-Q913	Edwards' syndrome	3	3	7	4	7	16
Q914-Q917	Patau's syndrome	1	3	4	2	7	5
Q92-Q99	other	0	1	6	5	6	8
	Other conditions total						
P00-P04	fetus affected by maternal factors	1	1	2	0	1	1
P05-P08	fetal disorders related to gestation and growth	1	0	0	0	0	1
O30	multiple gestation	0	1	1	0	1	1
O41	disorder of the amniotic fluids	0	0	0	2	0	0
Z20-Z22	exposure to communicable disease	0	0	1	0	0	0
Z80-Z84	family history of heritable disorder	0	0	0	1	0	2
	other complications of pregnancy						1
G71.1	disorder of the muscles						1
LIFE LIMITING CONDITIONS:					41	34	42

¹ ICD-10 codes are taken from the International Statistical Classification of Diseases and Related Health problems (Tenth Revision) published by the World Health Organisation (WHO)

It should be noted that this collation of disorders which may be described as 'fatal abnormalities' adopts a very prudent approach, since in at least three categories - Q06-07, Q86-89, and Q92-Q99 -there is not sufficient information to ascertain whether these conditions may, in fact, cause a severely limited life or have a poor prognosis of life within the womb, but those categories have been included in the total of so-called fatal disorders so that the collation cannot be said to under-estimate the total.

Appendix 2

About Every Life Counts

ELC is a support network for parents whose children were diagnosed with a severe or sometimes life-limiting condition while in the womb. We are working to make better support and care available in Ireland and to ensure every child has a right to life, however short that life is.

Our website is at www.everylifecounts.ie - and you can see some of the beautiful stories from our members here.

The videos on Every Life Counts have been viewed almost **120,000** thus far. We are hoping to help many more families share their stories.

What we do:

- **Provide a forum** for parents of children who were diagnosed with a terminal condition to share their memories, their joy, their pain, and their love.
- It's a place where the lives of our much-loved children are **celebrated**, and where we can **reach out** to parents in similar situations.
- **Seek to establish a support network** for parents who have received this devastating diagnosis and want to talk to parents who have been in similar situations.
- **Provide resources and hope** to families and their children who, above all else, seek the gift of time.
- **Lobby for perinatal hospice care** to be made available in every maternity unit in Ireland.
- **Protect the right to life of every child**, however short that life may be.
- **Correct the misinformation** which is currently causing distress to parents in this situation.
- **Seek an end to the term 'incompatible with life'** and other misleading and incorrect terms.

Children whose lives are shortened are no less precious than any other child. In fact, many parents say they are the most special children of all.

They deserve to be loved and celebrated - and they are worthy of protection.

SEE our stories at www.everylifecounts.ie



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