



Paper of

Every Life Counts

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The Citizens' Assembly

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Every Life Counts

SUMMARY of the SUBMISSION to the CITIZENS' ASSEMBLY

FROM PARENTS WHOSE BABIES HAVE BEEN DIAGNOSED WITH LIFE-LIMITING CONDITIONS

WHO WE ARE

We are families whose babies were diagnosed with life-limiting conditions such as anencephaly or Trisomy 18. For some of us, our babies' lives were all-too-brief, and we have experienced the terrible loss and pain of the death of a child. However, we have also experienced the tremendous love and pride that comes with carrying and holding our children, and we know how that shared time brings love and joy and healing after loss and pain.

We work to provide a forum for families to share their experiences and stories, and to create public awareness of life-limiting conditions and of the value of every child's life. We also seek better care and support for families who receive the devastating diagnosis that their baby may not live for long after birth.

It is our view that better support and compassionate care – called perinatal hospice care – best serve families and baby, and that abortion is not a pathway to healing.



THESE ARE BABIES WITH A SEVERE DISABILITY

- These are babies with a severe disability, who are alive and kicking in the womb, but who have been diagnosed with a condition which means they may not live for long after birth.
- There is no agreed category of medical conditions which can be described as 'fatal' or 'lethal', since for all of these conditions, research shows that children have lived beyond birth, sometimes for years. (1)
 - In fact, even with the most severe disorders, such as anencephaly, studies show that most babies do, in fact, live after birth and that parents will have time to make memories with their children.
 - Research shows that 72% of babies with anencephaly live after birth, even briefly, while babies with Trisomy 13 or 18 have lived for weeks, months and years after birth. Parents should not be deprived of the love and joy that comes from this precious time. (2,3)
 - These babies are not 'incompatible with life'. No baby is. This label, and ugly and misleading phrases like 'fatal foetal abnormality', are used to dehumanise these babies – and to justify ending their lives because of their disability. These phrases are NOT a medical diagnosis and misinform parents when they are vulnerable and fearful for their baby.
 - The Royal College of Obstetricians and Gynaecologists have pointed out that the term 'fatal, foetal abnormality' is not to be found in any medical textbook. (4)
 - The HSE, in revising its *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* decided to use the more correct term 'life-limiting condition'. (5)

THE EXPERIENCE OF PARENTS

- We know that the time we have with our babies, however short, brings love and joy, and is a pathway to healing. Our babies lives are of infinite value, they matter because every child matters.
- We want better services to be made available so that parents have the support they need to pour a lifetime of love into the time they have with their child. Making memories, holding your baby, making sure they knew nothing but love, are all enormously important achievements when a baby's life is too short.
- A recent study from Cork University Maternity Hospital found that up to 96% of parents continued with the pregnancy after a diagnosis of Trisomy 13 or 18. (6)

1. Wilkinson, D.J.C., Thiele, P., Watkins, A., and De Crespigny, L. Fatally flawed? A review and ethical analysis of lethal congenital malformations. *Br J Obstet Gynaecol.* 2012; 119: 1302–1307
2. Jaquier M, Klein A, Boltshauser E. 'Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly.' *British Journal of Obstetrics and Gynaecology* 2006; 113:951–953
3. Nelson KE, Rosella LC, Mahant S, Guttman A. Survival and surgical interventions for children with trisomy 13 and 18. *JAMA.* doi:10.1001/jama.2016.9819.
4. The Royal College of Obstetricians and Gynaecologists have pointed out that the phrase 'fatal, foetal abnormality' is not to be found in any medical textbook, with Dr Jim Dornan telling BBC "the View" (03/12/2015) that it was not a medical term and that "no doctor knows exactly when a foetus is going to die".
5. HSE National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death.
6. Houlihan OA, O'Donoghue K. The natural history of pregnancies with a diagnosis of trisomy 18 or trisomy 13; a retrospective case series. *BMC Pregnancy Childbirth.* 2013;13:209. doi: 10.1186/1471-2393-13-20



"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. I'm so proud of her that she lived for 6 days."

Aileen, mother to Lilly Ann, born with anencephaly.

Seán Hynes was diagnosed with Trisomy 18, caused by an extra chromosome, and he lived for two days after birth.

His mother, Sarah, says:
"So we wrapped him in love for those two days, two wonderful days we will never forget. Seán has made us the proudest parents in the world. He has made us better people, and for that we are forever grateful."



Kathleen Rose Harkin has now reached her 9th birthday, living with Trisomy 13 - a condition often wrongly often described by the media as a 'fatal abnormality'.

Her mother Tracy says: *"Children like Kathleen teach us how to love. It upsets me that parents are pushed towards abortion."*

"I look back knowing I did everything I could possibly do to make sure she got here and knew that she was so loved."

Baby Lilly Joy Sharp with her mam, Grace



WHEN 'CHOICE' BECOMES AN EXPECTATION

Parents say that the negative language and misinformation used in Irish hospitals, as well as by abortion campaigners, can push parents towards abortion, and to a lifetime of regret.

- Researchers at Cork University Maternity Hospital found that negative attitudes – from doctors and others – was unhelpful (1). “The doctor said the baby would not have any emotion or personality so what was the point?” reported one mother, while another added “I felt that he considered continuing my pregnancy with Talia was a waste of resources and a waste of his time”.
- Parents also said that “If abortions had been legal in Ireland I would have done it so I am glad it wasn’t”, and that “The media campaign for termination of pregnancy made me feel like I had something to hide”.
- A recent Parliamentary inquiry in Britain, the Bruce Inquiry (2), 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.
- Research by Janvier *et al* showed that 93% of families of babies with Trisomy 13 and 18 had been told their baby’s condition was ‘lethal’ or ‘incompatible with life’ and more than two-thirds felt under pressure to abort. (3)

CONTRASTING OUTCOMES

- In drafting its revised *National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death*, the HSE’s consultation document said that “It is acknowledged that women, who for whatever reason opt to have a termination of pregnancy, experience more intense emotional distress in the short and long term as compared with women after preterm birth or normal birth (Kersting et al., 2009).”
- A new (2015) study from Duke University by Cope *et al* has found that mothers who undergo an abortion after a diagnosis of anencephaly are significantly more likely to suffer depression and despair than those who continued with their pregnancy(4).
- In contrast, recent research has found that almost 90% of parents who continued with their pregnancy following a diagnosis of Trisomy 13 or 18 said that their overall experience was positive, while 98% of parents described surviving children as happy and as having an enriching influence on their lives, and on their families (5,6).
- Parents are being horribly misinformed and pushed towards abortion at a time when they are very vulnerable. Parents need the right support – perinatal hospice care – to give them time with their baby. That time brings great joy, and healing after the pain of loss.

1. Preparing for Stillbirth in Cases of Prenatal Lethal Diagnosis, Orla O’Connell, Cork University Maternity Hospital

2. <http://www.abortionanddisability.org/> – The Bruce Inquiry

3. Janvier, A., Farlow, B., and Wilfond, B.S. The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*. 2012; 130: 293–29

4. Cope, H., Garrett, M. E., Gregory, S., and Ashley-Koch, A. (2015) Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome. *Prenat Diagn*, 35: 761–768. doi: 10.1002/pd.4603.

5. Janvier, A., Farlow, B., and Wilfond, B.S. The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*. 2012; 130: 293–298

6. Guon, J., Wilfond, B.S., Farlow, B., Brazg, T., and Janvier, A. Our children are not a diagnosis: the experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18. *Am J Med Genet*. 2014;164A: 308–31

WHAT HELPS PARENTS

Our experience tells us that families need to know that almost all parents who continue pregnancy have reported a positive and enriching experience regardless of the lifespan of their child. They had some time with their baby and that was truly precious.

- Babies with these conditions do not suffer in the womb, and parents should not be misled in this regard. None of these conditions cause the baby in the womb to suffer pain. Any discomfort after birth will be managed by good palliative care. (1)
- Perinatal hospice care is the way forward to help families in this very difficult time – this support system for families is not expensive to provide and is hugely helpful. It means that parents are provided with the gift of time with their child by ensuring that they have the same medical team throughout the pregnancy, and that special bereavement counsellors and midwives and photographers help baby and parents through the pregnancy and birth.
- Research shows that, in jurisdictions where abortion was available, when perinatal hospice care services were explained and offered up to 85% of parents availed of them (Calhoun, 2003) (2)

1. Royal College of Obstetricians and Gynaecologists (2010) *Fetal Awareness: Review of Research and Recommendations for Practice* (Page 22).

2. Calhoun BC, Napolitano P, Terry M, Bussey C, Hoeldtke NJ. Perinatal hospice. Comprehensive care for the family of the fetus with a lethal condition. *J Reprod Med.* 2003;48:343–348

THE REALITY – LATE TERM ABORTION

- These are usually late-term abortions. The baby is either dismembered or given a lethal injection of potassium chloride into the heart, and the mother will then give birth to a dead baby. (3,4)
- These are not abortions for ‘medical’ reasons. There is no threat to the life or health of the mother, and abortion certainly brings no benefit to the baby. This is abortion for reasons of disability and we do not believe that abortion should be legalised in Ireland on disability grounds. This would introduce the most lethal form of discrimination possible, and, as the medical literature shows, will not help mother or baby.
- “Many patients are diagnosed late and therefore will undergo a late termination of pregnancy and this can be surgical, they go to sleep, they have an anaesthetic, they undergo this D&C procedure but the baby will not be removed intact and I think on the way in here today you will see pictures of what a baby will look like with such a procedure. If they are very late in gestation the physicians looking after the pregnancy will actually perform a procedure resulting in the heartbeat stopping, this is to prevent the baby from being born alive where the obligation might change and their labour would then be induced so they would deliver a still born baby and that's obviously a very difficult journey for any patient to undergo.” (4) *Dr. Peter McParland, CA Meeting, 7 January 2017*
- Instead, the gentle, compassionate and life-affirming support of best perinatal care should be made available.

3. Royal College of Obstetrics and Gynaecology

Guidelines https://www.rcog.org.uk/globalassets/documents/guidelines/abortion-guideline_web_1.pdf

4. Dr Peter McParland - Second Meeting of the Citizens' Assembly - 7 Jan 2017