

Every Life Counts



Seeking best care for families where baby may not live long after birth

Overview - what I'd like to discuss with you today

- These are babies with a severe disability – they are not a 'fatal abnormality'
- They are alive and kicking at time of diagnosis and deserving of the same right to life as every other baby
- Abortion in these circumstances is hugely distressing for mothers too –we want best care for families when baby's life might be very short and we passionately believe that this is a better answer than abortion.











"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.



“If our love could have saved you, you would have lived forever”

Vicky speaking about her little girl Líadán who had Trisomy 18.

"Maya lived for one hour and thirteen minutes after she was born, and those minutes will last in my mind, heart and soul for a lifetime. Maya was alive and kicking in my womb and she was a determined little fighter who was adamant she would meet her Mammy and Daddy."

Ciara Conroy speaking about her little baby, Maya Rose, who was diagnosed with a chromosomal condition.





"I was so proud that my body was Carragh's safe haven for those 38 weeks - it was her home. She knew nothing but love in our time together."

Mandy speaking about her daughter Carragh O'Neill Fox who was diagnosed with Trisomy 7 and Monosomy 13.

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."



"I am the mother of a dead baby. I know that ravaging and terrible pain, yet we have the comforting knowledge that we did all we could to give him life. Our greatest comfort now in the face of what was undeniably a tragedy, is that we didn't hurt him and he didn't hurt us."

Carmel Ó'Curraoin, speaking about her baby Marc who had anencephaly.





"Her imperfections are beautiful to me. I am blessed to have seen her beautiful face and touched her tiny hands. I wanted to give her every chance."

Tanya Coonan speaking about her daughter, Lillie, who was diagnosed iniencephaly.

"Muireann was born, two fists in fighting position... ready to take on the world. And fight she did, for six whole weeks. She was an amazing little girl who made a huge impact on us all."

Mandy Dunne speaking about her little girl Muireann who lived for six weeks after birth with Trisomy 13.





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

Grace Sharp speaking about her baby Lilly Joy who lived for 4 hours after birth with Trisomy 18.

Why is the term 'fatal foetal abnormality' misleading?



Because no doctor can say how long a baby with a life-limiting condition will live beyond birth



Because the term is not found in any medical textbook



Because most of these babies do live beyond birth, even with the most severe condition, anencephaly. (*BJOG, 2006*)



Because the medical literature says it is misleading and should not be used in counselling (*BJOG, 2012*)



The HSE's new Standards for Bereavement Care correctly use the term life-limiting condition





So these are babies with a severe disability



They do not suffer in the womb and any pain after birth is managed with palliative care



It's simply dreadful to single out these babies for abortion because of their disabilities



It's a form of discrimination that wouldn't be accepted in any other area



However short their lives, their lives have value, just as much as yours or mine

Lethal discrimination



In most countries where abortion is legalised, the majority of babies with a life-limiting condition are aborted. This lethal discrimination also extends to other less severe conditions, with 100% of babies with Down Syndrome being aborted before birth in Iceland, for example.



Choice soon becomes an expectation with parents reporting that negative attitudes can cause pressure to abort
(Pediatrics; Bruce Inquiry, CUMH)



In contrast, parents who carry their babies to term report experiencing great love despite their loss, and find the time together is a pathway to healing *(Pediatrics 2012)*

Abortion in these situations have proved very distressing for women



This is usually a late-term abortion. The baby receives a lethal injection into the heart, and the mother has to give birth to a dead baby



A new study found that mothers are significantly more likely to suffer depression and despair when undergoing abortion after a diagnosis of anencephaly (*Prenatal Diagnosis 2015*)



In contrast, parents who carry their babies to term report experiencing great love despite their loss, and find the time together is a pathway to healing (*Pediatrics 2012*)



A Better Answer - Perinatal Hospice Care



Perinatal hospice – or perinatal palliative care – is a model of compassionate care that begins at the time of diagnosis



As author Amy Kuebelbeck explains, perinatal hospice is not a place, it is more a frame of mind, and is a beautiful and practical response to one of the most heart-breaking challenges a parent will ever face



It means continuity of care, so that women see the same medical team. It also means providing factual information so that parents are properly informed about the condition being diagnosed

Perinatal Hospice Care

- It means providing bereavement midwives and counsellors, and ensuring that the necessary medical support is provided throughout the pregnancy and at birth.
- Parents are encouraged to draw up a birth plan, and the hospital ensures that, when baby is born, the family has their own room, and that a specialist photographer, such as those that work with Now I Lay Me Down to Sleep can be arranged, as well as a chaplain if that is desired

Perinatal Hospice Care



This care gives parents the gift of time with their baby, and when you've been told that your child may not live for long after birth, time is all-important. You hang onto that time, it is literally precious.



As one mother so poignantly and powerfully told us: "You learn to pour a lifetime of love into those hours or days."

Parents tell of the joy of holding baby in their arms; of family members coming to say hello & goodbye; of how proud they were of their little babies; of the love and joy they shared.



Of course, some children like Elaine Fagan and Kathleen Rose go onto defy all expectations. Anecdotal evidence suggests that misdiagnosis can also occur.

Not Just a Matter of Choice

- All parents will agree that to be told your child is very sick and is not expected to live long is absolutely devastating
- Abortion, however, is not simply another 'pathway of care' or another type of 'medical care'
- A reality check is needed here in regard to what abortion actually entails. The baby, while still alive and kicking, is given an injection to the heart to end his/her life - and then the mother still has to give birth to her baby which is highly traumatising
- The baby 's right to life is taken away because of their disability - the law changes culture



💬 Better care – perinatal hospice care - is the progressive and compassionate answer for these devastated families

💬 Very often, in these cases, there is pain and loss and it can seem unbearable

💬 Making memories and having support to make the most of your time, is a pathway to healing

➡ Abortion is not a pathway to healing

➡ We can do better than abortion: so let Ireland be an example to the world, by offering love and compassion - and a model of best care – when parents get the terrible news that the life of their baby may be all-too-short.

Thank you for listening!



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