



Achieving best care ..

WHEN A POOR PRENATAL DIAGNOSIS IS GIVEN

Achieving best Care

Current Frame

Parents perspective – what helps

Law and culture

Current Frame - What they said....

- ▶ *"Fatal Foetal Abnormality"*
- ▶ *"Incompatible with life"*
- ▶ *"Baby with no head"*
- ▶ *"Doomed Pregnancy"*
- ▶ *"Anencephalic"*
- ▶ *"Baby suffers in Womb"*
- ▶ *"No human life to protect"*



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

Why FFA should not be used

- ▶ 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*)
- ▶ *HSE New standards in bereavement care following extensive consultation use the term life limiting conditions*

Perinatal Hospice & Palliative Care....

- a model of compassionate care that begins at the time of diagnosis
- a beautiful and practical response to one of the most heart-breaking challenges a parent will ever face
- A pathway to healing
Continuity of Care , information, counselling & support

.....A Better Answer

"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.





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

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



"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.



"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.

"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.





"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.

"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.



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 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.



The choice - Abortion

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

The reality..

- ▶ 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 a form of discrimination that wouldn't be accepted in any other area
- ▶ However short , their lives have value, just as much as yours or mine

Abortion Law changes culture

- ▶ Choice becomes an expectation to abort
- ▶ Value judgements
- ▶ Lethal discrimination extends to other less serious disabilities.
- ▶ Chilling effect
- ▶ -Culture of contradiction

prenatal diagnosis & plan of care

- ▶ First, the single most important factor related to death of a trisomy baby before going home or before one year of age was a prenatal diagnosis.
- ▶ Janvier et al state, given differences in care offered, “It seems palliative care for children with prenatal diagnosis is directed to a goal of having as short a survival as possible, with medications being prepared even before delivery (Harlos et al 2013 Journal of Pain and Symptom Management).
- ▶ Giving the child an optimal death seemed to be the goal of palliative care after a prenatal diagnosis of trisomy 13 or 18.
- ▶ Sean & Kathleens story

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medical Ethics

- ▶ Can health care be value free?
- ▶ Are medics simply agents of choice?
- ▶ A Culture of contradictions



Raising standards of care

Reclaiming medical ethics

First do no harm

- ▶ Authentic human rights
- ▶ Meaningful equality

Culture Of Life

"Every child, every person needs to know that they are a source of joy; every person, needs to be celebrated. Only when all of our weaknesses are accepted as part of our humanity can our negative broken self-images be transformed"

"To love someone is to show them their beauty, their worth and their importance" **Jean Vanier**