

Lived Experience in relation to assisted dying & end of life care.

Many thanks for the opportunity to speak to you today around my lived experience in relation to end of life care & suicide.

Our son Donal came to national prominence in 2013 as he fought his final battle with cancer. Having your son die from cancer as a 16-year-old is the exception in life, but from the time Donal was diagnosed terminal, **he lived with dying** with the help of his palliative care team. The team not only took Donal into their care, but they also looked after us as a family and individually, they took our worries, fears & general wellbeing into consideration.

In October 2012 he was told he had weeks maybe months to live & that maybe we should have an early Christmas, then in February 2013 he was told he might not see Easter, yet in April 2013 following local publicity he was asked onto RTE & had a conversation with Brendan O Connor. In addition to the RTE coverage that conversation has had hundreds of thousands of hits on social media even to this very day, 10 years later.

He spoke about valuing life & appreciating every minute. He contrasted his circumstances of wanting to get every second out of life with those who were taking their lives by suicide and the devastation that caused in families. That conversation has saved many lives. It led to our family setting up the Donal Walsh #Livelife Foundation in order to promote his anti-suicide #Livelife message.

I have two different but related messages.

First with regard to palliative care.

Palliative Care should not be underestimated in this country. This type of care is focused in providing relief from the symptoms & stress of a terminal illness. The goal is to improve quality of life for both the patient & the family. This is what it did for Donal and ourselves, in Donal's final and most important challenge.

It doesn't hasten death.

Palliative care is a way of easing people into their final most important struggle. A fundamental principle of palliative care is (in the words of the World Health Organisation) "neither to hasten nor to postpone death". **Palliative care is about care at the end of life, not about ending life**, as I'm sure the experts are reminding you.

As an organisation, the Foundation has been involved in campaigning for greater resources to be allocated to Palliative Care. In 2015/2016 we donated €80,000 to Kerry Hospice & €40,000 to Milford Hospice, although we don't ask for money, people generously contribute to our mission which enabled the foundation to make these & other donations to other Hospices and Mental Health Care.

If we neglect palliative care or turn it into something that it isn't, by linking it with euthanasia. It will be to the detriment of living. Palliative care provides opportunities for making memories & enjoying what time we have left with family while knowing our time is short. And really when you think about it, in some ways they are the lucky ones, because we are all dying – every day.

For me any introduction of assisted suicide or euthanasia would undermine the trust placed in doctors when it comes to end-of-life care, they would be seen as death givers. In some countries

where it is legalised such as Canada & Holland the deadly drug can now be given for autism, tinnitus and mental health issues. Surely this is not what we want for some of the more vulnerable population of this country.

I can honestly say with the help of palliative care Donal died with dignity and got to complete most of the things he wanted to do.

I fear what this committee could set in motion, because if it removes the present legal requirement that Doctors do what they can to save lives, the **value of life** will be significantly reduced.

Can anyone here guarantee that elderly people won't be subtly or overtly pressured into taking life ending pills, in a situation where they are living in a family house and the child or grandchild is looking for a house? We already know that coercion happens around handing over monies and going into nursing homes. All the elderly often want to do is live in their own home & community, that they have earned & lived in all their lives, but they are made feel guilty by taking up a space a younger family may need.

The second message I want to convey is about Suicide.

Donal spent his last months encouraging people to value life, four months after Donal died the recently deceased Kerry Coroner Terence Casey said, "Donal's appeal to young people about suicide has considerably reduced suicides in Kerry". Mr Casey said "Donal speaking out in the way he did has made a huge difference, I usually deal with 18 suicides a year, about 1 & half a month on average. But since Donal spoke out about suicide, I have no suicides from March to August" (the Journal.ie Sept 12th, 2013).

Over a year later Tralee Today reported the coroner as saying that since Donal appeared on Radio Kerry "Kerry Today" programme in March 2013 to receive a local hero award, there have been 4 reported suicides in the South Kerry Area. **This is a drop of 24 from 28 reported in the 12 months prior to that interview**".

Society must promote Hope, assisted suicide is a statement of No-Hope. Palliative care allowed Donal to spread a message of hope and reduce suicides. Telling young people that their life itself is valuable, no matter how uphill it may seem at the time, as Donal said, "Everybody has their own Mountain to Climb". Legalising assisted dying at the same time is to bring about a clash in Society. Life is whole from Beginning to Natural End. It's valuable no matter our age or circumstances. We can all help fight against suicide by turning our back on assisted suicide. Our lives are for sharing to the end.

If Donal had taken the euthanasia drug either of the two times, he was told he would not live for long more, suicides in Ireland would not have dropped. This is a potential that would have been lost, All people with long term illness have potential to change & improves the lives of family & friends, as long as the live.

That is a message of Hope.

Thank you for hearing what I have to say & I Hope it will be taken into consideration.