

Thank you Chair, Members of this Joint Committee on Assisted Dying. As a volunteer-led advocacy group, End of Life Ireland greatly appreciates the invitation to present today and I want to begin by thanking you for the humanity granted in the naming of this committee. For there is a distinction to be made between suicide and assisted dying. The former may trip off the tongue of academics, legals and indeed some medics based on decades of study and practice but there is good reason across the globe it is not used. As chair of End of Life Ireland, EOLI and all those we represent, thank you. Language matters.

Every one of us at EOLI has a personal reason for being involved in this time sensitive campaign, from having one or more serious life limiting diagnoses ourselves, having cared for and in some instances still caring for loved ones whose quality of life diminishes by the day. Some know well what it is to see one's life partner die and the lasting impact of pain endured over weeks, sometimes months.

- Legislation for assisted dying means a kinder death is possible.
- Lived experience shows it brings peace of mind
- Most importantly, the quality of what life remains to a dying person improves when they know assisted dying is an option.

The impact of a 'bad death' cannot be underestimated. With more time, I could tell you about Orla and her mother. Julie and her granny. David, who contacted me after his mother's funeral just a few weeks ago. People who have sold their home to travel abroad in secret for an assisted death to die alone, so as not to incriminate a loved one. These are Irish stories. Ireland can do better than this. A desperate way to die when a kinder, assisted death could be possible.

If we're being honest, most of us have probably said, if not at least thought 'if ever I get this, or that, or if I should lose my marbles....' I always said, when it's my time, let it be quick. And with one friend in particular, 'I need a plan B in case I need to get to Switzerland.' We'd laugh of course. Though now, as we're getting older, there's much that is left unsaid.

Why though, should anyone have to travel to another country for an assisted death, leaving aside the cost, stress and risk of imprisonment?

The people of Ireland have fought for marriage equality, divorce, abortion. 76% of the population of Ireland according to the June (2023) REDc poll, want to see legislation for Assisted Dying. More accurately, they want the right to be assessed and, if deemed eligible, to be able to have an assisted death, rather than be forced to endure what life remains to them in a way which they deem unacceptable. Once approved of course, as in any jurisdiction where legislation exists, one can always

change one's mind, even at the last minute. (around 35% of people in fact, do not proceed)

Assisted dying is an emotive topic on which many have plenty to say. It is multifaceted. Focus on the patient; draw on the international experience, expertise and evidence based best practices, Ireland can have not only legislation which we can stand over, but legislation that would allow someone in Marie Fleming's position, someone with an incurable, degenerative neurological condition to be deemed eligible.

We know safeguards can be included to both ensure capacity and protect personal autonomy as referenced by Professor of Ethics, Joan McCarthy. As a result of the Assisted Decision Making Act 2015 and the DSS, Decision Support Service in operation since April 2023, there's now the potential to support those who want/need assistance with decision making thereby ensuring an individual's end of life wishes, which may include for the Advance HealthCare Directive to allow for one's wishes for an Assisted Death are recorded from the outset whilst of sound mind. Legislation which is already in place as referred to in a document by Justin McKenna accompanying this opening statement based on his professional, legal career of over 40 years and on which you may have questions.

Our primary objective with EOLI is to foster conversations around death and dying whilst we're healthy. We believe **'Everything begins with a Conversation'**, of which I have many almost every day. However brief, they are never easy. Conversations with dying people, families of people who have died. Many of whom have witnessed prolonged periods of loved ones becoming increasingly less independent and their quality of life fast diminishing. These stories are as universal as the arguments 'for and against' assisted dying. For us, we believe choice lies at the heart of this legislation, obviating the need for 'sides' opting instead for greater understanding and acceptance of an individual's choice, even if it is in conflict with one's own beliefs/values.

EOLI has seen with the public information meetings we've been co hosting with Tom Curran and a group of Irish Doctors who also want to see legislation for Assisted Dying, that not only do people engage with this topic, they want to have control over how they die. How – and when people die matters. I know it matters to me and as the latest REDc poll from June indicates, so too does it matter to 76% of the population who want to see it for not only cancer patients, or 'terminally ill', but also those with neurodegenerative conditions. Without legislation, we are all at risk. People who can bear no more, will take matters into their own hands, whether it is through mail order procurement of drugs or other means. These are the unintended and often unreported consequences of no legislation.

Having come through cancer twice 20 years apart, and as a late onset type 1 diabetic, I am in 'that vulnerable' category and perhaps because I've seen the slow

decline and deaths of both family and close friends, I found myself on this advocacy path. I cannot help but wonder if it is only when something happens to you or someone you love, you move to a place of deeper understanding of why legislation matters.

I began making connections with advocacy groups on an early trip to NZ where my sister still lives and had her liver transplant some years back, going on to consult in NZ, then globally with legislators, legals, ethicists, researchers, and yet more advocacy groups. This means that information we provide is not only evidence based, but well sourced. It also means EOLI can facilitate access to an international network for Ireland's legislators, as well as with medics, which we have been doing in collaboration with www.maid.ie, the most recent sessions on Palliative Care in Australia and Alzheimers: A Canadian Perspective.

A professional network which has informed our two submissions submitted with our written statement and professional summary from Justin McKenna.

I've spent time also talking to those whose opinions and beliefs differ from ours to understand better what people are most fearful of. Importantly though, the greatest learning has come from the lived experience of people and the unreported cases and consequences where legislation does not exist.

Back in 2017, just over three years after Marie Fleming died of MS and the day after I heard Gaynor French speak I gathered a couple of friends together. This I realise now was the turning point for me and the beginning of what later would become End of Life Ireland. Gaynor French was a scientist, a mum, a granny. She was funny, loved life and had everything to live for. But she had metastatic breast cancer which had spread. Despite living with chronic pain, Gaynor kept campaigning right up to her death at just 48 years of age in 2018. Like Marie Fleming, Gaynor knew legislation wouldn't come in time for her. Just as Vicky Phelan supported the Dying with Dignity Bill of 2020 proposed by you Deputy Kenny, she did so in full knowledge it wouldn't come in time for her. Why? Because it was the right thing to do. When I asked NZ politician David Seymour what made him take on the campaign for Assisted Dying, the answer was simple. It was the right thing to do. No politician has ever lost votes by doing the right thing and the right thing to do is often not the easy thing to do either. I believe there is a moral imperative now to progress towards legislation irrespective of what the next general election brings. All parties should have assisted dying in their manifesto because Ireland is ready.

Last year I went to the World Federation Right to Die Conference in Toronto, to be hosted by End of Life Ireland in September 2024, where not only will there be an opportunity to hear and meet global experts, but also hear speakers reporting on the legislative reviews in NZ and Australia. All of which will help Ireland ensure legislation works effectively for those it is created to serve and safeguards do not

impede patient access. That expertise could also help us honour the autonomy of people who have lost capacity.

What I've seen is that legislation for assisted dying evolves, especially where it has been perhaps understandably overly conservative and governments have been challenged. Evolved where those excluded have been heard, changes introduced with appropriate routes to access to ensure patient safety.

Legislation evolves across all aspects of life, as Ireland has seen with same sex marriage and abortion. And society hasn't slid down a slippery slope or collapsed with either, or with the introduction of divorce. Democracy leads to legislative change. Fear ought not stop the progression to legislation.

Based on respecting an individual's end of life wishes, legislation ensures inclusion of voluntary assisted dying as a valid, patient centric compassionate end of life choice, supported by an administrative and medical framework designed to support the patient, which a doctor must be permitted to discuss along with all available EOL options. Prohibiting such conversation in my mind is akin to dereliction of duty, a failure to care.

Without legislation, people will continue to resort to mail order self medication kits. Risk imprisonment for helping a loved one. Take one's own life which can go terribly wrong and be traumatic for those left behind. Without legislation, nothing changes and the often unreported, unacknowledged, undocumented consequences continue.

Let us consider current legal options: to me they seem almost barbaric.

- **V-SED – Voluntarily Stopping Eating and Drinking** a legal, slow way to die and utterly inhumane.
- **Refusal of treatment:** Leads often to complications and deterioration of what quality of life remains. Impacting not only a person's suffering, mental, physical and spiritual but causes people who they love great distress.
- **Suicide:** Taking one's life. The word itself tells a different story, a perjorative term with negative, upsetting connotations.

The International Experience – Safeguards work: No evidence of coercion: No uncontrolled expansion. No legislation has been rescinded: And Switzerland not only operates within the law without legislation but will continue to be the 'go-to' destination when legislation is restrictive or does not exist.

Context: Only an individual can decide what is and will be acceptable to them. Conflation of societal issues referenced in this debate, poverty, housing, cost of medical care and assisted dying being offered instead are, of course, of concern but must be taken in context, evidenced rather than used to mislead and generate fear. Many of the much publicised scaremongering stories are rarely evidenced.

What we know is that coercion can go both ways. Is it only when someone has the direct experience of seeing someone they love dying, however long that process

may be, to have some inkling, an appreciation perhaps of why legislation for Assisted Dying matters?

It takes courage to voluntarily choose and have an assisted death. It may not be your choice, but why deny another the choice? Why not support them instead?

Being a burden.. Not wanting to be a burden is an understandable, natural, human response. Even if one finds themselves able to accept being a burden, if I do not feel ok, if I do not want to be 'that burden' then it is for me, as an individual, to determine. This is exactly how Brendan Clarke explained it to me. It has to be the individual themselves, who determines if their quality of life is acceptable. Brendan Clarke had MND and died before he could address this committee. I'd ask you to watch his video testimonial again. Live my life and you'll soon change your opinion, he said.

Which brings us to Autonomy.

The HSE, Irish Health Service Executive's appointed independent body HIQA (the Health Information and Quality Authority) set up to ensure 'high quality and safe care for those using our health and social care services) use a human rights-based approach to ensure safety and well being of our citizens. **Fairness. Respect. Equality. Dignity and Autonomy.** Guiding principles are summed up in this HIQA acronym FREDA.

For someone living with a terminal or incurable, life limiting condition, when you are in control of less and less in your life as each day passes and inevitably become increasingly dependent on others for the most basic, often most intimate of daily care, knowing that you can take control of how your life will end in a safe, legal manner matters. The FREDA principles are implicit in compassionate legislation for assisted dying, which will also regulate what is already happening for the person who does not wish to end their life being heavily or terminally sedated, instead allowing someone to be fully conscious and in control right to the end is, in my view a true act of compassion.

Do we want, as a society, to continue exporting our problems, as Ireland did with abortion? Do we want to continue to deny and gloss over, hush up the most tragic cases where people have taken their lives because there is no legislation?

This committee has the opportunity to consult with many specialists put forward by EOLI, like Dr. Greg Mewett on the Australian experience where assisted dying is part of the palliative care service where patients have made this valid end of life choice. Dr. Stefanie Green in Canada and Dr. Cam McClaren in Victoria. Hearing the experience of hospices like Totara, in NZ under the leadership of Tina McCafferty where the wishes of the patient are fully respected, unlike in other healthcare settings where patients have had to be trolled out because of the 'prevailing religious ethos' – we know a kinder death is possible.

In countries where legislation exists, palliative care and assisted dying do work together. It is not a case of either/or. We also know that in around 4% of cases palliative care does not alleviate pain. Pain is not just physical.

Evidence shows that where legislation exists, palliative care provision becomes better supported and more widely available.

EOLI, like the many dedicated global advocacy groups, has a deep understanding of Assisted Dying. We want to work with our government and help Ireland access the best specialists and advisors.

We and those we represent want the peace of mind legislation brings and not have to leave Ireland like a furtive criminal for an assisted death, or have to die earlier to be able to travel whilst still able.

No one should have to go through this to die alone because anyone helping risks up to 14 years imprisonment.

Instead, as so many reports show, the majority of us want to die at home. In our own country. Surrounded by those we love.

Much has been made in the media of society issues where more funding is needed. And End of Life Ireland fully agrees.

Yes. More funding is needed for palliative care.

Yes. More support is needed for suicide prevention.

Yes. More support for disability services provision.

Yes. More support for the elderly. The lonely. The homeless.

But these are separate issues and it's time to legislate.

We're asking you as legislators, to honour a person who has a terminal or life limiting diagnosis. Because time alone, 'foreseeable death' ought not be the sole basis for calculating eligibility criteria; some neurodegenerative conditions can go on for years as we see with Dementia, with MS. Debates around alleviating pain and claims of diminishing the patient/doctor relationship and the value of palliative care are the same the world over and need to be called out through respectful discussion of course.

Thank you. The last words Assisted Dying Providers hear from a patient. And the words providers of this vital, much wanted service will hear in the future. Dying people don't have time to waste campaigning, what we'd rather do is help create legislation we can be proud of with our government.

Thank you.