

Our Lady's Hospice & Care Services

Submission on Dying with Dignity Bill 2020

Thank you for the opportunity to make this submission in relation to the Dying with Dignity Bill 2020. I write on behalf of Our Lady's Hospice & Care Services (OLHCS), the largest single provider of specialist palliative care services in Ireland with a catchment population of over one million, and Hospices at three sites having community palliative home care teams covering all of south Dublin and east Wicklow, along with close links with the palliative care teams in all of the acute hospitals in these areas. OLHCS has also provided older persons care since its foundation in 1879.

OLHCS has experience over many decades in caring for patients and families facing the challenges and losses that come as end of life approaches. Our experience of providing care at end of life, of learning what patients and their families need, want and fear has informed our view that no form of "assisted dying" should be legalised in Ireland. We oppose the proposed Bill.

While our opposition to assisted dying is clear, we do acknowledge the value and strength of the opposing arguments; we have heard the voices of those we have looked after who have wanted euthanasia as well as the vastly larger number who have not. We recognise the very real fears of dependency, of being a burden to family and society and of suffering which can occasionally lead people to request hastening of their death. However, we do not believe that assisted dying – with the many risks it brings to the most vulnerable in society – is the way forward.

In considering this legislation, learning from individual patients' stories, from rigorous research, from experiences in other jurisdictions and from public discourse can all contribute and are important. However, what must also be acknowledged are the insights gained from directly relevant clinical experience of working at "the coalface" with the very same population and in the cultural milieu upon which this proposed legislation will most impact. It is this experience – gathered over many years and from caring for many patients and families - that we bring to the debate and which we wish to share with you.

Dying is part of life; it is normal, inevitable and sometimes sad beyond description. No two lives are the same; no two deaths are the same. Palliative care is concerned with how people live up until their death – we promote quality of life, we individualise care, we focus on the immense importance of good communication, of involving patients in decisions around their care. At the bedrock of what we do is that we neither hasten nor postpone death.

It is difficult to distil the learnings from years of caring for patients who are approaching the end of their lives but some themes recur and, we believe, show ways in which end of life care in Ireland could improve.

- We strongly advocate for more support for those living with a terminal illness and those facing end of life, for increased access to palliative care so that the pain and distress of patients and their loved ones can be comprehensively addressed.
- Modern medicine is normally focused on doing all that can be done. Approaching end of life, what **can** be done and what **should** be done can diverge and this distinction, when not recognised by patients, families or medical professionals, can lead to interventions that are futile and burdensome. More education is needed.

- We encourage more open discussion of death and dying and better advance care planning such that patients can receive the measured care that is right for them, so that their voices are always heard.
- We urge greater respect for patient autonomy. It is central to good palliative care and includes the right for a patient to decline or discontinue treatments and interventions which they view as burdensome or futile.

Providing assisted dying is not on this list and there are a number of reasons for this.

An observation we would make, while acknowledging that it can be interpreted in different ways, is that only very rarely do we meet patients with a persistent wish to have their lives actively shortened. Some will want this but fleetingly. A much larger group may be ready to die and perhaps even wish to die but that is not to say that they want to actively accelerate their own death or have someone else do this.

In contrast, fears of having their death accelerated are common and often cause distress and real problems. Frequently we meet patients or families who, fearful that their death would be hastened, refuse sound, evidence-based treatments that would help them. Add substance to these fears by making accelerated death in fact a service provided by healthcare and this issue can only grow.

Assisted dying, if legalised, would become seen as part of normal end of life care. It would be confused – not by everyone but by many - with palliative care. Consider that at present many patients will not come to a Hospice or even be referred to our home care teams for fear of what “Hospice” means. We meet this problem every single week and it is always challenging; it is sometimes heart breaking. Connect or confuse Hospice and palliative care with provision of assisted dying and this issue will increase - people will suffer as a result. Assisted dying for individuals comes with “side effects” for society.

Patients we care for with advanced illness can have profound feelings of worthlessness and guilt, can feel a burden to loved ones and to society. These feelings are understandable but in our experience they can be addressed and often pass. However, our view is that some patients would perceive assisted dying almost as a duty, as a way to relieve the burden on others. Again, assisted dying comes with side effects.

It is suggested that making assisted dying available would, for certain patients relieve their fears and bring back some control. We see the reason in this and, for a small number of patients, it would likely be true. However, for the much larger group of patients, those perhaps weary like never before from illness, questioning what their role in their family, in society, even in life is – what does it say to them that society is willing to hasten their death, that their doctors and nurses are willing to hasten their death? We believe the message would be undermining, would devalue life, would give basis to the fears they already have and would harm the therapeutic doctor-patient relationship.

Both sides in this debate agree that assisted dying – if legalised – would need to be limited to certain situations. To not do so is to systematically facilitate suicide. The difficulty is that limitations or exclusion criteria, no matter how carefully constructed, will exclude some of those who might have sought “with good reason” assisted dying. Thus the pressure not to exclude people builds; thus initial restrictions are inevitably challenged and then loosened. This has been seen in several jurisdictions; Ireland, we believe, would be no different. The oft-raised fear of a “slippery slope” is well founded and the concerns we have raised about the unintended consequences of legalising assisted suicide cannot be resolved simply by implementing restrictions.

If this legislation or some version thereof is passed, it will lead to a fundamental change in end of life care in Ireland. The repercussions will ripple throughout society, throughout healthcare and very definitely will impact on the delivery of palliative care.

The burdens and complexities faced by patients with advanced progressive illness and their families defy easy answers. We have met patients for whom assisted dying might well have been the right choice; we have heard them and we respect their views. But we have also met the many, many more for whom legalisation of assisted dying would bring fear, would bring uncertainty and would cause harm.

We acknowledge that the measures we suggest above will not address everyone's concerns. However, they strongly support and enable the individual patient and pose no threat to society. These measures are what patients and families have shown us they need, not assisted dying. We believe they are right.

January 25th 2021