## IHCA Opening Statement to Joint Oireachtas Committee on Assisted Dying, 17th October 2023

I would like to thank you Deputy Healy-Rae as Chair and your Committee colleagues for this opportunity to contribute to the Committee's considerations in relation to a statutory right to assist a person to end their life, or assisted dying.

The IHCA represents 95% of all Consultants working in Ireland's public hospital and mental health services. This includes Consultants in Palliative Medicine caring for patients with terminal and advanced progressive illnesses including advanced cancers, neurological and respiratory conditions, Consultant Physicians in Geriatric Medicine caring for older people, Consultant Psychiatrists working in such areas as General Adult Psychiatry, Psychiatry of Later Life, Learning Disability and Liaison psychiatry - treating mental health need in those with physical illness, Consultant Oncologists treating patients with late-stage cancer, and Consultant Anaesthesiologists/Pain Specialists who specialise in the management of pain related disorders.

The Association made a submission to the Committee on Justice on the Dying with Dignity Bill 2020 as part of the then public consultation process.

The perspective we bring is that of healthcare professionals. As healthcare professionals, we are entrusted with the profound responsibility of preserving life, but we also witness the pain and suffering that some patients endure. Hence, we also have a responsibility to enhance and optimise our patients' quality of life. These realities make the subject of assisted dying an intricate one for us, just as it does for so many people.

The debate on assisted dying raises complex medical, ethical, legal, and practical questions that deeply affect our role in patient care. It is therefore not surprising that, just like society as a whole, there is a diversity of views and opinions within the Association on the issue of assisted dying. These views are informed by the lived experiences of Consultants, particularly from those caring for the elderly, for persons with progressive incurable illnesses, mental health, addiction, cancer care, and pain among other specialities.

The standpoints will vary.

For some, assisted dying offers compassionate relief for those who often are experiencing intractable pain and terminal illnesses. These can be profound medical situations where we medical professionals are engaged in multiple efforts to cure or alleviate pain. There are times when every effort reaches its limitations. Some will conclude that assisted dying provides a humane means to reduce suffering and offer a degree of control in the face of that suffering.

Such realities also confront us with the opposite, equally valid perspectives.

Much of this is informed by the challenges faced every day in delivery of healthcare services. The challenge of timely access for patients to comprehensive health and social care supports, including pain and symptom control and home supports is considerable and today many patients do not have sufficient access to these services. We also at the outset need to be mindful that underdiagnoses is a reality in healthcare, both nationally and internationally which impacts persons with complex serious and progressive illnesses, older persons, and persons with physical or other disabilities.

For medical professionals, ethics, quality, patient safety and risk in healthcare matter. We see the importance of this every day, as do you as public representatives.

Ethical considerations must always be paramount in health. The ethical dilemma posed by intentionally ending the life of a patient could hardly be more profound. It challenges our fundamental commitment to preserving life and can potentially erode the trust that patients place in our care. We may find ourselves in a difficult position when asked to assist in a patient's death, straining the doctor-patient relationship to the ultimate limit. Doctors are required to act in the best interests of patients in their care and avoid causing any injury or harm to them. Section 46.9 of the Medical Council's 'Guide to Professional Conduct and Ethics for Registered Medical Practitioners' explicitly forbids doctors from participating in the deliberate killing of a patient.<sup>i</sup>

Equally quality, patient safety and risk are essential considerations in healthcare provision. All developments in healthcare are considered in the context of balancing potential risks and benefits. One of the risks from the introduction of any form of assisted dying is of the inappropriate death of a person. As we all know, death is irreversible. Hence, our keenness to contribute to this important and far-reaching discussion.

No two patients are the same. Rarely are two medical circumstances the same. Against the backdrop of this reality, you as legislators are informing yourselves not just of the merits of legislating for assisted dying, but what factors must feature in reaching any recommendations or conclusions.

Crafting effective safeguards to protect patients and medical practitioners alike if legislation or policy was to change on this issue is a central consideration, not least given the range of potential circumstances. However, the evidence internationally shows that safeguards in of themselves may be challenged, altered and sometimes removed.

Protecting vulnerable patients who may be placed at risk of coercion to end their lives to relieve the burden that they perceive is placed on their families, health services or society at large.

A major consideration which the Committee will need to consider in full is safeguards, both for patients and medical professionals. For example, the matter of a 'cooling off' period after a declaration of assisted dying, a requirement for a patient to be formally advised—in a fashion that is witnessed and recorded—of their right to withdraw from the process at any stage. How would this work? What would it mean for medical professionals? These questions also arise when it comes to oversight, scrutiny or investigation of the process by which declarations may be made and applied, as would consideration of this to be an independent process to protect patients' rights. We also must be mindful of 'freedom of conscience' provisions. How would this work in practice and implementation? Will medical practitioners be compelled by law to transfer a patient to another physician who can facilitate the request for assistance and how will that process be applied? Each of these and more are major considerations warranting evaluation in full.

Defining the clarity of the definition of assisted dying is important. For example, does it refer to self-administered medication or medication administered by another person? As signalled, rigorous operational guidelines on the eligibility criteria and ensuring informed consent are central considerations. Striking a balance between respecting patient autonomy and safeguarding persons who may be vulnerable is a substantial challenge here. Some of our members have shared examples from the relatively limited number of other jurisdictions of the potential unintended consequences and impacts. For example, in Canada, the criteria was extended from the initial inclusion of persons who have terminal illnesses to also provide for including persons with disabilities. Similarly in the Netherlands, criteria was expanded to include persons with dementia and psychiatric illnesses. The Netherlands allows children from the age of 12 to request assisted dying, with Belgium setting no age restrictions.

The area of mental disorders is one which warrants careful consideration as part of any conclusions and recommendations. We already know that patients are at increased risk of suicide in the six months following diagnosis but then the risk reduces. Caring for patients in these circumstances can be challenging. How to best do so, ensuring services are interlinked is key. If assisted dying was to become law, mental disorder care takes on an additional dimension, not least the interaction between mental health services and assisted dying services and what form this would take. As is always the case with healthcare, we must consider too here; the issue of resources, both for patients who may wish to choose end of life, for patients who do not wish to end their lives early but feel that they have inadequate supports to enable them to live as they wish. We know internationally that one of the main reasons why patients choose assisted dying is a fear of being a burden on others.<sup>ii</sup>

The severe resource and capacity deficits that exist in our health services may serve to further disadvantage patients suffering from life limiting or terminal illnesses and lead them to consider assisted dying and other end of life options that could otherwise be avoided with appropriately funded palliative care, pain management, mental health services, disability services, hospice or home hospice care and other services. To date the healthcare budget spends about 1% on specialist palliative care services.

The HSE estimates that the number of Palliative Care Consultants will need to increase by 175%, from the current 40 Consultants to around 110 Consultants by 2028 to address current shortfalls and meet increased patient demand.<sup>iii</sup>

How assisted dying may impact the provision of palliative care is fundamental.

Palliative care, which may include end of life care, can be instrumental in managing the symptoms of patients approaching end of life and is fundamental to ensuring that such patients have dignity both in living with advanced progressive illnesses and in dying. However, better access to pain management and treatment is needed to relieve the suffering that many patients experience as a consequence of terminal illnesses. This is important because many patients do not want to die, but rather want to be relieved of their suffering. This is equally true of patients with painful and debilitating chronic conditions that are not necessarily terminal.

It is estimated that 80% of deaths in Ireland are from conditions considered to have palliative care needs.<sup>iv</sup> While the majority of patients under the care of Consultants in Palliative Medicine will have a diagnosis of cancer, almost a fifth may have non-malignant illness mainly end-stage pulmonary and cardiac disease as well as neurodegenerative diseases. The aim must be to ensure that any patient who is suffering from a terminal or indeed chronic illness has timely access to appropriate and high-quality care to address their individual healthcare needs, including multidisciplinary care and the effective management of chronic illness and pain.

Indeed, the definition of 'terminal illness' itself would need to be specified such that it would not encompass long-term conditions or illnesses perhaps far outside those originally contemplated.

Our members have also rightly highlighted the need for this debate to take account of people with disabilities and their right of access to appropriate supports and services which are holistic in nature. Assisted dying cannot be an alternative to timely, accessible, comprehensive high-quality health and social care supports for the people of Ireland especially for those with complex serious illnesses. Members have also informed us that patients and families can be concerned or reluctant to get involved with palliative care because of fear that palliative care hastens death.

In conclusion, as medical professionals, the debate on assisted dying directly impacts what we do. We see the matter from all sides.

Compassion. Suffering. Ethical. Medical. Legal. Practical.

In short, complexity that requires thorough examination, consultation with healthcare experts and others, careful consideration, and a deep respect for the values that guide our medical profession.

To this end, this Committee, and all contributions to it, are to be commended and respected.

As we navigate this complex terrain, our involvement as medical professionals is pivotal in ensuring that the conversation remains focused on the best interests and well-being of the patients we serve.

Thank you.

## ENDS

<sup>iii</sup> Demand for Medical Consultants and Specialists to 2028, HSE NDTP, 2020 – updated; <u>https://www.hse.ie/eng/staff/leadership-education-development/met/plan/demand-for-medical-consultants-and-specialists-to-2028-november-updates-v2.pdf</u>

<sup>&</sup>lt;sup>i</sup> Medical Council Guide to Professional Conduct & Ethics 2019 (8th Edition).

<sup>&</sup>lt;sup>ii</sup> Oregon Death with Dignity Act 2022 Data Summary, Oregon Health Authority,

https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNIT YACT/Documents/year25.pdf.

<sup>&</sup>lt;sup>iv</sup> Adult Palliative Care Services Model of Care for Ireland, HSE, 2019.