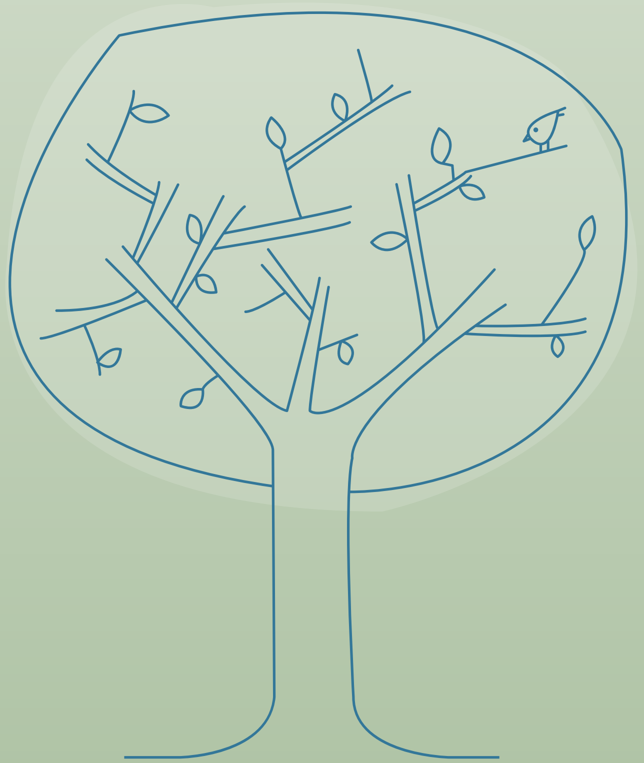
Irish Association for Palliative Care

Position Paper on Assisted Dying

May 2023



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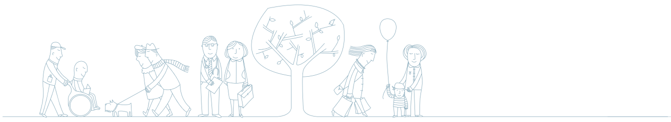

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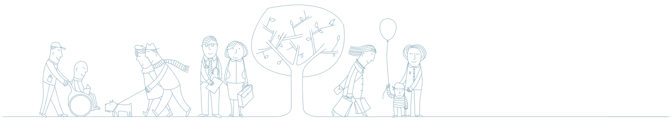


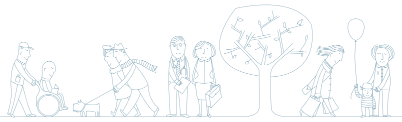
1. Executive Summary

Palliative care is a philosophy of care, focused on quality of life, and providing multidisciplinary holistic care to people with life-limiting conditions, and their families. Through the practice of palliative care, care can be provided not just at end of life but at any stage of a life-limiting illness. Palliative care should not involve any action or treatment which is designed to cause a patient's death. As such, the Irish Association for Palliative Care (IAPC) has put together this position paper, explaining why the use of euthanasia and physician assisted suicide is not compatible with the goals of providing palliative care.

In this position paper, we explore patient autonomy, supporting a patient's right to make choices, including the right to decline treatment, and to make advance healthcare decisions. We discuss management of symptoms, and appropriate care to support patients who are dying to do so with dignity. We examine the risks of coercion, both intended and implicit, and the experience of other jurisdictions and healthcare systems in which euthanasia and physician assisted suicide have been introduced.

The IAPC endorses the importance of access to palliative care for all who need it. We acknowledge the suffering of those with serious medical illnesses. Our focus is on supporting people experiencing physical and existential distress, seeking to alleviate that suffering, rather than ending their lives. The IAPC does not support any change in the law to legalise euthanasia or physician assisted suicide.

This document represents a consensus view of the IAPC. The views of individuals within the organisation may vary from those in this position paper. This document was produced by the IAPC Ethics Forum which is a multidisciplinary committee drawn from the membership of the IAPC.



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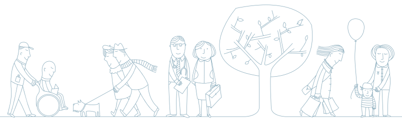
2. Glossary

Advance healthcare directive:	Assisted Decision-Making Capacity Act: Section 82 "advance healthcare directive"— "(a) in relation to a person who has capacity, means an advance expression made by the person, (in accordance with section 84), of his or her will and preferences concerning treatment decisions that may arise in respect of him or her if he or she subsequently lacks capacity" (Assisted Decision-Making (Capacity) Act, 2015).
Assisted dying:	The process where a person is helped to end their life by being prescribed or administered certain lethal medication by a clinician (College of Physicians and Surgeons of British Columbia, 2022).
Euthanasia:	Occurs when a doctor intentionally causes the death of a person by the administration of drugs or by carrying out an intervention at the voluntary request of the person who has decision-making capacity (World Medical Association, 2019).
IAPC:	Irish Association for Palliative Care.
MAID:	Medical Assistance in Dying (See Assisted Dying).
Palliative Care:	Palliative care is care that improves the quality of life of patients and their families who are facing the problems associated with life-limiting or life- threatening illness. Palliative care prevents and relieves suffering by means of early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems (World Health Organization, 2015).
PAS:	Physician Assisted Suicide describes the circumstance in which a physician, at the voluntary request of a person with decision-making capacity, enables that person to end their own life by prescribing or providing medical substances with the intent to bring about death (World Medical Association, 2019).



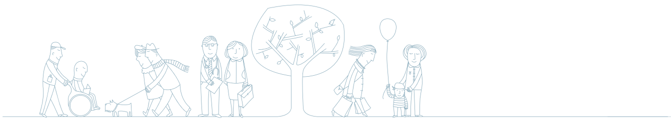
3. Introduction

Palliative care is a philosophy of care, providing multidisciplinary, holistic care to people with life-limiting conditions, and their families. It is focused on their quality of life. It seeks at all times to respect the integrity, individuality and unique worth of each person regardless of their ability or functional status. Palliative care recognises that it may not be possible or appropriate to postpone death, but, equally, death must not be hastened. Palliative care should not involve any course of action or treatment which is designed to cause a patient's death. For those in the terminal phase of their illness, palliative care is about caring for a person with a life-limiting illness, not about ending life.

Assisted dying is the process, where a person is helped to end their life by being prescribed or administered certain lethal medication by a clinician. Euthanasia is a doctor intentionally causing the death of a person by the administration of drugs or by carrying out an intervention, while physician-assisted suicide (PAS) refers to a physician enabling that person to end their own life by prescribing or providing medical substances with the intent to bring about death. Both of these are at the voluntary request of a person with decision-making capacity (World Medical Association, 2019).

Requests for euthanasia or assisted suicide are often motivated by fears of loss of autonomy, loss of dignity and reduced quality of life. Other motivations include worries of uncontrolled physical or psychological suffering, and the possibility of being subjected to treatments that are inappropriate, burdensome and ultimately not beneficial (Emanuel et al., 2016).

This position paper is written within the framework of ethical decision-making. We acknowledge that all actions must be weighed up against potential benefits, risks, alternatives and consequences. We acknowledge that people on all sides of the discussion on euthanasia and physician assisted suicide are motivated by compassion and a keenness to support people through to the end of their lives.



4. A Patient's Right to Make Treatment Decisions

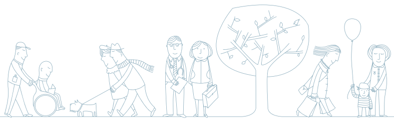
An integral part of the right to consent to medical care is the right to refuse treatment, even if that treatment is life prolonging. This right is recognised both legally and ethically (Medical Council, 2019). All patients are assumed to be competent to make decisions. If there are any doubts about this, competency to make decisions can be assessed by one or more clinicians. The IAPC endorses the right of the competent, informed patient to decline medical treatment, even if this leads to their death.

The situation is more complex when an individual patient is unable to make decisions regarding their treatment options independently. Where patients have written an advance healthcare directive, and the decision covers the situation that has arisen, then the advance healthcare directive should be followed, in line with Irish Medical Council guidelines and the Assisted Decision Making (Capacity) legislation (Assisted Decision-Making (Capacity) Act, 2015; Assisted Decision-Making (Capacity) (Amendment) Bill, 2022). An advance healthcare directive has the same ethical status as a decision made by a patient at the actual time of an illness and should be respected on condition that it was:

- an informed choice
- the decision covers the situation that has arisen
- the patient had not changed their mind (Medical Council, 2019).

In situations where no advance healthcare directive exists, and a person may require assistance in exercising their decision-making capacity, decisions should be made in accordance with the person's will and preference, in conjunction with any decision-making supports that may be in place (Assisted Decision-Making (capacity) Act, 2015). The risks and benefits of continuing treatments should be reviewed to ensure that the most appropriate care is being provided. Doctors are not obliged to initiate or persist with treatments that are disproportionately burdensome. In this context, it is the burdensome nature of the treatment, and not the disease, that is under consideration. Although a patient may request a certain treatment or procedure, they cannot force a physician to comply with the request, especially if the treatment or procedure is unlawful or medically non-beneficial.

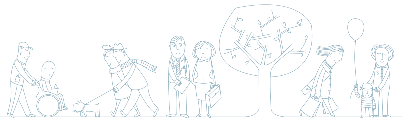
Palliative care emphasises good communication between patients and healthcare professionals and the collaborative nature of care. The importance of establishing trust between the patient and the healthcare team is vital so that patients know that their wishes will be respected, even when they are no longer able to voice them. Trust is a key element of any patient-doctor relationship. The legalisation of euthanasia / PAS could lead to the erosion of trust between patient and doctor (Hudson et al., 2015).



5. Treatment of Symptoms

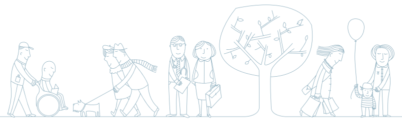
Both the Irish Medical Council (Medical Council, 2019) and Nursing Midwifery Board of Ireland (NMBI) (Bord Altranais agus Cnáimhseachais na hÉireann, 2021) state in their guidelines that when death is imminent, it is the professionals' responsibility to ensure that a patient dies with dignity. Basic principles of palliative care require that doctors offer patients appropriate medication to ensure that they are comfortable and pain free, which may include analgesia and sedative medication. There is no evidence that the judicious use of strong painkillers (opioids) shortens life (Sim et al., 2014).

The IAPC recognises that for a variety of reasons, a patient in the final days and hours of life may experience restlessness and agitation. The clinician must regularly reassess the patient in order to identify potentially reversible causes of this. On occasion, it is necessary to use sedative medication in the final stages of life in order to achieve an acceptable level of patient comfort (Cherny & Radbruch, 2009). The dosage of medication required by one patient may vary significantly from that required by another. It is the clear duty of the doctor to ensure that a patient dies with dignity and with as little suffering as possible. Treatment to relieve distress should not be withheld as long as a doctor acts in accordance with responsible medical practice, and seeks advice when necessary. Doctors and healthcare professionals should optimise treatment of physical, psychological, social and spiritual symptoms and they must avoid injury or harm to their patients.



6. Personal Autonomy

Excellent health services, including an excellent palliative care service, will not eliminate all requests for euthanasia / PAS. Requests for euthanasia or assisted suicide are often motivated by fears of loss of autonomy. Healthcare professionals have a duty to provide care which respects the values and wishes of patients, and which aims to enhance the patient's personal autonomy and sense of self-worth. For some, euthanasia / PAS may be considered an expression of this personal autonomy. However, individual autonomy is not absolute, and needs to be balanced against the rights of others, and the needs of society as a whole. It is particularly important to consider the rights of those who are more vulnerable, whether that be due to health status, frailty or social status. Regard for the autonomy of the individual cannot require health professionals to honour requests for euthanasia / PAS, given the harm which could ensue for the patient, for society and for healthcare professionals. The practice of euthanasia / PAS results in the death of a person. This is contrary to the principle of avoiding harm which is, in essence, the most fundamental principle governing the doctor-patient relationship. Our focus should be on supporting people experiencing physical and existential distress, rather than seeking to end their lives.



7. Dignity

Justice is generally interpreted as fair, equitable, and appropriate treatment of persons. The dignity of the human person is not only a fundamental right in itself but constitutes the real basis of all fundamental rights. The 1948 Universal Declaration of Human Rights enshrined human dignity in its preamble:

> *"Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world"* (United Nations, 1948).

Some associate the loss of physical and cognitive functioning, which can occur at end of life, as being synonymous with a loss of dignity, and see euthanasia / PAS as a solution to this. However, human dignity cannot be lost through illness or disability, because it is inherent in each person. This is affirmed in the Universal Declaration of Human Rights.

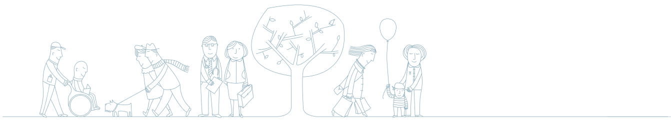
> *"All human beings are born free and equal in dignity and rights"*
> (United Nations, 1948).

Medical, nursing and other health professionals have a duty to provide dignity in care, to optimise the person's comfort and prevent suffering. This can be achieved without hastening death and shortening a person's life.

It is important to recognise the dignity of the lives of those affected by disability, long term health conditions and lower socioeconomic status. Experience from Canada and the Benelux countries where euthanasia and PAS are legalised, have shown the progressive expansion of eligibility in practice. The UN Special Rapponteur for Disabilities stated its concern about the risk to persons with disabilities from Canadian MAID practices (Devandas-Aguilar, 2019). These countries have shown the potential impact of relaxing criteria for euthanasia and PAS in practice on people living in poverty (Zhu, 2022).

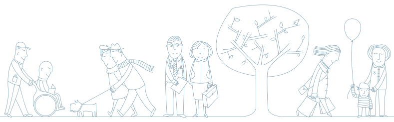
In Canada, a cost analysis demonstrated the net reduction of healthcare costs that result from the introduction of MAID (Office of the Parliamentary Budget Officer, 2020). It is stressed that this report should in no way be interpreted as suggesting that MAID be used to reduce health care costs. We also stress that potential financial savings should not guide decision making about assisted dying at an individual level (Trachtenberg & Manns, 2017).

Quality of life is not measured simply in terms of physical well-being or productivity. It can be enriched at a profound level, even for those who are severely ill. We need to support and affirm the meaning in people's lives, learn what is intolerable and respond to people's needs (American Medical Association Council on Ethical and Judicial Affairs, 2019).



8. Coercion

A key risk in allowing the option to request euthanasia / PAS is the assessment of whether a choice is being made freely. People respond to the wishes and feelings of others, most especially when we are dependent on them for care. Coercion, intended or implicitly experienced, may not be identified, by either healthcare professionals or others. Issues such as depression, loss of hope and the fear of being burdensome are more clearly linked to a desire to hasten death for terminally ill patients than the severity of physical discomfort (Racine, 2018). The ban on healthcare professionals shortening a person’s life protects those who feel they ought to die. It acts as a form of protection for vulnerable patients who may be basing their decision to die on confounding addressable factors, such as a sense of being burdensome or mental health conditions.



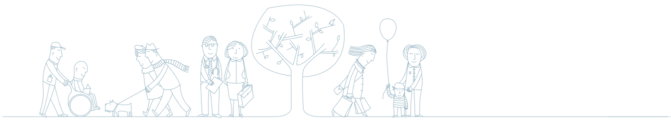
9. The Legalisation of Euthanasia

Introduction of legislation to legalise euthanasia / PAS usually invokes safeguards and limits of prognosis to seek to avoid misuse of euthanasia / PAS. In jurisdictions in which these have been legalised, safeguards have changed over time. Eligibility for PAS has expanded to include children in Belgium (Kelly, 2014), infants in the Netherlands (Verhagen & Sauer, 2005) and persons with disabilities whose deaths are not foreseeable in Canada (Government of Canada, 2021).

There is concern about the normalisation of euthanasia / PAS in societies where it has been introduced (Herx et al., 2020). Setting a permissible threshold below which people may seek assistance to end their life, changes the sense of equity and solidarity which sustains civil society (Royal College of Physicians Ireland, 2021).

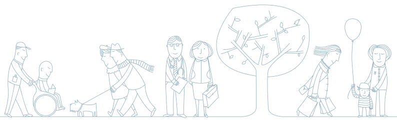
Access to adequate palliative care services is deemed essential by the World Health Organisation (World Health Organisation, 2023). There has been concern expressed in the international literature, by healthcare professionals and by medical professional bodies that legislation for assisted dying will shift the focus away from the development and delivery of palliative care services (Ho et al., 2021; Mathews et al., 2021; Royal College of Physicians Ireland, 2020).

A focus should be placed on ensuring that patients have access to resources and discussions about end of life and dying. Healthcare professionals need to be upskilled and supported to feel able to engage in conversations about death and dying with their patients. Too few are aware of options for end of life care, raising concerns that patients may request euthanasia / PAS because of fears around physical suffering which could be relieved (American Medical Association Council on Ethical and Judicial Affairs, 2019).The IAPC endorses equity of palliative care for all who need it.



10. Conclusion

The Irish Association for Palliative Care does not support any change in the law in order to legalise euthanasia / PAS. We acknowledge the suffering of those diagnosed with serious medical illnesses. Solutions lie in improving palliative care and social conditions, and addressing the reasons for euthanasia / PAS requests, rather than changing legal and medical practice to allow it. The IAPC endorses the importance of access to palliative care for all who need it.



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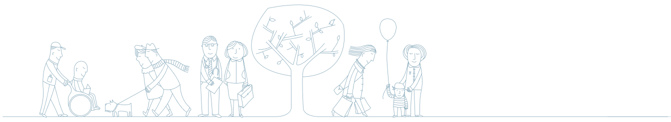

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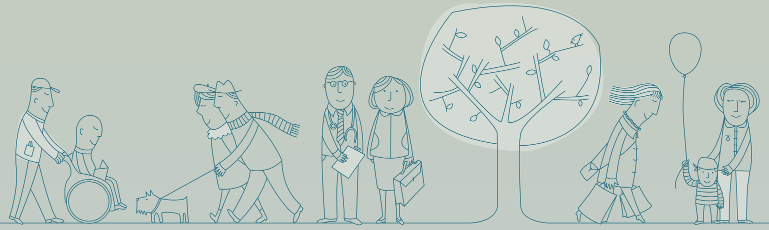

Established in 1993 as an all-island body with the purpose of promoting palliative care nationally and internationally, the Irish Association for Palliative Care (IAPC) is a multidisciplinary membership non-government organisation. The intention of the founders was that IAPC would be identified by its inclusiveness and would encompass the whole island of Ireland.

The IAPC membership reflects the entire spectrum of all those who work in or have a professional interest in the provision of palliative care. This includes doctors, nurses, social workers, chaplains and pastoral carers, pharmacists, psychologists, physiotherapists, occupational therapists, dietitians, as well as executive staff, academics and educators. Membership also includes clinicians and allied health professionals working in related areas such as geriatrics, oncology, psycho-oncology, paediatrics, and pain management.

The IAPC is organised around a number of working groups designed to create forums aimed at promoting best practice, professional development, research and learning in palliative care.education and research.

Irish Association for Palliative Care
Carmichael House, 4 Brunswick Street North, Dublin 7 D07RHA8
T: 01 873 4735
F: 01 873 5737
E: info@iapc.ie

www.iapc.ie for more information and on-line membership application