

Opening Statement to Joint Oireachtas Committee on Justice and Equality from the Irish Association for Palliative Care

Good morning Chairman and members of the Committee.

Thank you for inviting the Irish Association for Palliative Care to this meeting. The IAPC is an organisation of healthcare professionals involved in the delivery of palliative care across the country, and a collective and expert voice driving patient-centred, equitable and accessible palliative care for all who need it, and I am here to present the views of the IAPC on this issue.

Palliative Care is defined by the World Health Organisation (2002)¹ as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative Care seeks at all times to respect the integrity, individuality and unique worth of each person regardless of his/her ability or functional status. Palliative care affirms life and regards dying as a normal process and as a key principle intends neither to hasten nor postpone death.

Palliative care in Ireland is provided by healthcare professionals who care for people with life-limiting illnesses; this is provided by GPs, nursing home staff and hospital staff, for example oncologists and geriatricians, and by specialist palliative care staff, who care for people with complex problems related to life-limiting illness. The IAPC recognizes that palliative care should be provided on the basis of need, and not on the basis of diagnosis or prognosis.

The IAPC supports the work of the National Clinical Programme for Palliative Care. The IAPC welcomes the recent launch by Minister Simon Harris of the Palliative Care Three Year Development Framework².

The IAPC works to support healthcare staff who want to help people with life-limiting illness live with and die with dignity. The IAPC rejects the idea that 'dying with dignity' is associated with the right to assisted suicide or euthanasia.

A Patient's Right to Choose Treatment

One of the arguments advanced in favour of assisted suicide or euthanasia is a patient's concern that he/she will be subjected to treatments that are inappropriate, troublesome or futile. The IAPC recognizes that people have life-limiting illnesses, and regards dying as a natural process. Palliative care emphasises good communication between patients, those who matter to them and healthcare professionals. The IAPC endorses the right of a competent, informed patient to refuse medical treatment. We also recognize the right of a patient to make an

¹ WHO definition of Palliative Care - <http://www.who.int/cancer/palliative/definition/en/>

² HSE Palliative Care Three Year Development Framework

<http://hse.ie/eng/services/publications/Clinical-Strategy-and-Programmes/palliative-care-services-development-framework.pdf>

advance healthcare plan and for that plan to be respected in line with the HSE consent policy³ and the Medical Council Guidelines⁴. In situations where no advance healthcare directive exists, the health care professionals are obliged to act in good faith, and on behalf of the patient, considering the patient's best interest. As all parts of the Assisted Decision-Making Act are commenced, the IAPC will work to ensure its members are well informed and able to support patients.

Treatment of Symptoms and other causes of distress

Treatment of pain and other physical symptoms is a cornerstone of palliative care; symptoms can always be treated, and either reduced or eliminated. This requires input from all members of the multidisciplinary team, and specialists in other disciplines, for example radiotherapy. We recognise that for a variety of reasons, a patient in the final days and hours of life may experience restlessness and agitation, or may have other intractable symptoms. On occasion, it is necessary to use sedative medication in the final stages of life in order to achieve an acceptable level of patient comfort⁵. Treatment is appropriate when the intention of treatment is patient comfort, the harmful effects of treatment are foreseen but are not intended, and the benefits of treatment outweigh the burdens for the patient. Both the Medical Council of Ireland⁶ and the Nursing and Midwifery Board of Ireland guidelines⁷ state that when death is imminent it is the professionals' responsibility to ensure that the patient dies with dignity.

The IAPC is aware that there needs to be greater awareness among the public and healthcare staff about the value of palliative care, and greater education and training for healthcare staff to ensure that all staff meet the appropriate Palliative Care Competences developed by the National Clinical Programme for Palliative Care⁸.

There are areas within palliative care which need development, for example research into the best management of breathlessness and provision of advice and support outside regular working hours. These are among the top ten priorities for palliative care research identified by the All Ireland Institute for Hospice and Palliative Care⁹. The acceptance of assisted suicide and euthanasia could lead to an under investment in palliative care research and service delivery, as assisted suicide and euthanasia may be promoted as cheaper options than appropriate health care provision.

Personal Autonomy and Society

³ HSE Consent Policy http://www.hse.ie/eng/services/list/3/nas/news/National_Consent_Policy.pdf

⁴ Medical Council Guide to Professional Conduct and Ethics for Registered Medical Practitioners 7th Edition 2009.

⁵ IAPC Position Paper: Palliative Sedation 2011.

⁶ Medical Council Guide to Professional Conduct and Ethics for Registered Medical Practitioners 7th Edition 2009.

⁷ The Code of Professional Conduct for each nurse and midwife. An Bord Altranais 2000

⁸ HSE Palliative Care Competence Framework

<http://lenus.ie/hse/bitstream/10147/322310/1/CompetenceFrameworkFinalVersion.pdf>

⁹ AIHPC Top 10 Palliative Care Research Priorities <http://aiihpc.org/research/launch-of-top-10-palliative-care-research-priorities/top-10-palliative-care-research-priorities-list/>

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 patients the availability of high quality palliative care will seem to have no relevance. For some, assisted suicide or euthanasia may be considered an expression of personal autonomy. However, individual autonomy is not absolute: it must be balanced with consideration of the needs of society as a whole. The legislation of assisted suicide or euthanasia may put pressure on vulnerable people, including, to quote from a recent High Court case 'the aged, the disabled, the poor, the unwanted, the rejected, the lonely, the impulsive, the financially compromised and the emotionally vulnerable' who may elect to hasten death so as to avoid a sense of being a burden on family and society.

Changing the law to allow assisted suicide and euthanasia will endanger the lives of many. Despite suggestions that abuse of this type of legislation can be prevented, there is evidence even with laws and regulations, many vulnerable people are at risk currently. Last year, the HSE received close to 8,000 reports of abuse of vulnerable people. The National Safeguarding Committee published research earlier this year, revealing that half of the population had witnessed abuse of an adult; 38% believed vulnerable people were badly treated¹⁰. Given the current problems in society in relation to protecting vulnerable people, it may not prudent to assume vulnerable people can be protected in the context of assisted suicide and euthanasia. Recent research published in the British Medical Journal has shown failures in the Dutch regulatory system. Concerns have been expressed by the Swiss Medical Association about offering euthanasia to those who are not terminally ill. In Belgium, there is conflict among medical professionals about the practice of a psychiatrist who is offering euthanasia to people with significant psychiatric problems, while undermining the second opinion system required in that country.

A recent study has highlighted gender issues in assisted suicide; women are more likely to live longer with greater disability; they are more likely to have less social support, more likely to die because of euthanasia or assisted suicide, and also are more likely to be a victim of 'mercy killing' by a male family member in cases which have come to the criminal courts in different countries.

An argument sometimes used in support of a change of legislation in relation to assisted suicide is the fact that suicide is not illegal. However, the decriminalization of suicide was a recognition that those who survive a suicide attempt need treatment, not prosecution. Suicide is rightly considered a blight on society and there are many efforts made to reduce it. That there are some people for whom suicide is considered appropriate may suggest that there are people whose lives are not deserving of the same level of protection.

Conclusion

The IAPC represents healthcare professionals who have day to day experience caring for people with life-limiting illness, including many who are vulnerable either as a result of serious illness or because of other factors.

¹⁰ Vulnerable Adults in Irish Society Nationwide Public Opinion Survey <http://safeguardingcommittee.ie/wp-content/uploads/2017/04/Red-C-Survey-Vulnerable-Adults-in-Irish-Society-060417.pdf>

The IAPC believes that there should be no change in the law to allow assisted suicide or euthanasia because:

1. A change in the law would put vulnerable people at risk
2. It is not possible to put adequate safe-guards in place.
3. The drive to improve the care of people with life-limiting illnesses by education, service development and research may be compromised
4. Personal autonomy is not absolute and we are part of a society
5. Allowing assisted suicide or euthanasia for some populations for example the terminally ill or the disabled, devalues the lives of those compared to those targeted in suicide prevention campaigns.

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