

Executive summary

- Euthanasia, or assisted dying in any form, is antithetical to the purpose and practice of medicine in general and has the potential to put pressure on vulnerable people to end their lives, undermine palliative care services and change society's broader perceptions about killing.
- There is evidence that it may also affect suicide rates and have adverse impacts on the professionals who are involved with the prescription or administration of lethal drugs.
- Requests for hastened death are not uncommon but are rarely sustained once effective palliative care is provided. The most common factors precipitating such requests are psychological in nature. It can be difficult even for psychiatrists to identify depression in those approaching death and a major concern has been expressed about the ability of clinicians to determine who is psychologically suitable for (i.e. competent to request) assisted death services.
- The sense of hopelessness that accompanies many towards the end of life can be limited and hope can be restored once its absence is addressed. This requires effective and compassionate communication by clinicians over time to ensure all aspects of hope are addressed.
- Palliative care in the United Kingdom is widely available but not always understood by the public and the professions alike. Education on palliative care is inadequate in our universities considering the importance of this aspect of medical care. All doctors will have to care for people near the end of life, particularly in their early years of practice, so adequate and effective education is needed before graduation and subsequently.
- The effect on health professionals of legalising euthanasia is underestimated by many. The effects can seriously adversely impact on individuals' ability to continue to practice.
- International experience shows that the circumstances under which assisted dying can take place are often extended over time and the practice can also be open to abuse.
- Along with the majority of the palliative medical profession in the United Kingdom and worldwide I remain strongly opposed to legalising euthanasia or assisted dying in any form.

Introduction

I retired from clinical practice in 2019 when I was a Senior Medical Specialist in Palliative Care at Hibiscus Hospice in Red Beach, Auckland and Senior Consultant in Palliative Care for HammondCare, Sydney. In addition, I was, until 2019, Honorary Professor in the Sydney Medical School in Sydney, Australia. I have been involved in the provision of specialist palliative medicine for over 30 years first becoming a full-time specialist in palliative care in 1989 with responsibility for a large urban and rural population in Bath in the southwest England with the Dorothy House Foundation. While I was in the United Kingdom I also started to teach about end of life care.

In 1994, I moved to New Zealand to take up the position of Director of Palliative Care at the Mary Potter Hospice Foundation in Wellington. During my time in New Zealand, I have worked as a Medical Director of Palliative Care in hospices in Wellington, Dunedin and Auckland. In 2003, I was appointed as New Zealand's first Professor in Palliative Care (South Link Health Chair) at the University of Otago, Dunedin School of Medicine. In 2012, I was appointed as Conjoint Professor in Palliative Care at the University of Sydney, a position I held for five years.

In my current research, I work closely with colleagues at the University of Otago and the University of Sydney on aspects of spirituality in end-of-life care. I am also currently involved in the supervision of PhD students investigating topics related to care near the end of life. I continue to teach about palliative care and the nature of care near the end of life. I am one of the co-editors in chief of the *Textbook of Palliative Care* published by Springer.

In 2015, I was appointed a Member of the New Zealand Order of Merit by Her Majesty the Queen for services to hospice and palliative care.

Palliative care

Palliative care provides relief from pain and other distressing symptoms by incorporating treatment of physical symptoms with the psychological, social and spiritual aspects of patient care. The practice of palliative care operates to affirm life but acts to neither hasten nor postpone death. Palliative care offers a support system to both patients and their family to help them cope through the patient's illness and the grief and bereavement that results at the end of life. There is a broad international consensus on the need to recognise access to palliative care as a fundamental human right. This was most clearly spelled out in the 2005 'Korea Declaration' which called on governments throughout the world to recognise this right.¹

In the vast majority of cases, physical pain can be managed and is almost never irremediable. Over two decades ago, the World Health Organization reported that there were readily available methods for relieving pain in up to 90 per cent of patients.² Since then, pain management has only improved.

The broader suffering of terminally ill patients is a difficult concept to grasp. Suffering is inherently unique to individuals and is quite different to the presence of pain. Relief of pain will not always relieve suffering. Suffering includes holistic suffering, which can be multidimensional, oscillating and

¹ 2nd Global Summit of National Hospice and Palliative Care Associations (2005): 'Declaration on Hospice and Palliative Care March 2005', para 14. Viewed online, 5 August 2014, http://www.coe.int/t/dg3/health/Source/KoreaDeclaration2005_en.pdf

² World Health Organization, 1996. *Cancer pain relief* (2nd ed.), Geneva, 14.

difficult to express, articulate or explain. Nevertheless, opportunities should be provided for patients to express their suffering. The potential for suffering to be transcended needs to be recognised and facilitated by healthcare staff.

To do this, they must assess the individual strengths and coping styles, experiences and even previous losses of terminally ill patients and their families. The initial assessment by palliative care specialists will include a detailed medical and nursing assessment of the patient and their family's needs. The time invested in this initial assessment is essential in creating a framework for the provision of future care; a partnership between patient and professionals. The initial assessment may indicate the need for more formal psychological, spiritual or social assessment. This will include the need to maintain autonomy which includes respect for dignity and the opportunity to exercise choice.

Communication and understanding are critically important aspects of palliative care. Ensuring that patients, along with their family and friends, understand what they are going through, what they can expect, their options and their rights regarding treatment, are all at the core of good practice. Communication and full understanding allow patients and their family and friends to make informed choices about their care and treatment and to fully engage and have control during what is a very difficult time in their lives.

Hope is also a significant part of palliative care. The ability to maintain hope is an integral part of being a human being. For those suffering a terminal illness or who are at the end of their lives it is understandable why it can be difficult to maintain a sense of hope. Towards the end of life, it is often assumed that 'there is no hope'; indeed, that language has been used by clinicians in the past (and perhaps still is). Palliative care aims to restore, build or maintain hope in terminally ill patients, their family and friends in a way that assists their spiritual and emotional wellbeing. For example, rather than hoping for a cure or remission from disease, hope can be focussed on more immediate aspects of life such as hope for a good night's sleep or hope to feel the touch of a loved one again. This refocussing of hope is an integral part of palliative care.

Palliative sedation

Palliative sedation is a strategy of last resort in palliative care. It is used to minimise distressing refractory symptoms that are difficult to manage. In my experience, it is used very rarely and only when a patient near the end of their life is experiencing intractable suffering. It should only be used with the informed consent of the patient and family.

There is a common misconception that palliative sedation hastens death and some argue that this already amounts to euthanasia. This is incorrect. Palliative sedation does not hasten death. The aim of treatment is to 'mask' or 'cloak' (the literal translation of the verb to palliate) the symptoms, such as pain or breathlessness. The medications used are generally short-acting sedatives, used at a dose to reduce awareness, not to halt breathing. It is also reversible. The intention behind sedation therefore is to sedate, calm and reduce distress and anxiety. There is no intention to hasten the patient's death or that the patient's death should be brought about by such sedation. In all palliative care practice, the intention is to enhance the quality of the patient's life and that of the family, by preventing and relieving suffering.

Palliative care in the United Kingdom

Palliative care is now widely available in the United Kingdom. Since the 1960s hospices have been established in most regions, and palliative care has become recognised as a specialty in its own right. While there is still much to be done worldwide in terms of research, improved assessment and treatment, health workforce education and equitable access to services, the United Kingdom has earned an excellent reputation for the quality of its palliative care services and the quality of care provided is among the best in the world. Most health practitioners will be aware of the services available in their district and should be able to make referrals easily.

It is only over the last 40 years that palliative medicine has been recognised as a discrete area of medicine. During this period, there have been great advances in palliative care both in the understanding and development of palliative care practice as well as in the available medical technologies it is able to use. However, as an emerging practice there is still room for improvement and advancement in palliative care. There is a need for more and better education in cancer pain management and palliative care at undergraduate and postgraduate levels, through enhancement of existing education, introduction of new programmes, and better integration throughout the United Kingdom.

In my part of the world, real advances have been made in several of these areas, in particular by the development of the Royal Australasian College of Physicians Chapter of Palliative Medicine and the development of new programs to enhance the palliative approach. Similar advances have been made in the United Kingdom. However, we continue to be faced with many challenges. Palliative care education has been diverse and imaginative. At times, it is highly focussed and specific, while at others it is more wide-ranging and all-encompassing. Creative and culturally specific responses to the challenges of education are more likely to succeed than imposed formulae and concepts.

Education on palliative care for all health professionals will not only improve knowledge and skills in this area but it will increase the level of understanding in the community about what palliative care can realistically achieve. Recent media commentary from individuals with little or no experience in this field has provided misinformation about what medical practice at the end of life can and does achieve. At present for example, referrals come late to many services, leaving little time to deal with the issues presented.

Another area for improvement is access to palliative care for people with non-malignant diseases. Currently, the majority of people referred for palliative care have malignant disease and yet only one out of three people dying in the United Kingdom do so from a malignant illness. All people with a life-threatening illness should have access to the benefits of a palliative care approach. In particular, we need to address the complex needs of people with dementia.

Currently, palliative care in the United Kingdom relies heavily on charitable funding. Recent governments have better reflected the true cost of the provision of palliative care but most services still rely heavily on their own fundraising efforts to cover the costs of providing care to their communities. Hospice UK has increased awareness of the need for increased funding but more needs to be done to ensure that all citizens have access to palliative care when they need it.

Requests for hastened death

In my experience as a palliative care specialist, I have found it common for patients to express a desire to terminate their lives early or to request euthanasia or physician assisted suicide in the early stages of their illness or shortly after they have received a terminal diagnosis. However, it has also been my experience that people receiving palliative care almost never persist with requests for euthanasia once they are receiving optimum palliative care and have had time to adjust to their new situation.

Often, in my experience, the desire for death fluctuates and changes on a daily basis. On some days people with a terminal illness seem more ready to accept their dying than on others. Dying can be hard. Dealing with the losses associated with dying is one of the most challenging periods of a person's life, without the added pressure of thinking about whether or not to seek an early death on a daily basis. There may well be unspoken pressures from families or health professionals that interfere with the 'work' of dying, and not all families are compassionate and caring at this time. It is clearly not possible to detect coercion from behind a closed door.

The underlying reasons that lead people to request assistance in ending their lives are most often psychological in nature. At the core of most requests is a desire to maintain a sense of autonomy and control in the face of illness. In the US state of Oregon where physician assisted suicide has been legally practiced since the mid-1990s, a report from the state Health Authority lists the prevalence of common 'end of life' concerns among patients who have died after ingesting lethal medication. The three most common concerns among this group of patients between 1998 and 2016 were losing autonomy (91.4 per cent), being less able to engage in activities that make life enjoyable (89.7 per cent) and the loss of dignity (77 per cent). Other issues directly related to the physical progression of illness, while still common, were not as significant. They included losing control of bodily functions (46.8 per cent) and concerns about inadequate pain control (26.4 per cent). The other major concern, which could also be classed as a psychological reason, was the fear of being a burden on family, friends or caregivers (42.2 per cent).³

Psychiatric and mental health conditions, such as clinical depression, can also contribute to a person's desire to end their life.

However, it can be difficult for medical professionals to identify this type of mental condition. Even qualified psychiatrists cannot always easily identify or determine that a patient may be suffering from some sort of mental health or psychiatric condition which may affect the capacity of patients expressing a desire for assisted death. A survey of psychiatrists in Oregon identified that only six per cent felt "very confident" in deciding whether a mental disorder was influencing a request for medically assisted dying after a single consultation.⁴ Since then experts in the field have expressed the view that one of the most significant concerns about legalising assisted dying is the inability of psychiatrists to determine which patients are suitable, and which are unsuitable, for assisted death services.⁵

³<http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf> [accessed 22 December 2017]

⁴ Ganzini L, Fenn DS, Lee MA, Heintz RT, Bloom JD, 1996. 'Attitudes of Oregon psychiatrists toward physician-assisted suicide', *American Journal of Psychiatry*, 153 (11), 1469-75.

⁵ Macleod S, 2012. 'Assisted dying in liberalised jurisdictions and the role of psychiatry: A clinician's

Assisted dying and the medical profession

There is evidence that a majority of citizens are supportive of medically assisted dying in certain circumstances. However, there is increasing evidence that the general public fail to understand the true nature of assisted dying or euthanasia, often assuming that withdrawal of treatment or removal of life support is the same as euthanasia. However, there is less consensus around the conditions under which physician assisted dying is suitable. I believe that much of this support for medically assisted dying stems from a limited understanding of palliative care and its availability within the United Kingdom. On the whole, many citizens do not have an accurate insight into what palliative care can achieve, and this fuels support for euthanasia and assisted suicide.

While the general population is largely supportive of medically assisted dying in some circumstances, it is important to note that the professional bodies representing nation's medical practitioners is not.

In discussing the legalisation of euthanasia and assisted suicide, it is also important to consider the effects that legalising medically assisted dying would have on the medical practitioners who would then be required to facilitate it. Sanctioning physicians to assist patients to die would represent a fundamental shift in the role of the doctor. There is evidence to show that doctors who have taken part in euthanasia or assisted suicide in jurisdictions where it is permitted have experienced adverse consequences including feelings of discomfort and regret. In some cases, doctors have even reported that their response to assisting patients to end their life has had negative impacts on their ability to practice medicine.⁶

Instead of advocating for the legalisation of medically assisted dying, most professional groups affirm and support the right of terminally ill patients to access appropriate palliative care⁷ and recommend reforms to improve access to high quality palliative care services for dying patients.^{8,9} I also believe that efforts to improve the palliative care services available to all people in the United Kingdom is a more appropriate response to the numerous challenges associated with care at the end of life than legalising medically assisted dying.

The international experience of assisted dying

In countries where medically assisted dying – particularly in the form of euthanasia – has been legalised, the circumstances in which it can legally occur have been extended over time and it has been open to abuse. In both The Netherlands and Belgium, for example, access to assisted death has been broadened significantly since it was first made legal. When that occurred, euthanasia was not an option for children under any circumstances but now children above the age of 12 and newborn babies with disabilities can be euthanised in The Netherlands, while no age restrictions apply in

view', *Australian and New Zealand Journal of Psychiatry*, 1-10, 4-7.

⁶ MacLeod RD, Wilson DM, Malpas P, 2012. 'Assisted or Hastened Death: The Healthcare Practitioner's Dilemma', *Global Journal of Health Science*, 4(6) 87-98, 90

⁷ New Zealand Medical Association, 2005. *Position Statement: Euthanasia*, NZMA: http://www.nzma.org.nz/_data/assets/pdf_file/0004/16996/Euthanasia-2005.pdf [Accessed 21 December 2017]

⁸ Australian and New Zealand Society of Palliative Medicine, 2013. *Position Statement: The Practice of Euthanasia and Assisted Suicide*, ANZSPM, 4: <http://www.anzspm.org.au/c/anzspm?a=da&did=1005077> [Accessed 21 December 2017]

⁹ <http://www.hospice.org.nz/about-hospice-nz/euthanasia-our-opinion> [Accessed 21 December 2017]

Belgium.¹⁰ Despite the best efforts of legislators, it has proved impossible to protect the legal practice of euthanasia from abuse. During 2005, 560 people in the Netherlands were assisted to die without giving explicit consent.¹¹ As recently as 2009, the UN Human Rights Committee expressed concern about the extent of euthanasia in the Netherlands, making particular reference to people who received assistance to die without themselves being able to request ‘termination’.¹²

Turning more specifically to physician assisted suicide, recent research conducted in the United States suggests that legalising assisted suicide inclines some people towards suicide. The study¹³ examined suicide rates in four US states where medically assisted suicide had been legalised. It found that in those states where assisted suicide was legalised, there was a significant increase in the total number of overall suicides, particularly among people who are aged older than 65. It also found that, contrary to some hypotheses, there was no meaningful decrease in the rate of non-assisted suicides, even among those aged older than 65.

Given these trends that have been recorded in countries where medically assisted dying has been legalised, I remain concerned that the acceptance and normalisation of assisted dying practices will put significant emotional and psychological pressure on vulnerable people, including older people and people with severe disabilities, to end their lives. This is particularly important given that an extensive review of the international literature found that almost a quarter of older people who are dependent on carers have reported suffering “significant psychological abuse”.¹⁴ Legalising assisted dying would have serious implications too for the broader relationship between physicians and their patients. If, in addition to promoting good health and a high quality of life, medical practitioners also began to assist people to end their lives, there is a valid concern that this would undermine the relationship between other patients and their doctors, particularly those who are vulnerable.

Finally, allowing medically assisted dying could have significant negative implications for the practice of palliative care. As the European Association for Palliative Care has noted,¹⁵ such a change would threaten to devalue palliative care, threatening ongoing resourcing for and access to palliative care services. It may also result in diminished funding for hospice and palliative care. Although the United Kingdom has rightly earned an excellent reputation for its palliative care services, they are far from mature, and this could significantly affect their ongoing development and the advances that are already underway.

Conclusion

¹⁰ Boudreau JD, Somerville MA (2014). ‘Euthanasia and assisted suicide: a physician’s and ethicist’s perspectives’, *Medicolegal and Bioethics*, *Medicolegal and Bioethics*, (4) 1-12, 10.

¹¹ *Fleming v Ireland* [2013] IEHC, para 96. Viewed online, 5 August 2014.

<http://www.bailii.org/ie/cases/IEHC/2013/H2.html> [Accessed 21 December 2017]

¹² United Nations Human Rights Committee (2009). ‘Concluding observations of the Human Rights Committee: Netherlands’, 2-3. [shttp://bit.ly/1AQpYs9](http://bit.ly/1AQpYs9) [Accessed 21 December 2017]

¹³ Jones DA, Paton D, 2015, ‘How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide?’, *Southern Medical Journal*, 108 (10), 599-604, 603-604.

¹⁴ Cooper C, Selwood A, Livingston G (2008). ‘The prevalence of elder abuse and neglect: a systematic review’, *Age and Ageing*, (37) 151–160, 158.

¹⁵ Materstvedt LJ et al. (2003). ‘Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force’, *Palliative Medicine*, 97-101, 99.

Euthanasia, or assisted dying in any form, is antithetical to the purpose and practise of medicine in general and palliative care in particular. If it is legalised, it has the potential to put pressure on vulnerable people to end their lives, undermine palliative care services, change broader perceptions in society about killing, affect suicide rates and have adverse impacts on the professionals who are involved in prescribing or administering lethal drugs. For these reasons, I remain strongly opposed to the legalisation of medically assisted dying. Like many professional bodies, I believe the focus of end-of-life care in the United Kingdom should be on providing greater resources to existing palliative care services, extending existing palliative care services and educating both the general public and health professionals about the benefits of palliative care.

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