

APPENDIX: PALLIATIVE CARE AND END-OF-LIFE LEGISLATION

Introduction

Until the nineteenth century in the Western world, caring for the dying and the bereaved was seen primarily as the job of the family and the church. Today, caring for the dying is a new branch of medicine, 'palliative care', which offers specialised care to people suffering from fatal illnesses by maximising comfort and quality of life when curative treatments are no longer beneficial and the burden of these treatments outweighs their benefits, or when patients are entering the last weeks or months of life. Palliative care is not about dying, but rather about living as well as possible for as long as possible while suffering from a serious illness. The World Health Organisation defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.¹

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor to postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy;
- includes the investigations needed to better understand and manage distressing clinical complications.

The care offered to the dying is an indicator of how care is provided for all sick and vulnerable people. It is a measure of society as a whole and a litmus test for health and social services. In highly developed parts of the world, palliative care can be regarded as a success. There is evidence of increasing integration with mainstream health-care provision and the inclusion of

palliative care into national health-care planning processes. In a few places, specific Palliative Care Strategic Plans have been adopted.ⁱⁱ This bodes well, even in times of financial constraint and uncertainty. The deeper inclusion of palliative care into broader health policy, and the improvement of standards of end-of-life care, will yield significant gains for the quality of life. However, countries with a high level of development in this field of care are very few, and even within these countries there may be inequity for particular patients, such as those living in peripheral regions, the very old, those with dementia, or patients who do not fit comfortably into mainstream society.ⁱⁱⁱ There is a notable difference between the rich and poor nations of the world with respect to universal access to palliative care services. A population of over two billion lives on less than \$1 a day in Africa and India, where government spending on health is disproportionately low. Out-of-pocket expenses for healthcare combined with the lack of social security can have a domino effect on poor families. Despite that, in traditional societies it is rare to find a patient dying alone in a hospital or nursing home. Family members are actively involved in providing physical care and companionship. This is an invaluable resource to build on. However, family involvement has its negative aspects too. In societies where the family can override the autonomy of the patient, relatives may demand the continuation of futile treatments, regardless of the wishes of the patient, or a fatalistic attitude towards suffering and death may limit care.^{iv}

The Economist Intelligence Unit (EIU) developed a 'quality of death' index and recently applied it across 40 countries (30 OECD nations and 10 others for which data was available), measuring numerous indicators pertaining to the quality of end-of-life care, the cost of end-of-life care, the basic end-of-life healthcare environment, and the availability of end-of-life care. The UK ranked first overall for quality of death, as well as in both the subcategories of availability and quality of end-of-life care.^v The UK is indeed considered to be both the cradle and pioneer of modern care for the dying. Pain management was first addressed by John Bonica in 1953, but it is Dame Cicely Saunders (1918-2005) who is generally recognised as the founder of the palliative care movement.^{vi} She trained as a nurse, then as a social worker, and finally as a physician, and was the founder of St Christopher's Hospice in London, which is considered the paradigm for the care of patients at the end of their lives.^{vii} She studied pain control in terminal illness and introduced the concept of 'total pain' (or total suffering, with all its physical, emotional, social and spiritual components), offering a broader approach and framework for the understanding and care of patients at the end of life. Dame Saunders' work has been a source of inspiration and has radiated throughout the world, establishing the hospice and palliative care movement. Experts from the UK, other European countries, Canada and South America have

visited St Christopher's to study Dame Saunders' approach, which has been exported and applied to local circumstances.^{viii}

The compelling reasons for palliative care continue to be better symptom management and improving patients' quality of life. However, cost containment is necessary in order to ensure the best use of limited financial resources. When it comes to financing end-of-life care, governments are not always the only or even the main sources of funding. A range of funding models exists besides public funding, such as church support, philanthropic funds, aid to patients and families having to pay for the services themselves, and, in some cases, hybrid models relying on a mixed range of funding sources. In the UK, a well-established network of non-profit hospices plays an important role in cutting National Health Service expenditure. Charitable funds also support palliative care in Ireland and in other European countries.

Common trends for lowering costs for hospitals, governments and insurance funders include allowing more patients to die at home with better quality care. In every study to date, hospice and palliative care have been associated with equal or better survival and lower costs. This is because savings are generated by a shift away from the use of conventional hospital treatment towards palliative care, by an increase in homecare, and by a reduced use of emergency rooms.^{ix}

Caring for patients affected by a disease in its terminal phase is raising major ethical questions. Western countries' legislations are converging towards comparable regulations concerning many points, including patients' rights, advanced directives, proxy directives, the refusal of medical treatment, and the duties and responsibilities of medical staff and caregivers. Major differences, however, characterise the evolving legislation on euthanasia or physician-assisted-suicide.

In many countries, patients' rights address the following prerogatives of sick people: to receive quality services that respect their dignity and autonomy; to be clearly informed about their state of health; to consult their medical records and obtain a copy or to choose to remain uninformed; to appoint a trusted person to intervene either jointly with them or on their behalf while they are able to exercise their rights, and also a proxy to intervene and represent them if they are not able to exercise their rights; to give their consent to every clinical intervention after having received preliminary information; to express, when in full possession of their mental faculties, their advance healthcare directive, declaring their acceptance or rejection of clinical interventions, including artificial feeding (such statements remaining valid at a later date should patients no longer be capable); and to receive respect with regard to their private life and privacy.

Advanced directives, also called living wills, indicate patients' preferences in terms of treatment options, such as withholding or discontinuing therapy, or refusing artificial feeding.

These may also include proxy directives that allow patients to designate a person to represent them when they are no longer able to express their will.

Advanced directives should be easily accessible; for example, embedded in the microprocessor of personal ID-cards. This would make them available in the emergency room should a terminal condition result from an accident. This would assist medical staff in making decisions about patient survival dependent on therapeutic measures with an extreme risk of incurring a persistent vegetative state.

The duties, responsibilities and rights of medical staff and caregivers include a legal guarantee of indemnity from prosecution for health workers; respect for patients' dignity, confidentiality and privacy; respect for patients' right to give their informed consent for refusing or choosing their treatment; to act in the best interest of the patient; to respect in fairness and equality the distribution of scarce health resources and decisions concerning who gets what treatment.

A worldwide hot debate on euthanasia and physician-assisted suicide (PAS) is in course. The WHO considers neither action to be compatible with palliative care and, along these lines, in 2003 the Ethics Task Force of the European Association for Palliative Care (EAPC) produced a paper concluding that the provision of euthanasia and physician-assisted suicide should not be part of the responsibilities of palliative care.^x In Europe, the European Union leaves policymaking in this area up to the member states. The different approaches in a ten countries are addressed in the sections that follow this introduction in the printed version of this book.

Euthanasia is generally defined as an act undertaken 'only by a physician', who intentionally ends the life of a person at the latter's request by administering a lethal substance. To avoid any confusion, in this book I use the term 'euthanasia' in strict accordance with this definition. Some authors call this act *active voluntary euthanasia* and give definitions for non-voluntary euthanasia, involuntary euthanasia and passive euthanasia.^{xi} Physician-assisted suicide is defined as the self-administration of a lethal substance prescribed by a physician. Euthanasia or physician-assisted suicide are considered criminal offences in most countries. However, euthanasia or PAS – and sometimes both – have been legalised or decriminalised in a small number of countries and states.

To date, The Netherlands has legalised euthanasia (2002), while Belgium (2002) and Luxembourg (2008) have decriminalised it.^{xii} The laws in The Netherlands and Luxembourg also allow PAS. In the United States, the states of Oregon, Washington, Vermont, New Mexico and Montana legalised PAS between 1997 and 2013, and California might soon be added to the list, following a vote of 11 September 2015 at the State Assembly, which would allow terminally ill patients to legally end their lives with PAS if California Governor will promulgate the Bill.^{xiii}

Euthanasia remains illegal in all US states.^{xiv} Switzerland legalised PAS with a referendum in 2011, which approved an interpretation of a law of 1942 that punished assistance in suicide only in the case of non-altruistic motives. Colombia legalised euthanasia in 2010. In the province of Quebec, Canada a new law decriminalising euthanasia might come into force on 10 December 2015, unless the federal government challenges it.^{xv} In Australia's Northern Territory euthanasia and physician-assisted suicide were legalised in July 1966, but the Act was in force during only nine months being voided by the federal Euthanasia Laws Act in 1997.^{xvi} In Switzerland, private, for-profit organisations attract healthy foreigners to cross borders with a view to ending their lives. The German language has introduced a neologism, *Sterbetourismus* [death tourism], to describe this phenomenon. To date, no such practice is reported for euthanasia in the countries that legalised or decriminalised it,^{xvii} although the text of the laws in those countries does not explicitly exclude the request for euthanasia by non-residents.

In all jurisdictions where euthanasia or PAS are regulated by law, safeguards, criteria, and procedures have been put in place to control the practices, to ensure societal oversight, and to prevent euthanasia and PAS from being abused or misused. Some criteria and procedures are common across the jurisdictions; others vary from country to country. Prevention measures have included explicit, reiterated consent by the person requesting euthanasia, mandatory reporting of all cases, administration only by physicians (with the exception of Switzerland), and consultation by a second physician.

There is evidence that these safeguards are regularly ignored and transgressed in all the jurisdictions, and that transgressions are not prosecuted. Increased tolerance of transgressions in societies with such laws represents a social 'slippery slope', as do changes in the laws, criteria and practices that have followed legalisation. Although the initial intent was to limit euthanasia and assisted suicide to a last-resort option for a very small number of terminally ill people, some jurisdictions now extend the practice to newborn infants, children, prisoners, psychotic patients and people with dementia. A terminal illness is no longer a prerequisite.^{xviii}

An example of a slippery slope is the misinterpretation of the conditions justifying a 'double effect' (the permissibility of an action that causes a serious harm as a side effect of promoting some good end), which may occur in emergency rooms, or at the scene of murders or road accidents, when accident- or emergency-physicians disguise the mercy killing of agonised individuals as deep sedation.

In this Appendix we will cover the provision of palliative care services and the current status of end-of-life legislation in ten countries, seven of which are English speaking (Australia [AU],

Canada [CA], Ireland [IE], New Zealand [NZ], South Africa [ZA], United States of America [US], United Kingdom [UK]). The remaining three included are European countries with which author is personally familiar, namely Italy (IT), Belgium (BE) and France (FR), and has an interest in analysing the provision of palliative care in Belgium, a country where euthanasia is decriminalised, and in France, where the debate on end-of-life legislation has raised an ethical question of general relevance, and where a step forward in legislation was attempted and failed in 2015. Seven out of the ten countries covered in this appendix were among the ten top countries according to EIU's above-mentioned Quality of Death index (in order: UK, AU, NZ, IR, BE, CA, US).^{xix}

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- ⁱ <http://www.who.int/cancer/media/FINAL-Palliative%20Care%20Module.pdf> [accessed 18 July 2015].
- ⁱⁱ David Clark, 'International progress in creating palliative medicine as a specialised discipline', in Geoffrey Hanks (Ed.) *Oxford Textbook of Palliative Medicine*, Oxford University Press, 2011.
- ⁱⁱⁱ Sheila Payne and Tom Lynch, 'International progress in creating palliative medicine as a specialized discipline and the development of palliative care', in Nathan Cherny et al. (Ed.'s) *Oxford Textbook of Palliative Medicine* (5th ed.) Oxford: Oxford University Press, 2015.
- ^{iv} M.R. Rajagopal and Reena George, 'Providing palliative care in economically disadvantaged countries', in Nathan Cherny et al. (Ed.'s) *Oxford Textbook of Palliative Medicine* (5th ed.), cit.
- ^v *The quality of death: ranking end-of-life-care across the world*. Economist Intelligence Unit, London; 2010. www.qualityofdeath.org [accessed 2 June 2015].
- ^{vi} John J Bonica, *The Management of Pain: With Special Emphasis on the Use of Analgesic Block in Diagnosis, Prognosis and Therapy* (London: Henry Kimpton, 1953).
- ^{vii} The first hospices were opened over a century ago in Dublin (Our Lady's Hospice, 1879) and in the East End of London (St Joseph's Hospice, Hackney, 1905) by Catholic nuns as a charitable and religious mission caring for those dying of tuberculosis and living in poverty. Considerably later, St Christopher's Hospice opened in South London in 1967.
- ^{viii} Mary Baines, 'From pioneer days to implementation: lessons to be learnt', *European Journal of Palliative Care*, 18, 5, (2011).
- ^{ix} Thomas J. Smith and J. Brian Cassel, 'The economic challenges of palliative medicine', in Nathan Cherny et al. (Ed.'s) *Oxford Textbook of Palliative Medicine*, cit.
- ^x Ethics Task Force of the European Association for Palliative Care, 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force', *Palliative Medicine*, 2003.
- ^{xi} Non-voluntary euthanasia is defined as an act conducted where the consent of the patient is unavailable. Involuntary euthanasia is defined as an act conducted against the will of the patient. Passive euthanasia is defined as an act that entails the withholding of treatment.
- ^{xii} In The Netherlands, the penal code was changed, whereas in Belgium and Luxembourg it was not, and thus in these latter countries euthanasia remains voluntary premeditated homicide, punishable by penal law, and non-punishable solely under the conditions specified by the law.
- ^{xiii} See details in the section on the US at page 28.
- ^{xiv} An overview (current as of September 3, 2015) of the current status of legislation and legislative proposals in each US state is presented by the Death with Dignity National Center at <http://www.deathwithdignity.org/advocates/national> [accessed 20 September 2015].
- ^{xv} See details in the section on Canada at page 33.
- ^{xvi} See details in the section on Australia at page 42.
- ^{xvii} There is one exception in the Northern Territory, Australia, as described in a following section, at page 42.
- ^{xviii} J. Pereira, 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls', *Current Oncology*, 18, 2: (April 2011), pp. 38–45.
- ^{xix} *The quality of death* Economist Intelligence Unit, cit.