

Plunkett Centre for Ethics

A joint centre of Australian Catholic University and St Vincents & Mater Health Sydney

Submission to the Inquiry on the provision of palliative care in Australia

Re (a): the factors influencing access to and choice of palliative care that meets the needs of the population.

There is still a perception that palliative care is the option you choose when you have 'given up', that it is code for 'since you are going to die, we are going to give up on trying to help you'. Palliative care needs to be normalized: it's the kind of care you need when your symptoms need palliation, whatever else you need. Normalization requires changes to health care provision, changes to education in medicine and nursing and health care administration, etc. In this regard the WHO definition of palliative care is apposite.¹

There is always pressure on health care budgets: categories of patients are unwitting competitors for the same health care dollar. Hard decisions have to be made and defended. These decisions should be made on ethical grounds, not on political grounds. They ought to be made on the basis of need, not on any other basis. Any reasonable account of justice in the allocation of health care resources would make the provision of palliative care a priority.²

¹ **WHO Definition of Palliative Care:** Palliative care is 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:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or 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 patients 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, and includes those investigations needed to better understand and manage distressing clinical complications.

² In this regard, I have reservations about instruments such as 'quality adjusted life years' since they may favour treatment for the young and those likely to live long and productive lives, they may favour preference being given to those most likely to receive the greatest benefit in terms of improved quality and length of life and those likely to make greatest future social contribution, to short term services over long term care, and to the diminution of care for the terminally ill and dying and chronically sick and handicapped and permanently unconscious, etc. See B. Tobin. The principle of justice: a bioethical perspective, *Bioethics Outlook*, Vol 12, No 4, Dec 2001, www.acu.edu.au/plunkettcentre/

In addition, Australia should recognize a need for palliative care for new born infants, and their families.³

Re (b): the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent.

Attention need to be given to the palliative care needs of people in aged care institutions, and to people who are ageing in place in the community. So attention needs to be given to the educational requirements of people who work in aged care.

Re (c): the efficient use of palliative, health and aged care resources.

Here the main effort needs to go into addressing the palliative care needs of people in the community, so that they do not need to be transferred into an institution to have their palliative care needs met: all kinds of things can go wrong if elderly people are inappropriately admitted to hospital emergency wards. Aged care institutions themselves could be encouraged, perhaps required, to have outreach services for the community, in which palliative care is a priority.

And aged care institutions need to be supported to provide the best possible palliative care.

Re (d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities.

The Guidelines for a palliative approach in residential aged care should be (i) updated, (ii) promulgated, (iii) used as the basis for a standard care that must be met for accreditation purposes, etc.

(e) the composition of the palliative care workforce.

³ **WHO Definition of Palliative Care for Children:** Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Training in palliative care needs to move beyond its early emphasis on the palliative care needs of people with cancer. Most older people will now die following a long and very gradual trajectory towards death. Palliative care should be reoriented to this demographic fact. In addition, it ought to be rethought so as to respond to the needs of people with 'progressive cognitive impairment' (dementia). These people too need the 'impeccable symptom management' to which the WHO definition refers.

Training also needs to respond to the variety levels of specialist knowledge of palliative care: that required by specialists, by generalists, by untrained care givers, by volunteers.

Training also needs to respond to the variety of forms of palliative care: pain relief and the relief of other physical symptoms; psychological care; psycho-spiritual care, etc. ⁴

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians.

Standard 7 states that the 'service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care'. In this regard it is crucial that the deliberate hastening of death, even at the request of the individual, is not portrayed as part of the 'philosophy' of palliative care. ⁵ Euthanasia, whether voluntary or non-voluntary or involuntary, and assisted-suicide, have no place in a palliative care program. People ought to be able to trust that they can be forthright in expressing their fears about their illness and frailty and disability, especially in the last part of their lives, confident that they are speaking to professionals who are committed to providing 'impeccable' palliative care in a context in which both killing their patients and helping them to commit suicide are out of the question, impeccable palliative care which avoids futile treatment (even if it is life-prolonging) and overly-burdensome treatment (even if it offers therapeutic benefits) and which embraces the relief of symptoms (even if that foreseeably hastens death). Indeed, we think that a position of 'studied neutrality' with respect to the legalization of 'euthanasia' and 'assisted suicide' is both unprofessional and incoherent for people working in palliative care.

Standard 8 refers to bereavement care: there is a general lack of support for people suffering from bereavement. Bereavement services need to be instituted or augmented.

Standard 12 refers to appropriate qualifications for staff and volunteers. I would urge that thought be given to upskilling volunteers. Much can be accomplished by dedicated volunteers when they feel confident in the usefulness of their contributions.

⁴ See for instance Harvey Chochinov's Dignity Therapy. See B. Tobin. It may be okay in practice but will it work in theory? Dignity therapy in palliative care, *Bioethics Outlook*, Vol 21 No 3, September 2011; www.acu.edu.au/plunkettcentre/

⁵ Even when voluntary, it violates the intrinsic value of the human being, and it sends the wrong message to those most likely to be in need of palliative care: it says 'you are expendable', 'yes, we agree, you no longer deserve our protection and care', etc.

(g) advance care planning.

Advance care planning is useful for a variety of reasons. First, medical successes mean that many more people die having lost decision-making capacity. Second, in developed countries, virtually everyone has access to advanced medical treatment so this is not a problem just for the wealthy. Third, the power of technology is so great that these decisions affect everyone: most people who die in hospital die after a decision has been made not to do something. Fourth, it is useful because the burden of decision-making falls largely on third parties, most of whom find it very stressful. Fifth, increasing numbers of people have no family to make decisions as they die.⁶ And, finally, it is useful because families are often unable to agree on decisions.

So good advance care planning should be encouraged. At its best, advance care planning is planning for the future to ensure both that the proper goals of medical treatment inform the care of people who become unable to make decisions about their own treatment, and that the means used to seek those goals reflect the judgments of the patient.

Two main instruments can be used: a written set of instructions or a person appointed to represent the patient. However it is now eight years since the publication of ‘Enough: the failure of the living will’ by Angela Fagerlin and Carl Schneider⁷, in which it was conclusively shown that written instructions simply don’t work: few people have them; few people can predict their actual preferences accurately; few people can articulate their preferences clearly; and ‘living wills’ are often not available when they are needed. In addition, written instructions are not self explanatory and need interpretation; the course of illness is unpredictable and a doctor needs to be free to provide good care in the actual circumstances of a patient’s illness as well as when unanticipated circumstances arise; and written instructions can privilege past wishes over the provision of reasonable care. So initiatives to encourage advance care planning should focus on encouraging people to appoint someone to talk to the doctors and nurse when they are unable to do so. Professor Jane Ingham, director of the Cunningham Centre for Palliative Care at Sacred Heart Hospice in Sydney, supports this. She says: ‘All I need is to be able to talk to *someone* whom the patient trusted.’

Patients in hospitals and residents in nursing homes in Australia (including those who have loving families who care about them) should not be required or even encouraged to fill out ‘directives’. Directives tend to focus on interventions in themselves: ventilators, antibiotics, feeding tubes, etc. But in good advance care planning, one does not focus on an intervention itself, *a priori*, but on an intervention in a particular circumstance. In the circumstances of a ruptured appendix, one might require a ventilator and other things being

⁶ Thus, there is a place for written instructions.

⁷ *Hastings Center Report*, March-April 2004

equal the use of a ventilator would be ordinary care in that circumstance. But in the case of a patient with an untreatable or widespread cancer, a ventilator might not appreciably forestall death. Even if not strictly futile, the burdens could be judged to outweigh the benefits and the use of a ventilator in such circumstances would be optional.

There are, that is to say, legitimate concerns about advance care planning: its *de facto* promotion of a reductive theory of ethics, in particular an unrestrained notion of autonomy, and its possible association with euthanasia and assisted suicide. It can tend to reduce the idea that interventions are optional to the common law's notion of the obligation to respect refusals. For instance, in the Statement of Choices document associated with the **Respecting Patient Choices** literature, the second box concerning 'Life prolonging treatments' (ventilators, dialysis, feeding tubes, surgery) offers three choices: *I would like life prolonging treatments in order to prolong my life as long as possible, OR, I would like life prolonging treatments only if the doctors expect a reasonable outcome (and then there is space for the person to nominate what would be a reasonable outcome for him or her), OR, I do not want life prolonging treatments at all.*⁸ This set of choices focuses on interventions in themselves, *a priori*, regardless of circumstances, whereas the judgment that an intervention would be futile is a judgment that the treatment will not work (it won't cure the patient, or reverse the condition, or appreciably forestall an imminent death, etc): that is to say, the idea that an intervention may be futile relies on the prior idea that medicine has its own goals in the light of which interventions can be judged as therapeutic, non-therapeutic, insufficiently therapeutic, etc. This is a subtly different idea from that which is implied in the statements 'I would want my life prolonged' and 'I would not want my life prolonged.' And, again, the judgment that an intervention would be overly-burdensome is a judgment about an intervention-relative-to-particular-circumstances: the use of a ventilator in *these* circumstances. Only the second of the three choices hints at that proper relativity.⁹

In addition, it is well known that organizations which promote the legalization of euthanasia and assisted suicide also promote advance care planning.¹⁰ True, the difference *is* made explicit on the website of the *Respecting Patient Choices* program but not prominently so. And the difference is not well explained: the explanation of euthanasia which is given does

⁸ And then there is the addition: If life prolonging treatment has been commenced I request that it be discontinued and that I receive palliative care.

⁹ William Silvester and Karen Detering. Advance care planning and end-of-life care. *Medical Journal of Australia*, 2011, 195, (8): 435-436. This is not quite what our *Code* actually says.

¹⁰ Both Dying with Dignity NSW and Dying with Dignity Victoria do so. Both endorse the filling out of written instructions over the appointment of a person to speak on behalf of the patient or resident. Both encourage the refusal of *kinds* of intervention *a priori* (antibiotics, ventilators, etc) rather than an-intervention-in-particular-circumstances. Both recommend a tick-a-box approach to refusal of interventions: 'If I am in the terminal phase of an incurable illness, I do not/do want cardiopulmonary resuscitation, assisted ventilation, artificial hydration, artificial nutrition, antibiotics (unless it is part of my palliative care)'.

not make it clear that one can 'do' euthanasia by an act or an omission, by doing something or by not doing something.¹¹

So, if advance care planning is to be a way of ensuring that the proper *goals* of medical treatment inform the care of people who become unable to make decisions about their own treatment, and that the *means* used to seek those goals reflect the judgments of the patient, an approach which avoids the bureaucratic solution of written instructions and which relies on a trustful, collaborative relationship between *senior* doctor and person representing the patient is needed. So too are institutional arrangements which support collaborative relationships between senior doctors and authorized decision-makers. And a culture of openness to the right kinds of conversation in ordinary Australian families.

A campaign which encourages people to think about what forms of treatment and care they would and wouldn't want if they were not able to speak for themselves, and to have the relevant discussions with their families, may be desirable. So too may be encouraging families to attempt, sensitively, to initiate the relevant discussions with their elders.

(h) the availability and funding of research, information and data about palliative care needs in Australia.

There is much research to be done: into the effectiveness of different forms of pain and other symptom relief, into the capacity of people to anticipate their actual preferences about end of life treatment and care ahead of time, etc.

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¹¹ There are five main pages of explanation, an instructional video, and a set of Frequently Asked Questions. The only place at which advance care planning is explicitly differentiated from euthanasia is in the list of Frequently Asked Questions. The very last question is: *Is this euthanasia?* And the answer is: *No, definitely not. Euthanasia is the deliberate action of causing the death of someone who otherwise would not die. This is completely different from the withdrawal of treatment that is regarded by the patient, the doctors, the substitute decision-maker or family as futile or overly-burdensome. In this circumstance the patient is dying from the underlying illness and nature is being allowed to 'take its course'. Note: In all Australian states and territories euthanasia is illegal.*' Accessed 16th December 2010