

ADVANCE CARE PLANNING

Interim Position Statement

As considered by Palliative Care Australia Council on 9 October 2008 and 1 December 2008, and Palliative Care Australia Executive on 2 December 2008

Final draft for consideration by PCA member organisations and for public comment



**Palliative
Care
Australia**

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.¹

Palliative Care Australia believes

- Dying is part of life.
- Quality end of life care is realised when it meets the person's needs and *upholds their care preferences*.
- Advance care planning provides a *mechanism* to improve the quality of end of life care for people. It enables the coordination of their desired access to resources and services, to match their anticipated care needs.
- Advance care planning offers everyone, and especially people living with a terminal condition, their families and significant others the opportunity to *take control of decisions which affect their care*.
- Advance care planning should not be considered only relevant to people nearing the end of life but be considered by everyone. It should be considered as an *ongoing conversation* between the individual, their care team and as appropriate their family, significant others and carers.
- All Australians should be supported to consider and provided the opportunity to specify the type of care they would like to receive at the end of life. Continual reassessment of current circumstances and likely future scenarios are part of this consideration.
- Advance care planning should be applied and promoted across the health sector. Facilitating end of life discussions and supporting and engaging in advance care planning is the responsibility of the whole health care system, and should engage all members of the care team. It is not the exclusive domain of any particular health care sector or setting.
- Health workers across all levels of the health system should be skilled and educated to engage in end of life care discussions and advance care planning with patients and their families, significant others and carers. Specialist palliative care providers have expertise to support all involved in advance care planning.
- Promoting awareness of end of life options and engaging in end of life care discussions and planning is not the singular responsibility of the health care system but should also be considered a responsibility of the community and the individual.
- The role of *substitute (or proxy) decision makers* needs to be promoted.
- Formalised *advance care directives* can form an integral part of the advance care planning process for those who wish to develop one, serving as a vehicle for decisions about the type and level of medical intervention people wish to receive at the end of life. Care needs to be exercised to ensure that people fully understand and

¹ The following definitions of end of life, end of life care and palliative care are used throughout this position paper. Source: Palliative Care Australia *Palliative and End of Life Care – Glossary of Terms*, PCA, Canberra 2008.

End of life: That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.

End of life care: End of life care combines the broad set of health and community services that care for the population at the end of their life. Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the people requiring care.

Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goals is quality of life.

consent to the provisions of their advance care directives.

- Advance care planning should not be reduced to a singular focus on advance care directives. There is no one “right” advance care planning answer or option. The process should be owned by the consumer, who should be free to choose or create an advance care plan to suit them. There should be no force or coercion.
- Legal differences governing advance care planning between each State and Territory make greater uptake of advance care planning difficult.

Palliative Care Australia calls for

- Development and implementation of initiatives to increase *community awareness* of end of life planning options and community capacity to discuss and plan for death and dying.
- The development and roll out of *national guidelines* to promote good practice in advance care planning by specifying the key elements to be addressed in working through this process with patients and their carers. These national guidelines and their promotion should be of relevance regardless of the particular method employed for noting and recording advance care plans.
- *Training* in strategies to engage in end of life discussions and advance care planning to be incorporated into end of life care education for primary and specialist health care providers.
- *Greater national consistency* between the States and Territories in legislation governing the scope and implementation of advance care directives and plans and the appointment and status of substitute decision makers to ensure they are valid across jurisdictions.
- Development and implementation of a nationally harmonised system for recording advance care directives and plans based on evidence of best practice from similar programs internationally.
- Recognition that increased community awareness of the need for open discussion about death and dying, and the importance of end of life decision-making may have many positive community benefits.

Background

In 2005, PCA endorsed a population needs-based approach to end of life care service development which articulated a plan for providing equitable access to end of life care while promoting effective and ethical use of resources². PCA recognises population needs-based end of life care as a quality management approach that involves the evaluation of individual holistic needs of patients, their families and carers and involves the coordination of appropriate care.

The 13 *Standards for Providing Quality Palliative Care for all Australians*³ define the standard of care that all Australians should be able to expect in different care settings. For the purposes of population needs-based service planning, all people at the end of life can be considered to fall within three broad subgroups whose care needs can be categorised as:

- complex, or
- intermediate, or
- appropriately addressed through primary care services.

Patients may need to move at different times between these subgroups. This should be as seamless as possible.

Advance care planning is a process to help people to formulate and communicate their preferences regarding care during future incapacity. Advance care planning gives the person the opportunity to determine the likely scenarios coming towards the end of their lives, including the treatment they receive and the way they would like to be cared for.⁴

Advance care planning may lead to, but should not be reduced to, the development of an advance care directive and/or the appointment of a substitute decision-maker. Advance care directives, alternatively termed advance directives, advance health directives or ‘living wills’, may be defined as a set of documents containing instructions that consent to, or refuse, specified medical treatments and that articulate care and lifestyle preferences in

² PCA, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005.

³ PCA, *Standards for providing quality palliative care for all Australians*, PCA Canberra, 2005.

⁴ PCA, *Standards for providing quality palliative care for all Australians*, 2008.

anticipating future events or scenarios.⁵ Advance care directives have legal status and are intended to support a person's previously articulated preferences to be upheld when they are not competent or capable of making informed decisions.

A substitute decision maker may be described as someone who has legal authority to make decisions on behalf of a person who no longer has decision-making capacity.⁶

Advance care planning and advance care directives emerged as a way to provide a practical mechanism for promoting patient autonomy and self determination at the end of life, including when patients are no longer capable of decision-making, by promoting treatment decisions that reflect those the patient would have made.⁷ Evidence shows that, in general, we cannot assume congruence between physicians, family, carers and patients regarding care preferences and as such we must remember that the most reliable source for patient preferences is the patient.⁸ The central goal of both advance care plans and advance care directives is to ensure the centrality of the patient's voice in medical decision-making and honour patient preferences about end-of-life care.

The goal of many current advance care planning practices is to encourage planning by the patient and their care team to avoid 'surprises'. In this way care can be provided according to their preferences. As Wilkinson, Wenger and Shugarman⁹ highlight, advance care planning can include making practical arrangements (e.g. anticipating treatment modalities to have them in place) and identifying what course serves the patient best and outlining specific steps to make that course more likely. Addressing practical arrangements in planning to meet care needs and uphold care preferences has the potential to support both quality care for patients and health care resource management and coordination.¹⁰

A primary concern with the emergence of advance care planning was whether end of life discussions would negatively impact patients. Wilkinson, Wenger and Shugarman's¹¹ review of the evidence clearly indicates that advance care planning is not distressing to most patients, and in many cases provides comfort and security in knowing that their wishes are understood and will be respected. Notably, however, some patients prefer not to engage in advance care planning and the enhanced autonomy implied by advance care planning is not necessarily an empowering experience for all.^{12, 13} PCA believes that respect for patient preferences must extend to respecting decisions not to engage in advance care planning. However, continuous assessment and review of the patient's circumstances should provide patients with the opportunity to reconsider advance care planning.

Advance care planning is an ongoing process

There is substantial evidence to attest that patient care preferences change over time and in accordance with their changing health status and personal circumstances.^{14, 15} Further, over time it is reasonable to expect that a patient's health status and likely future scenarios may change. This underlines the necessity of situating advance care planning as an ongoing process rather than directed toward a static plan.

Indeed, Street and Ottmann's 'State Of The Science Review'¹⁶ concludes with a recommendation that advance care planning is recognised as an ongoing communication process that: begins as early as possible in a patient's illness trajectory; is embedded in clinical routines and professional practice; and is preceded by a screening process that assesses the capacity of people.

Situating advance care directives as one aspect of advance care planning

Advance care planning can be understood as having broader goals than the development of advance care directives. As discussed above, advance care planning is, ideally, an ongoing process that supports the patient to consider (and re-consider) their care goals and care preferences in a realistic way and in the event of a number of likely scenarios. Advance care directives may be recognised as one possible mechanism that may be explored through the advance care planning process to support the realisation of care goals and preferences. However, it is

⁵ PCA, op. cit. 2008.

⁶ M Parker, C Stewart, L Willmott and C Cartwright, 'Two steps forward, one step back: advance care planning, Australian regulatory frameworks and the Australian Medical Association', *Internal Medicine Journal*, vol. 37, 2007, pp. 637–643.

⁷ A F Street and G Ottmann, *State of the Science Review of Advance Care Planning Models*, La Trobe University, Bundoora, 2006.

⁸ Street, et al., 2006.

⁹ A Wilkinson, N Wenger and L R Shugarman, *Literature review on advance directives*, RAND Corporation, United States, 2007.

¹⁰ J Lynn, '(Re)orienting towards quality care at the end of life', Presentation at *A matter of life and death: National stakeholder forum*, Canberra, 2008.

¹¹ Wilkinson, et al., 2007.

¹² R Say, M Murtagh and R Thomson, 'Patients' preference for involvement in medical decision making: a narrative review', *Patient Educ Couns*, Vol. 60, 2006, pp. 102–14.

¹³ J Benbassat, D Pilpel and M Tidhar, 'Patients' preferences for participation in clinical decision making: a review of published surveys', *Behav Med*, Vol 24, 1998, pp. 81–8.

¹⁴ T R Fried, A L Byers, W Gallo, P Van Ness, V R Towle and J R O'Leary, 'Prospective study of health status preferences and changes in preferences over time in older adults', *Arch Intern Med*, vol. 166, 2006, pp. 890–95.

¹⁵ P H Ditto, J A Jacobson, W D Smucker, J H Danks, and A Fagerlin, 'Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences', *Med Decis Making*, vol. 26, 2006, pp. 313–22.

¹⁶ Street, et al., 2006.

highlighted that advance care directives are not an end in themselves.¹⁷ Indeed the poor uptake of advance care directives in numerous initiatives promoting directives to patients or the broader community may potentially be an indication that many individuals may not consider advance care directives necessary or desirable in their circumstances.

Further, Wilkinson, Wenger and Shugarman¹⁸ have noted limitations of a singular focus on advance care directives. They note the weakness of advance care directives as a stand alone intervention in achieving the goal of substantially affecting care at the end of life or promoting care that accords with expressed preferences and observe that studies of interventions that simply aim for completion of advance care directives fail to improve patient/provider communication, end-of-life decision making, or the concordance of life-sustaining treatments with patient goals.

On the basis of their review of the literature Wilkinson, Wenger and Shugarman conclude that in the context of a comprehensive community effort advance care planning and advance care directives can support the realisation of quality end of life care that accords with patient preferences. It appears that advance care directives are most effective when incorporated into a comprehensive advance care planning process¹⁹.

Health worker responsibilities and competencies in advance care planning

PCA believes that quality end of life care is realised when care works to address patients' needs and seeks to uphold their care preferences.²⁰ In this sense, providing patients the opportunity to consider and identify care preferences through advance care planning discussions is one mechanism toward achieving quality end of life care, and should be regarded as part of the role of the end of life care team whether it is comprised of specialist or generalist palliative care providers.

A review of the state of the science has found evidence from clinical research studies that the quality of end of life and advance care planning discussions between patients and their care team are predominantly poor and that there is a substantial gap between what patients want to discuss and what is being discussed in end of life discussions.²¹ The review further concluded that lack of knowledge and competency on behalf of health workers impacts on the quantity and quality of these discussions.²²

Wilkinson, Wenger and Shugarman's²³ review of the literature found that practitioners in the United States receive little or no formal training in initiating and undertaking advance care planning discussions and that many health care professionals feel unprepared for end of life discussions and the process of advance care planning. A number of initiatives in Australia provide education and support to a limited number of health practitioners around advance care planning (notable in this regard is the work of the Respecting Patient Choices program²⁴). However, anecdotal evidence attests that, overall, a similar situation for health care professionals with limited education and expertise in implementing advance care planning processes exists in Australia.²⁵

Notably, Wilkinson, Wenger and Shugarman²⁶ and Street and Ottmann²⁷ concluded that while interventions to improve health practitioner communication skills were a central part of multi-pronged strategies to better integrate advance care planning into everyday end of life care practices, as stand alone interventions they have had inconsistent results. More intensive and community-wide interventions that involve collaborative advance care planning mechanisms have demonstrated more positive results.

Supporting end of life discussions as a community

Death and dying must be understood as much more than medical events. Death and dying are profoundly social occurrences; not only do they have an impact beyond the individual patient, but they occur within a social context that is a key determinant of the meaning given to these events.²⁸ In this sense, capacity to promote and support advance care planning and end of life care discussions rests within a broad social context in which the community, as well as health professionals, individual consumers, their families, significant others, and carers all have a role to play.

¹⁷ Wilkinson, et al., 2007.

¹⁸ Wilkinson, et al., 2007.

¹⁹ Wilkinson, et al., 2007.

²⁰ PCA, *End of life care is everyone's affair - tackling the challenge of 'end of life'*, PCA, Canberra, 2008.

²¹ Street, et al., 2006.

²² Street, et al., 2006.

²³ Wilkinson, et al., 2007.

²⁴ Austin Health, *Respecting Patient Choices program: Report on the Evaluation of the National Implementation of the Respecting Patient Choices Program*, Austin Health, Victoria, 2006.

²⁵ Delegate discussion at *A matter of life and death: confronting the new reality*, a national stakeholder forum convened by PCA, Canberra, March 2008.

²⁶ Wilkinson, et al., 2007.

²⁷ Street, et al., 2006.

²⁸ MJ Lewis, *Medicine and care of the dying: A modern history*, Oxford University Press, Oxford, 2007.

Further, and as noted above current evidence suggests that initiatives to promote advance care planning are most effective in the context of a comprehensive community effort that includes system-wide processes. Multi-pronged strategies directed at integrating advance care planning into care practices have demonstrated greater uptake of the planning process and care that is better aligned with patient preferences than single mode interventions aimed at educating health professionals and promoting directives to individual patients. On the basis of this evidence Street and Ottmann²⁹ recommend a multi-pronged strategy based on an ongoing values-directed discussion involving health professionals, clients, and family, a transformation of systemic processes to support ACP across a range of institutional settings, the insertion of ACP into clinical practice and culture, and the involvement of communities and the wider public.

PCA believes that supporting greater capacity to engage in community discussions around death and dying may offer benefits that extend to other social interests. End of life discussions that ensure that the person and their wishes take centre place in planning may also provide a process for considering how to realise preferences around organ and tissue donation that accords with the agenda of some Australian jurisdictions to better support uptake of organ donation.

Access to and awareness of established directives

Evidence shows that advance care directives and plans outlining end of life treatment preferences are often not available or are overlooked by people providing care to terminally ill or dying patients.³⁰ Rationally, for an advance care directive to be of use in guiding a patient's care, it must be accessible to health care providers.

Internationally, central depositories where individuals can voluntarily deposit their directive can assist the identification of people's wishes. While research assessing the efficacy of initiatives to support awareness of, and access to, established directives is limited, there is some evidence that computer-based systems may improve access to and awareness of advance care directives, including across providers.³¹

Inconsistent legal standing of advance care directives and substitute decision makers

Legislation regarding advance care directives is not consistent across Australian jurisdictions. Several jurisdictions in Australia have passed laws that recognise advance care directives though these tend to offer particular, and often differing, restrictions on the recognition of directives.³² Generally speaking, treating staff who provide treatment in opposition to a known directive may be criminally liable. However, legislative inconsistencies across jurisdictions extend to protection of health professionals who do not follow directives.³³ Advance care directives which are deemed valid are recognised under common law, however, to date there have been no Australian cases that have considered when a common law directive will or will not be accepted as valid.³⁴

Similarly, most Australian jurisdictions have passed laws which empower various kinds of substitute decision makers, though these are not nationally consistent. Substitute decision makers can be appointed by the individual or, in accordance with the statutes, provision is provided for appointment by a tribunal or of someone close to the patients.³⁵

Anecdotal evidence suggests that legislative inconsistencies across Australian jurisdictions are implicated in failure to uphold advance care directives and in confusion amongst treating staff about rights and responsibilities in relation to directives. For these reasons, Street and Ottmann's State of the Science Review³⁶ recommends that Australian Government agencies promote the national uniformity of legislation and policies regarding the implementation of advance care plans.

²⁹ Street, et al., 2006.

³⁰ Street, et al., 2006.

³¹ Wilkinson, et al., 2007.

³² Parker, et al. 2007.

³³ Parker, et al. 2007.

³⁴ Parker, et al. 2007.

³⁵ Parker, et al. 2007.

³⁶ Street, et al., 2006.

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