

The Right for an Individual Choice: advance care planning.

Submission to the Productivity Commission inquiry into
Caring for Older Australians

On behalf of Monash University & the University of Tasmania

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On behalf of Monash University Gippsland & the University of Tasmania Department of Rural health
(UDRH)

The authors of this submission commend the Productivity Commission for the opportunity to advocate on issues that reflect on the delivery of care to older persons. The rights of older persons to determine individual health choices and treatments are an imperative in the context of current limited resources and financial constraints. The relationship between cure and managed care has been eloquently voiced through Palliative Care Australia and others over a number of years, however, the concept of advance health care planning in later life is limited, poorly understood by older persons and is fragmented by different States in Australia having conflicting legislative requirements. Further confusion arises when an individual's competency is questioned and a substitute (or proxy) decision maker has to engage in conversations pertaining to available treatments offered and, an individual's apparent wishes. This submission advocates for individual choice through a nationally legislated concise and consistent document of advance care planning to provide dignity, respect and self determination at the end of a person's life. Whilst older persons generally are our focus area; we wish to state the special requirements of older persons living in rural areas who are often overlooked in a Metro centric environment.

This submission acknowledges data and conversations from a successful Monash Small Grant Research Support Scheme (SGRSS) study that enquired into the knowledge and understandings of advance care planning in rural residential aged care facilities in Victoria.

Introduction

Australia's life expectancy (2002) has risen to be one of the highest in the world with more than 2.6 million Australians in 2005 being aged 65 years and over (Australian Institute of Health and Welfare, 2008). Society's current expectation is for early diagnoses through technological advances, with a prognosis of cure not care. Healthy Ageing, Active Ageing, Social Engagement and Volunteering are amongst some of the current 'buzz words' associated with those who are healthy and ageing well (65 and above). Toward the end of this spectrum of activity around ageing and older persons is a concern with end-of-life matters and respecting the wishes of older persons in planning for this event.

Advance care planning (ACP) is therefore essential, in meeting the treatment wishes and care expectations of older Australians now and into the future. ACP promotes autonomy and dignity, reduces stress on health professionals, family members and significant others by respecting an individual's lifestyle, treatment choice and care wishes at the end-of-life. ACPs are opportunities for individuals to reject invasive costly treatments when the prognosis is poor, to be replaced with care options that are self determined, provide respect, quality and dignity at the end of life. ACPs conserve un-necessary health expenditure thus promoting and providing responsible resource allocation and management.

Since the introduction of the *Aged Care Act (Australian Government Department of Health and Age Care, 1997)* and, more recently, in *The National Guidelines for a Palliative Approach in Residential Aged Care (the Guidelines) (Australian Government Department of Health and Ageing, 2004, 2006)* ACP has been recognized as an important area in the provision of care for older persons. The *Aged Care Act (1997)* provides for resident care choices to be determined in a number of Standards, especially Standard 2 *Health and Personal Care*, Standard 3 *Resident Lifestyle* and again in 3.9 *Choice and Decision Making*. These standards whilst relating to care choices, generally do not convey determine the resident's wishes in specific treatment situations, and have no legal standing within Victoria (and some other States). Furthermore ACP in the community is generally unknown, fragmented and can be seen as another obligation (to be imposed) on overworked General Practitioners. Older persons prior to entering a Residential Aged Care Facility (RACF) should have the opportunity to have their end of life care wishes discussed and documented appropriately in an ACP.

Background to ACP

Exponents for living wills and substitute health care decision-making in Australia can be traced back to the early 1990s (Ashby & Wakefield, 1993). The research work and publications of Michael Ashby, a South Australia medical activist for ACP at the time, brought to the fore the need for patient autonomy to be respected by health professionals (Ashby & Stoffell, 1995; Komesaroff, Lickiss, Parker, & Ashby, 1995). These early proponents for respecting an individual's right of treatment choice were mainly associated with the delivery of Palliative Care and the establishment of Palliative Care Units in Australia. Other researchers and ethicists were actively publishing in favour of autonomy and self determination for the community at large (Cartwright & Steinberg, 1995; Steinberg, Cartwright, Williams, Robinson, & Tyler, 1997; Steinberg, Cartwright, MacDonald, Najman, & Williams, 1997). Advanced Health Directives became a conversation prior to 1998 through the

work of Colleen Cartwright (Cartwright & Steinberg, 1995; Parker & Cartwright, 1999; Steinberg, Cartwright, Williams, et al., 1997).

In the United Kingdom, similar support for respecting patient's autonomy in decision making with the right of an individual to refuse treatments was again being accepted as part of Palliative Care Services for the terminal ill (Doyal, 1995). The Netherlands, in the late 1970s, was exploring the euthanasia question (Ashby, 1997). In America by the end of the 1970s, most States '*...had ratified pieces of legislation that enabled patients to document end-of-life treatment decisions in the form of Living Wills, do not resuscitate (DNR) orders, or do not hospitalise (DNH) order*' (Austin Health, 2008, p. 3; Street & Ottmann, 2006, p. 7).

Chronic illness in Western society including Australia has increased dramatically over recent years (Australian Institute of Health and Welfare, 2006). This phenomenon is exacerbated by an ageing population (Australian Bureau of Statistics, 1998) and is expected to become a major burden on Australia's delivery of health services. A program based on the *Respecting Choices* developed by the Gundersen Lutheran Medical Foundation (GLMF) in Wisconsin, USA was piloted by Austin Health Victoria, with funding from the National Institute of Clinical Studies in 2002-2003. Further funding from the (federal) Department of Health and Ageing enabled the program to be extended to one lead site in each state and territory (Austin Health, 2007). Increasingly the program of Respecting Patient Choices (Austin Health, 2007) has had some impact, though the penetration of these initiatives appears to have been greater in metropolitan areas. It would appear that rural communities have had a lesser involvement, even though rural Australia is ageing in greater proportions than urban centres. The Respecting Patient Choices logo acknowledging the work of Austin Health appears on each State's document, however, in reality the legislation requirements differ considerably.

State legislation regarding ACP

In Victoria, no specific legislation or policy exists that specifically deals with ACP. The *Guardianship and Administration Act (1986)* provides for a substitute decision maker to consent to medical and dental treatment where a resident is unable to do so. The *Medical Treatment Act (1988)* allows for refusal of treatment by a person deemed competent to make such decisions. This personal decision is invoked for the current condition only and is **not** an advanced care plan or directive for progressive or future health issues. *The Mental Health Act (1986)* provides for holding and

administering treatment (legislated voluntary and involuntary patient) for the care and protection of people with a mental illness in Victoria.

Under the *Powers of Attorney Act 1998*, the Queensland Government took the initiative to introduce “Advanced Health Directives” (AHD) for people over the age of 18. AHDs give directions about medical treatment in the event that a person (over the age of 18) loses mental capacity in determining their own care. This legal document respects the medical directives and care determined by an individual living in Queensland. There is guidance in completing the 24 page application document with adequate explanations and inclusions. The document can be revoked by the applicant at any time and a new document completed. Legally, AHDs are not accepted outside Queensland, but may be taken into consideration (respected) by other States in determining treatment options.

South Australia has a four way system in which to record ACP. The appointment of a Medical Power of Attorney (MPoA) which is a legal document that appoints another person (medical agent) to make medical decisions on a person’s behalf. An Anticipatory Direction (AD), which again is a legal document that enables a person to record their wishes about medical care and treatment consented too or rejected. This AD, made whilst competent to do so, only takes effect when a person is in the final stages of a terminal illness. An Enduring Power of Guardianship (EPG) enables a person to make personal life style decisions when a person is deemed no longer able to make such decisions. This EPG allows, in the absence of a Medical Agent for decisions relating to medical treatments to be made. The fourth aspect to ACP in South Australia is for a Statement of Choices (SC) to be made. SC require discussions with a previously appointed Medical Agent or Enduring Guardian, family members and the doctor. Unlike an AD, SCs are not legally binding. Any or all of the four ways to make an ACP can be revoked at any time providing a person is still legally competent.

The Northern Territories also embraces four ways for ACP to be communicated to health professionals. Choice through *The Natural Death Act 1988* records a person’s terminal illness wishes (specific definition applies) on a prescribed form. A Statement of Choices (SCs) enables what treatments an individual would undergo or reject. This document permits an individual to appoint another person to make decisions on his/her behalf. Again, emphasis is made on communicating that an ACP has been made to health professionals involved in the delivery of care. Family members and significant others inclusive of the person’s doctor should be involved.

Western Australia has two essential components relating to ACP. The first is by documenting a person's wishes in a Statement of Choices (SC), the second way is discussing those wishes with a person's General Practitioner, family members and/or significant others. *The Guardianship and Administration Act 1990* provides for certain people to give consent on behalf of another person if that person is incapable of doing so themselves. SCs allow for a person to record their wishes relating to medical treatment options. Again these documents can be revoked at any stage in a person's life providing that they have competency.

ACP in Tasmania is a written statement of a person's wishes regarding future medical treatment that is signed and dated. It may be referred to as a 'statement of wishes', 'advanced directive' or 'a living will', these terminologies are not defined but are used interchangeably. This ACP will only be used to guide future medical decisions when a person has lost the ability to make or communicate their medical treatment preferences. Medical treatment decisions are made in the interests of the individual in Tasmania in the context of current best practice treatments, however, a person's written directive is taken into account. Again the ACP may be revoked at any time and communication with family members and significant others is highly recommended.

The Australian Capital Territory has three ways in which to record individual ACP choices. The legal formality of appointing an Enduring Power of Attorney (EPA), appointing another person to make medical treatment decisions, including consenting to treatment or consenting to withhold treatment. The Statement of Choices (SC) records future medical treatment wishes and is used to inform the EPA and health professionals of acceptable medical treatments. For treatments that an individual does not wish to undergo the *Medical Treatment (Health Directions) Act 2006* (MTHD) is a legally binding document that is valid into the future should an individual be incapable of making decisions. The noted position of the MTHD is that palliative care (relief of pain and suffering) is excluded from legal compliance and is to be administered as a human right. The legal documentation may be revoked, or amended at any time.

Such inconsistencies threaten the rights of aged care consumers to determine the care that they wish to receive when death approaches. Ideally, progress to ACP should be more uniform across the States and standardised procedures used to document the end-of-life care wishes of all older persons especially those in the rural community. ACP is not infrequently regarded as the domain of the palliative care team; however older persons need to have the same opportunity to document their wishes irrespective of the services they are receiving.

Our recent study data indicates that consumer choice in the form of an ACP in rural RACFs is not understood. The limitation of community engagement, knowledge and education on ACPs is generally profound. In some rural areas however the preliminary conversations and understandings of ACPs has been expressed as a whole of health concept that requires strong media promotion. Consumer choice in the form of one national, consistent and concise document has been expressed. Such a document needs to be easily accessible and be individually owned. This document should include current and future health issues, be discussed with family members and significant others and is regularly revisited and updated especially on admission into health care services. Universality of the acceptance of ACPs in all regions of Australia was highly supported by the study participants.

Recommendations:

- That a universal national ACP document be made available.
- That the ACP document relates to all illnesses not just the current ailment, it should include progressive chronic illnesses, future health issues, be culturally appropriate and suitable for use by persons of non-English speaking backgrounds.
- A media campaign be conducted to inform older Australian's of the benefits of ACP to themselves, family members and health professionals.
- Determination of who besides family members, significant others and the General Practitioner would be involved in discussing and documenting an ACP.
- Document storage and location of the ACP requires consideration – needs to be confidential, secure and accessible; possibilities that could be investigated further include incorporation into e-health records or the development of a credit card sized ACP card with colour-coding relating to specific ACP directives.
- Further research be conducted into which health professionals would be most suited to commence the conversations for developing ACP and for maintenance of currency of an ACP.
- That research be conducted into the point on the life continuum at which ACP would be most effectively targeted and also into how often reviews should be conducted
- A more extensive education program for Health Professionals, especially those working in rural areas and Residential Aged Care Facilities, on the concept that ACP is more than DNR or DNH.
- A national unit costing of ACPs should be undertaken to inform resource allocation for future uptake.

- National ACP documents should include the right of the individual to revoke the ACP at any time following family involvement and for a new ACP be created.
- All ACPs should be discussed with the older person's family members, significant others and health professionals

Conclusion

This submission supports Palliative Care Australia in recognising that ACP is an important social investment to help ensure quality care at the end of life that accord with the individual's needs and preferences. ACP should be consumer driven and controlled, providing a reliable and flexible mechanism to anticipate and express care choices. It should be made whilst a person is deemed competent and should include all future illnesses and known treatment choices. ACP should be universally promoted through all media channels especially in rural communities. Documentation of ACP should be respected in all states of Australia providing seamless care from one legal document. Through the acceptance of the recommendations for ACPs ageing Australian will achieve end of life care that includes respect, dignity and self determined choices that are individually tailored.

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