

Victorian Parliamentary Inquiry into End of Life Choices

Legal and Social Issues Committee

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Submission by:

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This submission is based on:

- a Literature review investigating Advance Care Planning with respect to quality of end of life
- my clinical experience working in Rehabilitation, Aged care and Palliative care
- my personal experience of being Medical Enduring Power of Attorney(MEPoA) for a relative

Terms of Reference:

A. “How current Medical practices and Palliative Care (PC) can assist a person manage their end of life”

1. With regards to **Life-sustaining medical treatment (LSMT)** - which includes, but is not limited to; CPR, artificial respiration , artificial nutrition, artificial hydration, antibiotic treatment, dialysis.....

It must be noted that, Australia is a multicultural society which holds a wide variety of views on planning for end of life and the extent of LSMT which is desired or acceptable to them (Johnstone & Kanitsaki 2009; Taylor & Box 1999). On one end of the spectrum there are those who would want everything medically done to maintain life at any cost, through to those who do not wish to engage in the discussion in advance, or are just unsure of how much medical intervention they *would* want (until the time comes), through to the other extreme, those who hold strong stable beliefs about the limits of intervention they would wish for. Most people do not wish to make binding decisions about future care and are thus in the middle of this continuum (Hawkins et al. 2005).

Advance care planning (ACP) is a theoretical means of empowering people to choose the extent of medical intervention desired and ultimately to shape the manner in which they die (Brown 2003; Howarth 2007). However this theory assumes that everyone knows in advance what they would want in every scenario.

Advance Care Plans have primarily been in the form of either an **Advance Directive (AD)** which is defined as “*an instruction given by an adult about health care in advance of loss of capacity intended to operate after loss of capacity*” (Grano & Salek 2007); and or by the appointment of a **Substitute Decision Maker (SDM)** (Wilkinson et al. 2007).

ACP discussions can however be used to establish where someone lies on the continuum of views and then - to guide them to make their wishes (to the extent that they know them in advance) known in the most appropriate way (see Palliative Care Victoria’s “*A Guide to Decision-Making in Health Care*” - PCV 2012 and Barwon Health’s “*Personal Values Profile: Attitudes to Medical Treatment*”)

Research suggests that it is near impossible to accurately predict future wishes with regards medical treatment. Preferences, when given, have been shown to be context, time and affect

specific (Ditto et al. 2006; Fried & O’Leary 2008; Sharman 2011; Halpern & Arnold 2008) - and as such - it has been suggested that there is ‘*almost always some question about the validity of the directive*’ (Brown 2003).

Currently ACP is being widely advocated in Australia (AHMAC 2011) but many feel it lacks the generalisable evidence, infrastructure and streamlining to translate the cost & effort required into meaningful benefits that effect positively on everyone’s end of life experience (Corke et. al. 2009; Fagerlin & Schneider 2004; Kirk et al. 2010; Johnstone & Kanitsaki 2009; Lynn 2005; Phillips 2000; Robins-Browne et al. 2014; Sabitino 2010; Teno et al. 2007; Wilkinson et al. 2007; van der Steen 2010).

Research warns that when ACP indicates preferences for *less* LSMT, there is an increased need for quality Palliative care (Molloy et al. 2000; Tilden et al. 2004); when ACP indicates preferences for *more* LSMT, *as it sometimes does*, (Hickman et al. 2010; Silvester et al. 2006) this may increase the conflict medical teams have in negotiating ‘withdrawal and withholding treatment’ (WWT) in futile cases (Rivera et al. 2001).

Medical treatment cannot be *demanded* by either individuals or their legally appointed agents. (Grano & Salek, 2007; OPA 2010). Allowing more legally binding ACPs however, could lead to increased conflict and undermine ‘*best medical practice*’ - which ultimately may diminish the quality of care available to all.

ACP is also only relevant when one loses capacity to make ‘*in-the-moment*’ treatment decisions. In many chronic disease populations capacity is retained until the end - negating the need for ACP (Schneiderman et al. 1992).

Due to the many limitations of ACP and the heterogeneity of populations, many have argued that promoting the appointment of SDMs would be the most efficient public ACP policy to adopt (Fagerlin and Schneider 2004; AHMAC 2011; Fins et al 1999; Hawkins et al. 2005; Winzelberg et al. 2005).

However relying on SDMs to make treatment decisions is associated with a negative emotional burden which can last months or years (Wendler and Rid 2011). This may account for the general reluctance for some SDMs to create ACPs. A recent randomised control trial (RCT) studying Dementia carers in the UK failed to result in many written ACPs despite intensive support from experienced Nurse specialists (Sampson et al. 2011).

As a legally appointed SDM (MEPoA) – it is my view that not many SDMs feel comfortable with the burden of decision making -unless the person they are deciding for, has consistently voiced strong, clear, stable views – which research tells us is not the majority of people (Hawkins et al. 2005). In the absence of strong clear views (voiced by the patient prior to incapacity) there is a clear need for guidance by *best medical practice*.

It is important to note that, The Office of the Public Advocate (OPA) *does not* support the signing of common law ACPs by third parties /SDMs (OPA 2010, OPA 2014)- and for good reason.

Fagerlin and Schneider (2004) do however ‘*imagine recommending [ACPs] to patients whose medical situation is plain, whose crisis is imminent, whose preferences are specific, strong and delineable*’.

Indeed research suggests that appropriately targeted ACP programs can impact favourably on quality EOL issues (Detering et al. 2010) - on those who are ready to engage with the process (Pearlman et al. 2005).

Some however, warn of “*risks of unintended consequences that can flow from the development and operationalization of given public policies & related programs (advance care planning being a case in point)*” (Johnstone and Kanitsaki 2009).

Some scholars recommend shifting the focus of ACP to devoting more attention ‘*to the process of clinicians arriving at a terminal prognosis, communicating this to patients and family, and planning palliative care*’ (Fins et al. 1999).

ACP itself, does nothing to ensure that quality Palliative Care options are available when and where needed.

2. With regards to **Palliative Care in Australia**

A number of important factors have been identified in the definition of a ‘*good death*’. The ‘*management of symptoms*’, ‘*avoiding a prolonged dying phase*’, ‘*achieving a sense of control*’, ‘*relieving family burden*’, and the ‘*strengthening of personal relationships*’ - all rate high on the list (Singer et al. 1999; Steinhauser et al. 2000; Teno et al. 2004; Wenrich et al. 2003).

Despite evidence that most individuals would prefer to die at home – roughly 72% of Australians die within institutions (Howarth, 2007) - just over half of them die in Hospitals (AIHW 2011).

The reality of achieving a good home death however is dependent upon the existence of able bodied, willing carers with ready access to quality trained palliative care staff able to provide symptom control when needed.

It is important to note that there are significant concerns regarding the quality of EOLC depending upon the location of death and the availability of Palliative care services within those locations (DoHA 2010; Hardy et al. 2007; Le and Watt 2010; McNamara et. al. 2006; NHHRC 2009; Partington 2006; Productivity Commission 2011; Seymour et al. 2011).

Inequity of access to PC services and care of the dying in Nursing Homes is of particular concern (DoHA 2010; McInerney et al. 2009; NHHRC 2009). In Australia it appears as though – the elderly, female and non-cancer patients are under-represented in PC services (Le and Watt 2010; McNamara et. al. 2006) and that most inpatient palliative care is provided through the public hospital system (85% vs. 15% within the private hospital system) (AIHW 2011).

Increasingly, studies are suggesting that Palliative care programs, which by definition, focus on holistic symptom management, communication regarding goals of care (*advance* and *in-the-moment* planning) and meeting the subjective needs of patients and families dealing with life-limiting conditions- is associated with improved quality, and satisfaction with EOLC; as well as with less aggressive treatment near EOL (Finlay et al. 2002; Morrison et al. 2011; Dy et al. 2008; Penrod et al. 2010; Smith et al. 2003; Temel et al. 2010).

Overall the evidence suggests that the provision of early Palliative Care can combine any perceived benefits of ACP with the actual provision of appropriate services - which may provide the best chance for reducing futile aggressive treatment whilst improving the satisfaction and quality of End-of-Life care.

However....

In Australia, there is reluctance to refer to Palliative care (*for fear of diminishing hope*) as well as a public reluctance to accept referral (Broom et al. 2014).

There is also, a widely held misconception that Palliative Care is *Terminal Care*, when in fact Terminal Care is just one part of Palliative Care. Palliative Care can occur for years; *Terminal Care* is usually very short-lived.

Palliative Care referrals however often come at '*the 11th hour*' (just prior to the Terminal phase) when it is too late to provide all the benefits of Palliative care including addressing the issue of futile aggressive treatment near EOL - which is associated with a worse quality of death (Silverman et al. 2007; Zhang et al. 2009).

And yet....

Survival is not necessarily reduced by early referral to Palliative Care (Temel et al. 2010). What *is* affected positively is - the *Quality* of life left (Finlay et al. 2002; Morrison et al. 2011; Dy et al. 2008; Penrod et al. 2010; Temel et al 2010, Greer et. al 2012).

More about Palliative Care....

Palliative Care teams are multidisciplinary care teams meeting the many varied needs of patients and families dealing with life-limiting conditions (PCA 2015).

Each member of the team helps provide elements essential to achieving quality holistic EOLC- beginning well before the Terminal phase of an illness.

'To some,

the place of the Physiotherapist in palliative care may appear a contradiction: a profession dedicated to the rehabilitation, enablement and empowerment of patients juxtaposed with the domain of terminal illness death and dying.' (Jennings 2013)

However,

'through [a] positive blurring of the boundaries between chronic condition management and Palliative Care, Physiotherapists [adopt a] rehabilitative approach to palliative care [which] embraces health promotion and self-management across the spectrum of [Life limiting illness]' (Cane et al. 2001 as cited in Jennings 2013)

And,

in today's society where personal autonomy is paramount, *Physiotherapy in Palliative care*, which strives to improve a person's dignity, quality of life and to maintain independence in the face of advancing disease, helps to highlight some of the lesser known positive benefits of early referral to Palliative Care (Jennings 2013).

3. With regards **Euthanasia**

Euthanasia needs to be considered as a separate issue as it does not fall into the realm of medical treatment at the end of life; rather - it is a request for assisted suicide (Finlay 2015).

Consider... do we really ‘*put down*’ dogs because it is the most humane thing to do? – or is it just more convenient? Is anyone willing or able to offer good Palliative care to a dog? I love my dog, by the way, but I cannot ask him what he would want. However, when his time comes, I do not think he would object to good Palliative care and dying at home in the arms of his family.

4. With regards **Palliative Sedation**

Palliative sedation ... is the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health care providers (Cherny & Radbruch 2009).

It is considered part of good palliative care but it is used only *as a last resort* in the terminal phase of an illness and ‘*does not have the intent to directly hasten or to end a life*’ (Caresearch 2015).

Palliative Sedation **is not** Euthanasia.

For the humane relief of intractable suffering at the end of life - what is needed - is more flexible and timely access to Palliative Care.

B. How other jurisdictions assist a person to manage their end of life

1. USA

Most of the research surrounding ACP has come out of the USA and whilst POLST-type programs (Physician’s Orders for Life-Sustaining Treatment) are spreading to cater to the seriously ill, there remain serious legal and cultural barriers to its widespread dissemination (Hickman et al. 2008). In the US the RC® program has also had limited dissemination (Marchland et al. 2006).

Fagerlin and Schneider (2004) suggest that rather than promoting autonomy the trend in the US has been to ‘*promot[e] the execution of uninformed and under-informed advance directives*’ which undermines the argument of self-determination.

‘Increasingly,... individuals are being counselled that appointing a health care agent [SDM] is best practice due to the clear limitations of living wills as an advance care planning tool’ (Bomba 2011).

Sabatino (2010) suggests that the USA will continue to move towards a ‘*communication model*’ of ACP rather than a ‘*legal transactional model*’.

2. FRANCE

In France '*Advance directives are not legally binding*' (Baumann et al. 2009).

France's *Leonetti's law* of 2005 created a legal framework for end-of- life decision making surrounding *futile* treatments and authorizes the withholding or withdrawal of treatments (WWT) when they appear "*useless, disproportionate or having no other effect than solely the artificial preservation of life*". The law clarifies the acceptable code of practice for WWT. Doctors must weigh the burden and acceptability of an investigation or treatment against expected benefits before deciding to initiate or withhold it and must seek collegial consensus from the medical team and family as well as documentation of their rationale.

Whilst France encourages the appointment of a 'trusted person' during any hospitalization, according to Leonetti's law however, 'the trusted person is not a surrogate decision-maker because the burden of medical decisions is thought to remain with the physician in charge of the patient and not with the relatives'. Leonetti's law also stipulates that 'any decision of treatment cessation must [also] be accompanied by appropriate palliative care' (Baumann et al. 2009).

Since enactment - a recent study revealed that an intensive ICU communication strategy on end-of life practices (following the code of practice) has been associated with a significant reduction in the time delay between admission to ICU & the initiation of a decision-making process with respect to WWT. Whilst the number of actual deaths did not alter significantly – the LOS in ICU was significantly lower post intervention (Quenot et al. 2012). These findings give strength to the argument that ADs may be superfluous if ongoing communication between all affected parties occurs.

As fear of litigation has been shown to impact medical practice with respect to WWT (Prendergast et al. 1998) – it is thought that this '*new law has the advantage of providing a legal framework to free physicians of the burden of unguided decision making*' (Quenot et al. 2012).

3. UK

Currently in Wales, Palliative Care is an automatic referral on all oncology wards and bolstered by recent successful Palliative care studies (Temel et al. 2010; Greer et al. 2012) proponents are advocating for increased funding of core Palliative Care services across all sectors with access to specialist Palliative Care advice 24/7 (Finlay 2012).

C. Potential changes to our legislative framework

1. With regards to the Current Victorian Legislation surrounding ACP

Current Victorian legislation surrounding ACP allows for all contingencies (see Appendix 1) without risking the harm that potentially uninformed, binding ACPs or coerced, guilt-ridden third party ACPs could cause.

The difficulty lies, not with the laws, but in the process of streamlining ACP practice to efficiently guide those with differing views to best use the existing legislation to have their wishes known and then - for all to have timely access to appropriate care.

SUMMARY

ACP is complex issue. It has benefits when used in the right form and context but it is not without risks.

Current Victorian legislation caters for all ACP contingencies without risking the dangers of allowing more binding ACPs.

ACP does not guarantee quality Palliative care is available when and where needed.

Palliative Care has always incorporated EOL discussions as core to its service (which is what the current ACP evidence is now advocating).

Early referral to Palliative Care is associated with improved EOL experiences.

Changing the focus to promoting & funding Palliative Care combines any potential benefits of ACP with the provision of quality end of life care.

If the image of Palliative Care were to change to reflect the positive outcomes associated with it- perhaps more people would be accepting of Palliative Care as a means to achieving a dignified, pain-free end of life.

RECOMMENDATIONS

With regards to ACP

1. **Do not allow more binding ACPs within the legislation** – research evidence does not support the creation of binding ACPs
2. **The many qualifications and limitations of ACP should guide the form and extent to which they become general public policy** - in order to avoid unintentional negative consequences

With regards to Palliative Care

3. **Promote changing the image of Palliative care** from that of a *'failure of curative medicine'* and a *'pathway to death'* to that of a *'means of improving the quality of life left'*.
4. **Focus funding on equitable, flexible provision of Palliative Care**– because regardless of a person's stated wishes, without sufficient quality Palliative care services, there is less hope of achieving a *'good death'*.
5. **Incorporate Palliative care referrals at:**
 - point of diagnosis of rapidly progressive Life limiting illnesses
 - sentinel stages of chronic/slowly progressive Life limiting illnesses
 - when considering WWT
6. **Expand Palliative Care Services and training** to ensure high quality end of life care is available to all in need of it.

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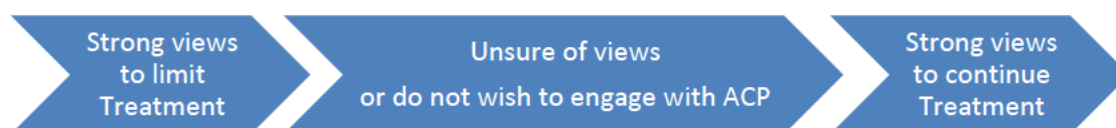
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Appendix 1

Current Victorian law surrounding ACP is able to cater to all along the continuum of views.



1. Currently those who hold very strong beliefs about limiting treatment have the option of completing a RTC for current condition and appointing a MEPoA who would be able to refuse treatment for them in the future if a new condition were to arise. These forms have a requisite of ensuring capacity and requiring medical witnessing which, given the gravity of the decision, is appropriate and should not be altered.

2. For those, in the majority, who may either wish not to engage or whose views may change with time, affect, context - appointing a MEPoA (if the *Next of Kin* is not who they wish to be SDM) and regularly discussing their views with their medical team and SDM would be considered best practice.

3. Those who wish to have maximal medical support to be kept alive –also have the option of making their preferences known in the form of a non-binding SOC and by appointing a MEPoA to advocate on their behalf should they lose capacity to do so.

	Strong views to limit Medical Treatment	Unsure of views (Majority of People)	Strong views to continue Medical Treatment
Existing current Medical condition	Complete a Refusal of Treatment certificate (RTC) <i>and</i> Appoint MEPoA	Consider SOC Consider MEPoA Discuss your views regularly with SDM and Medical team	Complete SOC <i>and</i> Appoint MEPoA Discuss your views regularly with SDM and Medical team
Future condition	Complete a SOC <i>and</i> Appoint MEPoA RTC- competent person <i>or</i> RTC-MEPoA	Consider SOC Consider MEPoA Discuss	Complete SOC Appoint MEPoA Discuss

* Remember ACP only takes effect if you lose the capacity to decide for yourself

* A SOC can only guide treatment- it cannot and should not ever be allowed to demand treatment