Advance Care Planning for People with Dementia in Western Australia: An Examination of the Fit Between the Law and Practice*

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This article examines the ‘fit’ between the Western Australian legislation on advance care planning (ACP) and health professionals’ experiences implementing this in relation to persons with dementia. The legislative provisions are outlined, and a qualitative study of experiences with ACP among 19 health professionals, all engaged in the care of persons with dementia, is described. Based on these interviews, the authors propose three themes: ‘navigating risk’, ‘the therapeutic journey’ and ‘the most agreeable outcome’ to describe current practice in this area. The authors conclude that ACP in this context is aimed at minimising risk, establishing consensus and achieving the ‘most agreeable outcome’ for the person and their family, rather than privileging the individual autonomy of the person engaging in ACP. The implications for policy and law makers regarding possible reform of ACP in relation to persons with dementia are discussed.

Key words: advance care planning; advance directive; autonomy; capacity; dementia; law; practice.

1. Introduction and Legal Framework

The concept of advance care planning (ACP) derives from an ethical and philosophical perspective that prioritises respect for an individual’s autonomous views and preferences in relation to their health care.¹ By undertaking ACP, a person who has capacity can express preferences and make anticipatory decisions about their health and medical treatment in the event of the loss of this capacity. The concept has found legal expression mostly through parliamentary intervention, largely as a result of inherent limitations and practical impediments associated with the common law.²

Western Australia, in common with all Australian jurisdictions, has formalised advance care planning in legislation.³ Part 9B of the Guardianship Act was inserted following the Acts Amendment (Consent to Medical Treatment) Act 2008 (‘Amendment Act’). The Amendment Act entered Parliament through the Acts Amendment (Consent to Medical Treatment) Bill 2006 (‘Bill’).⁴ The Amendment Act altered the Guardianship Act by inserting provisions providing for enduring powers of guardianship (‘EPG’) and advance health directives (AHDs).⁵ An EPG allows persons with capacity to appoint one or more substitute decision makers for

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lifestyle and treatment decisions in the event of incapacity.⁶ This is distinct to guardians appointed by the State Administrative Tribunal ('SAT'), who make treatment decisions for already incapacitated persons.⁷ Prior to the Amendment Act, SAT appointed guardians, and enduring powers of attorney ('EPA') were the dominant forms of statutory substitute decision making. EPAs relate to financial and property decisions and do not permit medical decision making.⁸ Parliamentary intention was to enact further legislation allowing for end of life (and other health care) decision making, with a view to upholding a person's expressed wishes about health treatment, thereby prioritising their personal autonomy in this realm:

The principle of personal autonomy is central to the bill. The bill establishes a simple, flexible scheme whereby persons can ensure that, in the event that they become mentally incompetent and require medical treatment for any condition, including a terminal illness, their consent, or otherwise, to specified treatment can be made clear in an [AHD].⁹

The Guardianship Act provides for statutory ACPs while expressly preserving the position at common law, which allows for anticipatory decision making in relation to future health treatment.¹⁰ Common law AHDs are preserved 'to enable a person to make treatment decisions about his or her future treatment, other than by means of the formal [AHD]'.¹¹ The Amendment Act was aimed at formalising pre-existing legal principles governing common law AHDs and creating certainty for patients and medical practitioners.¹² Many jurisdictions uphold the right to refuse medical treatment at common law¹³ but this remains contentious. For instance, authority differs on whether a common law AHD needs to be made with sufficient information¹⁴ or whether it can be made for any reason if done so by a competent individual.¹⁵ The provision of statutory mechanisms to uphold personal autonomy therefore

represents a significant advancement in ACP within WA.

Are the formalities associated with the execution and operation of ACP in WA consistent with and supportive of the legislative intent? The following section examines the formal requirements and extrapolates the concepts which are fundamental to the legal framework.

1.1 Execution of ACP

An individual must be at least 18 years of age and of *full legal capacity* to execute an AHD¹⁶ or an EPG.¹⁷ Both a statutory AHD and the EPG must be in the form prescribed by the regulations¹⁸ although, in the case of an AHD, lack of compliance with the prescribed form may nonetheless constitute a common law AHD.¹⁹ While a person seeking to make an AHD or an EPG is encouraged to seek legal or medical advice under the legislation, it is clearly not a requirement to do so.²⁰

An AHD will be invalid if the treatment decision is not made voluntarily or the maker did not understand the nature or consequences of the treatment decision.²¹ This reflects the common law principles for valid consent to treatment: capacity, voluntariness and sufficient understanding of the decision.²² There is no corresponding provision in relation to EPGs.²³

1.2 Operation of ACP

1.2.1 AHDs

An AHD operates as if the treatment decision was made by the maker with legal capacity,²⁴ and only operates in the circumstances specified in the AHD.²⁵ A treatment decision in an AHD may be invalidated if circumstances arise which the maker did not anticipate when making the directive, which would conceivably cause a reasonable person to change their mind.²⁶ In determining whether such circumstances exist, certain factors may be

considered: the maker's age, review of the AHD, treatment required and family views.²⁷ A treatment decision in an AHD is revoked if the maker has changed their mind since making the AHD.²⁸ Revocation must be made with full legal capacity.²⁹ AHDs are foremost in the hierarchy of treatment decision making, above EPGs.³⁰ This is reflective of the intention to promote personal autonomy as paramount in the legislation.³¹

1.2.2 EPGs

Under the legislation, a person appointed via an EPG has the same responsibilities, and is subject to the same limitations, as a plenary guardian.³² This means that the EPG acts as a parenting order, and therefore gives the guardian power to make decisions about where the person is to live and work, and, of most relevance here, to make treatment decisions for the represented person.³³ However, an EPG may be limited in its scope and applicability, and may also provide directions about how the guardian is to perform his/her functions.³⁴ This again reflects the legislative intent to prioritise the autonomy of the person executing the EPG.

1.2.3 'Treatment Decisions'

A person executing an AHD or appointing an EPG under the GAA 1990 (WA) makes directions relating to 'treatment decisions'.³⁵ Under Section 3, these are defined as decisions to have or refuse treatment, and include decisions in relation to the withdrawal or withholding of life-sustaining or life-saving treatment as well as palliative care. Therefore it is possible, as part of ACP, to request that no palliative care be given. Western Australia is the only Australian jurisdiction that explicitly extends ACP to include the refusal of palliative care. This indicates that the type of decisions that can be made within the scope of ACP under the GAA is particularly wide, again indicative of the weight given to personal autonomy.

1.2.4 The Western Australian State Administration Tribunal (SAT)

SAT has jurisdiction in relation to AHDs and EPGs on the application of a person with a proper interest.³⁶ SAT may make declarations on the validity of an AHD, EPG or treatment decision³⁷ and incapacity of the maker (of an ACD) or appointor (of an EPG).³⁸ SAT may also provide directions construing the terms of an AHD or EPG³⁹ or revoke a treatment decision in an AHD or the EPG, or the appointment of a person under an EPG.⁴⁰

1.2.5 Other Decision Makers

In the absence of a person having executed an effective ACP, the GAA's hierarchy of decisions moves then to the decision of a SAT-appointed guardian. Where there is no such appointment in place, a 'person responsible' under the GAA is next in place to take the treatment decision. All substituted decision makers under the GAA 1990 (WA), including the EPG, must make decisions on the basis of what is perceived to be in the 'best interests' of the incapacitated person. Section 51 provides that in making the decision, the substitute should have regard to the wishes of the person – what he or she would have wanted in the circumstances. It is clear, therefore, that the WA legislation does not prescribe a substituted judgment standard for decision making. Such an approach would require the decision maker to 'step into the shoes' of the incapacitated person, and make the decision that the person would have wanted, without regard to other factors.

1.2.6 Health Professionals

Consistently with ACP provisions in other Australian jurisdictions, the GAA provides 'protection' for the health professional who treats or does not treat on the basis of an apparently valid AHD or decision of a substituted decision maker, whether that be under an EPG, SAT guardianship order or by a

'person responsible'.⁴¹ For example, it provides that, where the health professional reasonably believes that the patient is unable to make reasonable judgments about a treatment action and relies in good faith on what is purportedly a treatment decision made in an AHD or by the relevant substitute decision maker,⁴² then this has the effect as if the patient had made this decision him/herself and was of full legal capacity.⁴³ A health professional can provide 'urgent treatment' if it is not practicable for him/her to ascertain whether there is an AHD, or to obtain a treatment decision from a relevant substitute decision maker.⁴⁴

1.3 Identification of Integral Concepts

The introduction of statute-based ACPs in Western Australia was clearly underpinned by an agenda to give a voice to those previously capable of making decisions about their own health care. This is evident in many of the provisions canvassed above. While the value of self-determination is compromised in some instances,⁴⁵ the 'hierarchy' set out in the legislation emphasises the trumping effect of the AHD and, below this, the EPG; both forms of ACP in which the person has formally expressed a preference. This agenda has particular relevance for the older person who has had the opportunity to develop a deep understanding of their own preferences and values, and who is also nearing the end of his or her life, when the technological advances and treatments available may be applied to extend life beyond a time and in circumstances which that person would regard as unacceptable.

This study is concerned with exploring the 'fit' between the legislative provisions for ACPs in Western Australia and the operation of ACP 'on the ground' with application to persons with dementia. Examination of Hansard debates indicates that, during Parliamentary discussion of the Amendment Act,⁴⁶ specific consideration was not given to the application of AHDs for persons with

neurodegenerative disorders such as dementia, in which the process of cognitive decline, being permanent and irreversible, may pose challenges. Although dementia was noted as a condition likely to impede medical decision-making capacity, the overarching aim of the Bill was to enable medical decision making consistent with a person's specific wishes (through an AHD) or by his/her preferred substitute (through an EPG) in the event of his/her legal incapacitation.⁴⁷

The following section identifies key concepts in the operation of ACPs under the GAA. This study therefore begins with the requirements of the legislation, before moving to describe and analyse the findings of the study. It is submitted that reflection on the 'fit' can only take place against the backdrop of the legal framework and the key concepts associated with this.

1.3.1 The Requirement for and Meaning of Legal Capacity

An ACP that involves making an AHD or executing an EPG under the GAA requires 'full legal capacity', a term which is not defined.⁴⁸ The legislation provides that a person is presumed capable to look after their own health, unless the contrary is proven.⁴⁹ Parliament indicated that AHDs did not require a definition of capacity, as the test for appointment of guardianship applies.⁵⁰ A guardian may be appointed where a person is *unable to make reasonable judgments* in relation to matters relating to his or her person. This definition incorporates varying notions of capacity.⁵¹ Parliament concluded on capacity for AHDs:

The definition of 'legal capacity' is laid down in the [Act]. It describes the circumstances in which a guardian should be appointed ... it goes very much to that capacity to make a reasonable judgment. We have incorporated those notions in this legislation. That concept is carried forward ... in respect [of] the capacity to make a living will.⁵²

Fundamentally, therefore, the capacity to make an AHD or to execute an EPG is premised on the ability to make *reasonable judgments*. The term ‘reasonable’ employs notions of rationality, objectivity and normative values, originating from negligence and duty of care, where the objective standard of a reasonable person prevails.⁵³

Given the lack of a definition in the GAA, it is relevant to consider the common law approach to capacity. Capacity to consent or refuse medical treatment is presumed at common law ‘unless and until that presumption is rebutted’,⁵⁴ a presumption which has been expressly acknowledged as founded on the right of self-determination and personal autonomy.⁵⁵ The test for capacity was enunciated in *Hunter and New England Area Health Service v A* (‘Hunter’)⁵⁶ and cited with approval in WA through *Brightwater Care Group (Inc) v Rossiter* (‘Brightwater’)⁵⁷ as follows:

[I]n deciding whether a person has capacity to make a particular decision, the ultimate question is whether that person suffers from some impairment or disturbance of mental functioning so as to render him or her incapable of making the decision. This will occur if the person:

- (1) is unable to comprehend and retain the information which is material to the decision, in particular as to the consequences of the decision; or
- (2) is unable to use and weigh the information as part of the process of making the decision.⁵⁸

In contrast to the ‘reasonable judgments’ standard given in the GAA, the common law standard is expressed subjectively. Refusal of treatment is valid notwithstanding the reasons and irrespective of whether such reasons are ‘rational, irrational, unknown or even non-existent’.⁵⁹ In practice, this creates difficulties, as ‘the lack of any discernible basis for a decision to refuse treatment’ is a factor in ascertaining the validity of a decision.⁶⁰ The

common law capacity test also requires information to be ‘retained’.⁶¹

1.3.2 Scope of the Decisions Within ACPs

As noted above, the ACP provisions (and indeed all decisions of substitute decision makers) within the GAA 1990 (WA) apply to ‘treatment decisions’. Under [Section 3](#), treatment is defined as ‘medical or surgical treatment’ or ‘other health care’, while a decision means a decision to consent or refuse consent to the commencement or continuation of the treatment. In relation to both ‘treatment’ and ‘decision’, the definitions are exhaustive; the legislation uses the term ‘means’, and therefore does not permit the inclusion of other situations within the definitions.⁶² The meaning of ‘treatment’ is therefore integral to the operation of the law on ACPs.

1.3.3 Substituted Decision Making

The way in which the GAA 1990 (WA) is worded suggests that the power that is accorded to substitute decision makers is associated with *contemporaneous* treatment decisions, not *advance* treatment decisions. This is reinforced by the wording used in Part 9B dealing with AHDs, which refers to the necessity of the person having ‘full legal capacity’ and the decision being about *that* person’s future treatment, not another’s. Moreover, in Part 9A, dealing with the operation of EPGs, there is no reference to any power on the part of persons appointed as EPGs to make AHDs on behalf of the now incapacitated persons. Section 110G(1) notes that an enduring guardian has the same functions and is subject to the same limitations as plenary guardians (SAT-appointed guardians). Section 45(2) notes that plenary guardians may make ‘treatment decisions’, there being no reference to a power to make advance treatment decisions.

In terms of the nature of the decision-making test for substitute decision makers,

West Australian law currently prescribes a 'best interests' approach, albeit recommending that the decision maker have regard to the views of the incapacitated person to the extent that this is possible.⁶³ This should be distinguished from the substituted judgment approach – by which the decision maker 'steps into the shoes' of the incapacitated person. Currently, only South Australia prescribes an unfettered substituted judgment test;⁶⁴ two other Australian jurisdictions appear to permit the substituted judgment approach to be overridden where the treatment decision would adversely affect the interests of the person.⁶⁵ Proponents of substituted judgment argue that this decision-making standard is more closely aligned with the principle of personal autonomy, but research also indicates the difficulties of translating this principle into actual execution.⁶⁶

1.3.4 Revocation of AHDs

The GAA provides that an AHD is revoked if the maker has since changed their mind about the treatment directions expressed therein.⁶⁷ Further, a treatment decision in an AHD is void if circumstances arise which the maker of the AHD did not anticipate, and which would have caused a reasonable person in the maker's position to change their mind.⁶⁸ This involves an assessment of what the patient would have decided, and family members may be consulted.⁶⁹ It appears that Parliament may have intended these provisions to act as a safety net and ensure an AHD is adaptable to changing situations.⁷⁰ However, this provision also poses a risk to personal autonomy by shifting focus from the autonomy of the previously competent person to what a third party considers 'reasonable'. Moreover, given that an AHD can only be revoked while a person has full legal capacity, it is clearly possible that the now incapacitated person's current preferences carry no legal weight where they conflict with an existing valid ACD.

2. Methods

2.1 Study Design

The empirical component of this study was informed by the issues raised in the preliminary analysis of legislation. The researchers were interested in exploring:

- (1) the extent to which the objectives of legislation enabling AHDs are being practically implemented in dementia care
- (2) the practical issues associated with ACP and AHDs in dementia care, and whether these converge or diverge from the issues raised in the analysis of legislation.

For the purposes of this article, we focus specifically on those aspects of the interviews that provide information and perspectives on how advance directives, and the broader process of ACP, are currently implemented in the context of the care of people with dementia. These data enable analysis of the extent to which the intentions and objectives of the legislation are implemented in practice in the context of dementia, one (prevalent) category of progressive, terminal illnesses.

2.2 Sample

We employed a purposeful sampling technique, recruiting health professionals with a significant focus on dementia care as 'key informants'. This included generalist and specialist health professionals working in hospital, community and residential care settings in metropolitan and rural locations, with experiences arising from care provision at different points on the dementia trajectory. Recruitment was facilitated through contact with aged care organisations, general practice clinics, older adult mental health services and the researchers' own clinical networks. Nineteen participants were recruited, with a range of participants from each of the three core groups of 'geriatric services', 'primary care'

Table 1. Participant characteristics

	Geriatric services (N = 4)	Primary care (N = 7)	Residential aged care (N = 8)
Gender N (%)			
Female	3 (75%)	3 (43%)	8 (100%)
Male	1 (25%)	4 (57%)	-
Location			
Metropolitan	4 (100%)	2 (29%)	6 (75%)
Non-metropolitan	-	5 (71%)	2 (25%)
Profession			
Medical (specialist)	3 (75%)	-	-
Medical (generalist)	-	5 (71%)	-
Nursing*	-	2 (29%)	8 (100%)
Social work	1 (25%)	-	-
Care setting			
Sees residents/patients in residential care setting?	2 (50%)	6 (86%)	8 (100%)
Sees patients admitted to hospital?	4 (100%)	2 (29%)	-

*Nursing category included nurse practitioners, community nurses, and registered nurses practicing in residential care facilities (typically as care managers)

and ‘residential aged care’ (see Table 1). Interviews were conducted between April 2015 and March 2016, approximately seven years following the passage of the Amendment Act.

2.3 Interview Methods

A standard discussion guide provided a general framework for semi-structured interviews, with scope for exploring additional areas of interest. Participants were asked to explain their role and the contexts in which they provided care for people with dementia. Specific questions probed participants’ understanding of ACP and the legislation enabling people to complete advance directives. The remainder of the interview focused on participants’ practical experiences in implementing ACP and/or advance directives in the context of dementia, and their views on how law, policy and/or service provision might change to enable better outcomes. The researchers specifically explored practical issues associated with initiating ACP discussions, assessing decision-making capacity, storing, retrieving

and communicating ACP documentation and the role of ACP and advance directives in clinical and treatment decision making at the end of life for people with dementia.

Interviews were recorded using a digital voice-recorder and transcribed verbatim by the researchers. Interviews lasted for an average of 49 minutes (minimum 35 minutes, maximum 89 minutes). Transcripts were analysed using a General Inductive Qualitative Method (GIQM).⁷¹ Each transcript was read multiple times, and research memos were created to document initial impressions. Transcripts were coded line-by-line to inductively identify a coding framework. Codes were refined through a constant comparative approach, and discrepancies in coding decisions or interpretation of the text were discussed until consensus was reached. Analysis commenced from the early stages of data collection, enabling the emerging themes to inform ongoing purposeful sampling and modification of the discussion guide. Specifically, this approach prompted a broadening of the recruitment process, to actively include community-based practitioners who provided

services to people prior to the diagnosis of dementia.

The study methods were approved by the Human Research Ethics Committee of the University of Western Australia.

3. Results

3.1 *Understanding of ACP*

Participants broadly understood ACPs as a means by which people with decision-making capacity could express their wishes for future treatment (and/or preferred means of decision making) in advance of a situation in which they lacked decision-making capacity. All of the participants interviewed expressed support for the principle of autonomy, and for ACPs as a method of advancing this principle. Other frequently cited benefits of ACPs included promoting higher quality substitute decision making, reducing the burden of substitute decision making and avoiding unwanted treatments. Less commonly, some participants identified the ACP process as being helpful in promoting patient or family member acceptance during the terminal phase, while others identified ACP as a means of reducing inappropriate healthcare use.

I think dementia takes away so much of your dignity, that we should be giving you every piece of it that we can, so if you have an opportunity to make decisions for yourself in the future, then that will give you dignity. (Interviewee 9, Geriatrician trainee)

Participants' understanding of the legal requirements of ACPs were broadly consistent with the existing legislation, with some misunderstandings relating to the details of the legislation. The majority of participants understood that the AHD was a legally binding document, voluntarily completed by a patient with decision-making capacity. Some participants exhibited evidence of misunderstandings relating to the witnessing requirements (belief that a doctor or lawyer had to

witness the form) and/or its relative legal standing in a situation of conflict (belief that the AHD was not legally binding or that a patient's substitute decision maker could easily override it).

And also we've been fed a lot of the time that 'it's not a legal document', it doesn't count you know so why are you doing it?' You know there's almost like a stigma attached to the advance health directive that it's not legal so what are you doing it for? (Interviewee 8, RACF manager)

A minority of participants (particularly those without medical training) expressed the (inaccurate) belief that in the context of a patient without capacity, and in the absence of a valid AHD or substitute decision maker, medical staff were generally required by law to provide life-prolonging treatment. Participants with higher qualifications (e.g. medical specialists) and specialised roles in geriatric care tended to demonstrate more nuanced understanding of the legal requirements. A number of participants (particularly those in primary care and residential aged care) identified a lack of exposure to necessary training in the legal aspects and clinical practice areas of ACPs. Those in settings where training had been provided had higher levels of knowledge about the legal requirements and expressed increased confidence in facilitating ACP discussions.

3.2 *Professional Approaches to ACP*

Participants' understanding of ACPs and its legal requirements, issues associated with dementia and the characteristics and limitations of their own work and organisational context all influenced the way that ACP was approached and implemented. General practitioners usually had ongoing contact with patients and were typically the first to detect evidence of possible cognitive impairment, often as a result of concerns expressed by relatives. They often diagnosed dementia, or referred complex cases to specialist memory

services or visiting geriatricians. Advance care planning was typically broached during a routine 'over 75 year health assessment', or otherwise in response to declining health, a 'crisis' event or a transitional point in care (e.g. admission to residential care facility). The GP's established relationship and ongoing contact with the patient enabled them to take a phased approach to broaching and facilitating ACP discussion:

The diagnosis of dementia is devastating, and families panic, and the person ... sometimes they will panic. And it's a lot to take on board. So from a personal point of view I'll tend to phase it in. It isn't something I'll bring up at the initial diagnosis. I'll wait some time, maybe some weeks, even some months. These are my own patients in the practice. However once we get beyond the practice and we get patients moving into a nursing home. At that stage ... there's an urgency to ... get decisions made. (Interviewee 18, general practitioner)

Geriatricians typically saw patients in an outpatient setting (on referral from the GP), in an inpatient setting and occasionally during home visits. Often their role was to make a definitive diagnosis of dementia or provide specialist advice regarding a patient's capacity to make certain decisions. Their contact with patients tended to be more episodic, and they typically broached the idea of ACP, before referring patients to their GP for further discussion:

So usually if it's something I'm bringing up we won't, it'll be more of an education sort of thing, and then often they'll be referred back to complete it with their GP or someone who knows them well. (Interviewee 9, Geriatrician trainee)

Respondents in the RACF setting mostly cared for people who were in the late stages of their illness. Admission often followed a hospital admission or some form of 'crisis', characteristically brought about by functional decline and the inability of family or support services

to manage risks (e.g. falls). This typically led to assessment by the aged care assessment team, and a negotiated decision that the person required admission to residential care. Respondents expressed the view that very few residents arrived with existing ACP documents, and only a small percentage would have the necessary decision-making capacity to complete a valid AHD once admitted. Staff mostly turned to family members or other substitute decision makers for decisions about treatment or hospital transfer, and also described working closely with the patient's GP:

So if a treatment is required, then either the doctor or the registered nurses will be discussing it with the guardian, the next of kin, or someone like that and then we come to a decision about it that way. (Interviewee 3, RACF manager)

3.3 Types of ACP

A range of different 'types' of ACP were identified. These included the legally binding AHDs or EPGs, as well as more flexible 'advance care plans', which were recognised as not legally binding.⁷² A number of residential aged care facilities developed and used their own non-statutory ACP forms. These typically emphasised the type of care to be provided within the RACF itself, and often overlapped significantly with routine 'care plans', covering domains such as room ambience, or preferred music and foods. One respondent, who provided care to residents across a number of RACFs, explained this approach:

I find they've all got their own sort of policy or protocol or paperwork that they have to do on admission, because sometimes they've got like 'End of Life wishes' or something, that you know the family can sit down and go through. And a lot of that to me, seems to be related to their sort of nursing home needs, and not so specifically with like medical needs. (Interviewee 15, community nurse)

While ACPs were identified as ideally being a way of the individual patient expressing their own wishes for future care, concerns about the capacity of patients with dementia to undertake an ACP often led to staff conferring with family members and developing 'proxy advance care plans'. This process was differentiated from regular substitute decision making by the fact that it was a form of advance care planning, undertaken by substitute decision makers in advance of the actual decision. This situation was particularly prevalent in the RACF context, in which non-statutory organisational ACP forms were often completed by family members around the time of admission, or in response to a change in the resident's health status or disagreement about the goals of care.

I think it's important to try to map out what's going to happen, or what the pathway is if the person can't eat or drink what are we going to do ... I think what, well the patient may be blissfully unaware but I think what families want is a, is a clear pathway that they understand and they come to accept that their relative, this is what's going to happen and if things happen then this is what we're going to do. (Interviewee 13, general practitioner)

While this process of 'proxy advance care planning' occurred frequently and was identified as being beneficial for family members and care providers, it was also seen as a less authoritative process than a formal AHD. Where there was uncertainty or dispute between different family members, some respondents expressed a preference for the legally binding AHD:

but it's the ones where um, perhaps there's some dispute within family members, where having the legal document would be really helpful. (Interviewee 19, general practitioner)

Because of this uncertainty, the typical approach taken by RACF staff was to reassure family members that their plan could be

updated and would be confirmed with the substitute decision maker at the time that a decision was required. Staff worked proactively to communicate the person's ongoing situation to family members, with the aim of keeping people informed and avoiding conflict:

Because the ones that we do at [residential care facility], we tell the residents, and their families, that they can change their minds whenever they want to, that it's not in concrete. We will speak to them, and they can decide which way they want to go. (Interviewee 6, RACF manager)

Applications to the State Administrative Tribunal for appointment of a Guardian were seen to be resource intensive, and were typically only undertaken as a last resort. Interviewee 17 felt that family members of a person with dementia were often reticent to pursue applications to the Tribunal, as this could endanger their relationship with their family member. SAT applications were seen as useful in situations of intractable conflict (e.g. between family members) when an independent and authoritative arbiter was required. Participants also noted that Public Guardians appointed by the Tribunal refused to engage in the 'proxy advance care planning' process on behalf of a person who lacked capacity, instead gathering information and providing decisions at the time these were required:

So when we ask the ... public advocate, to fill out the form, our [organisational advance care plan] form, they won't do it. (Interviewee 6, RACF manager)

3.4 Factors Influencing the Use of ACP by People with Dementia

While participants expressed broad support for the principles underpinning ACPs and a generally sound understanding of the legal requirements, they identified a range of issues

with ACP implementation. General issues included low levels of community awareness about ACP (particularly among the ‘older generation’), a tendency to avoid talking about end of life care, difficulty planning for hypothetical future scenarios, lack of access to specific ACP training (particularly among less qualified staff) and lack of time or appropriate funding (particularly among GPs). There were also a number of issues identified as being specific to the context of dementia (see [Table 2](#)).

Table 2. Factors influencing the use of ACP by people with dementia (with exemplar quotes)

Sub-theme	Exemplar quote
Low community awareness about dementia	<i>even I think when someone is diagnosed with dementia, they come in here and the families know very little about it. They don't understand – one of the hardest things that we have to deal with is explaining about the physical changes that are going to occur. Now that's one of our biggest tasks because people stop walking, they become incontinent and they can't swallow. And they'll say 'I didn't know that' (Interviewee 1, RACF manager)</i>
Difficulty confirming a timely diagnosis	<i>...there are a number of patients that don't get picked up. Particularly the ones who are on the borderline. Like you pick them up like in the mild stage, and they might be reasonable to make an advance care directive even at that stage. (Interviewee 13, General Practitioner)</i>
Uncertain prognosis and gradual decline	<i>I think a lot of it is, I think the really hard thing is particularly things like Alzheimer's. Where you've got an unpredictable time course, so I think we've got to sort of identify when for certain patients is it the right time to have these sorts of discussions. (Interviewee 9, Geriatrician trainee)</i>
Difficulty identifying most likely scenarios	<i>Obviously if you've got a patient with motoneurone disease say, you can, to some extent predict what may happen to them and what might be applicable and whether they want a feeding tube and those sorts of things... But sometimes if you've got someone who is reasonably healthy and you're going 'well what do you want in this scenario, what do you want in this scenario, what do you want in this scenario', you don't know! (Interviewee 16, General Practitioner)</i>
Patient capacity to undertake ACP	<i>So I think if you were in the early stages of dementia and you were able to make sound decisions for you then I think yeah that would be good. But the residents that I get here, they're almost end stage dementia and they can't even dress themselves. So you're not gonna expect them to make rational and clear decisions. (Interviewee 5, RACF manager)</i>
Communication in dementia	<i>I suppose it all comes back to valuing the person with dementia, [the family] say "oh they don't understand what you're talking about." But a lot of the time if you provide the information in a way that the person can understand, as far as communication goes... They can understand what you're saying about. (Interviewee 15, Community Nurse)</i>
Changed preferences or temperament	<i>Because once they've got dementia, it's very difficult – they can't change their mind. You've got your directive, which they've signed, so having dementia sort of cancels that out because they don't have a choice in the end. It's written down so that's what you follow. It's a legal document, you have to follow what's in it. Unless the person is cognitively intact and says 'no I don't want to do that anymore'. (Interviewee 4, RACF manager)</i>
Family members overriding the person's decisions	<i>So sometimes the relatives can be obstructive, and they try and give the information. So if that's the case then I'd have to get them out. So that I can make sure that the actual person knows what they're doing, not the relative who wants it done. (Interviewee 9, Geriatrician trainee)</i>

3.5 Explanatory Themes

The perspectives and practices articulated by practitioners with respect to the use of ACP in the context of dementia care are explained with reference to two explanatory themes: '*navigating risk*' and '*the therapeutic journey*', and an overarching theme of '*autonomy versus the most agreeable outcome*'.

3.5.1 '*Navigating Risk*'

Respondents identified that ACPs for people with dementia raised areas of uncertainty and required sound judgment and a careful approach. Risk was conceptualised in terms of professional medico-legal risk, risk to the patient, and risk to both family and/or clinical relationships. In the context of uncertainty about a person's mental capacity to understand the information relating to a decision, GPs considered the broader familial context in the decision-making process. Where there was perceived to be a supportive context that was in line with the person's decision, the GP would err on the side of endorsing the person's capacity to make that decision. Where there was a perceived risk of dispute arising from the decision, the GP would tend to escalate the issue, seeking specialist medical opinion or a tribunal ruling about the person's capacity to make the decision:

Now we're pragmatic people, and if someone wants their enduring power of attorney, and the relatives are frequently visiting they're obviously, they love their mum or their dad, everyone's on board, there's no dispute between the relatives, it's obviously the right thing to do. If the assessment of the mental state is a bit grey as to whether they have capacity or not, we will go ahead and say yes. But if there is dispute of any sort, then we can't sensibly and pragmatically say yes. (Interviewee 18, general practitioner)

Risk was also conceptualised in terms of the risk of conflict between family members about the treatment decisions specified in an

AHD. Some respondents expressed their uncertainty as to how to respond where the AHD was inconsistent with the family's view:

So if you've got someone who is saying I don't want any treatment, I don't want any active treatment at all, and families are saying yes we want everything, and then that person becomes incapacitated, and you follow the health directive that may have been set out by that person, who supports you, almost against that family? (Interviewee 8, RACF manager)

One respondent suggested that even where there is conflict, the existence of an AHD does not help; in fact it can aggravate the conflict:

sometimes that can just aggravate things even more I suppose ... I think it just may help to make sure that the patient does receive the care that they wanted, but in terms of the actual conflict situation, no probably not. (Interviewee 16, general practitioner)

3.5.2 '*The Therapeutic Journey*'

The therapeutic journey refers to the way that respondents viewed care provision and the associated decision making in a temporal and relational sense. Often the 'ethically preferred' approach of autonomous, anticipatory decision making was tempered by considerations of the broader context in which decisions were made. The maintenance of existing family and clinical relationships was seen as important.⁷³ Participants recognised that there were significant emotional issues for residents and family members associated with admission to residential care, and end of life decision making more broadly. Staff in the RACF setting described how a person's family members would often change their approach to decision making over time. Rather than seeing this as reflecting 'inconsistent views', it was perceived as part of a 'therapeutic journey':

So sometimes they will put on there that they definitely want us to do all resuscitation, they're wanting us to transfer them to hospital every time, and ... if the resident is being sent to hospital quite a few times, sometimes they'll come to us and they'll say 'listen, we'll change this now, we find that you are looking after the resident, and we don't want them to go to hospital every time'. I suppose when they first come in, they're not as confident as later on, with our care decisions, or with our clinical decisions. (Interviewee 6, RACF manager)

A number of respondents spoke about challenges associated with family members becoming involved late in the course of the illness. Respondents described 'fly-in relatives', who were typically located far away from the resident's place of care and only minimally involved in the person's day-to-day care. These relatives could potentially disrupt the planning and decision-making process by arriving late in the course of the illness and advocating for different treatment without understanding this broader context of the 'therapeutic journey':

It's not because the fly-in relative is all mean and bad, it's because the fly-in relative hasn't had the experience of how distressing this has been to the patient, to be gradually becoming less and less able. (Interviewee 19, general practitioner)

In these situations, respondents felt that family members who had been involved in the therapeutic journey (e.g. by providing care or domestic assistance to the person over an extended period of time) typically had greater understanding of the person's wishes and the real consequences of making certain decisions. On the other hand, a number of respondents identified that problems associated with the 'fly-in relative' could be avoided to some extent by proactively involving the relevant people in decision making and keeping family members 'on the same page' with respect to the evolving decisions about treatment and care:

some family members aren't as involved, and there's that guilt that they are not involved as much. So to have that input is important to them, whereas the person that's around their loved one all the time thinks that they have all the rights ... I think all that I can do, is to ensure that the whole family are involved if we do have a meeting or a discussion, and even if they can't be present, you know that they get sent you know a summary of what was discussed, so that they feel that they're involved. You know I think it would be worse to exclude somebody or to only involve one family member. (Interviewee 15, community nurse)

3.6 Overarching Theme – Autonomy Versus the 'Most Agreeable Outcome'

While respondents typically supported the ethical principle of autonomy, there was evidence of a disconnect between this principle and its practical implementation. The overarching theme of '*autonomy versus the most agreeable outcome*' incorporates the above explanatory themes and illustrates how practitioners working with people with dementia talked about accommodating diverse preferences, navigating risk and viewing decision making and ACPs as part of a broader therapeutic journey. One respondent sums up this tension between the principle of autonomy and its practical implementation:

Yeah it's a strange thing, this death and dying experience. It's having systems in place to facilitate that person's wishes that are met without too much judgment or disharmony amongst everybody. (Interviewee 2, RACF manager)

We could think of this as an approach that is focused on achieving a most agreeable outcome rather than one that privileges individual autonomy. One GP expressed the view that this pragmatic approach reduced the risk of dispute:

Yeah, I must say I recoil from taking the sort of legalistic point of view you know I

think I'd much more have an agreeable environment and get everyone agreeing for the right reasons, rather than you know 'this has been signed, take it or leave it' you know? My point of view is that it's much more important to have everybody on board, and to have a general consensus. (Interviewee 18, general practitioner)

In keeping with this approach, a number of RACF managers talked about consulting with a resident's family members at the time of any treatment decision to confirm a previously agreed management plan with the resident:

Part of our admission is to ask them if they become ill do they want intervention? Some people say yes, some people say no. But even when that happens we always ring the family and ask 'do you still want us to send them to hospital or keep them here'? (Interviewee 4, RACF manager)

When conflict occurred between family members, respondents across all settings typically adopted a consultative approach in the first instance, aiming to resolve issues. Conflict was sometimes interpreted as part of the therapeutic journey associated with end of life care, with resolving issues seen as part of the process of reaching closure and acceptance prior to death, and more important than the principle of autonomy:

people that are in conflict or are in emotional distress because they've obviously got issues in their life with their loved one that haven't been resolved. That's the important part about the end of life care, is that they all resolve their issues and that person can pass on peacefully. And we try to facilitate that. (Interviewee 2, RACF manager)

However, several respondents suggested that negotiating a position of consensus also raised the difficulties associated with substituted decision making. One respondent noted that:

if you're a guardian, an appointed guardian like whether you're from the office of the public advocate or the family, you are only

guessing – 'I guess that's what she would have wanted'. But if you've got it written by the person there's nothing better than that. (Interviewee 3, RACF manager)

Another observed that:

One of the big things ... is that some people are greater advocates than others, for the individual. So while one carer can go in and tell you everything about this person and what they like and what they don't like and whatever, another might come on and doesn't have that capacity to advocate, and give that information in the, at the level that's required. (Interviewee 7, RACF manager)

These comments illustrate how even the preferred, consultative approach was not always satisfactory. In these situations, respondents reflected on the value of the person's own preferences being clearly documented.

4. Discussion

While the ethical principle of autonomy underpins the WA GAA, the foregoing analysis of the experience of various professionals with ACPs in the context of dementia care indicates a disconnect between policy and practice. Practitioners identified a range of issues associated with the implementation of ACP in this context, particularly relating to individual-centric approaches to ACPs. While practitioners express a strong sense of moral alignment with the ethical principle of autonomy, we suggest that contextual factors that occur in dementia care result in practice reflecting 'negotiated consensus-building' towards a 'most agreeable outcome'.

One explanation for the adoption of this approach is that, in this context, a broader ethical value has more purchase. The ethical principle of autonomy has been recognised by several scholars as grounded in the overarching principle of human dignity,⁷⁴ which entails more than just ardent respect of each

person's autonomy. Perhaps, in advocating for a 'most agreeable outcome', RACF staff and other professionals involved in the care of those with dementia are in fact reflecting a desire to promote human dignity, which could include (but not be limited to) respect for individual autonomy.⁷⁵

A 'most agreeable outcome' approach to decision making and ACPs in the context of dementia may yield benefits (a, b and c) but also has potential drawbacks (x, y and z). In terms of benefits, the interviews implied that this approach encourages a more fluid and collaborative style of decision making which may help to promote the will and preferences of the person with dementia (a), as it will involve a number of different people and perspectives; as such, a more complete picture of the person's wishes may be derived from this process. A common point made in the interviews was the burden of the formalities associated with the individual, autonomy-driven model which requires an evaluation of capacity, the completion of forms and witnessing of the signing of the documentation. A model based around collaboration may avoid the bureaucratic formalities which are perceived by some as overly time consuming (b). Finally, it could be said that the identification of the therapeutic journey speaks to the role that a process aimed to achieve the most agreeable outcome can play in managing the grief associated with the decline and death of a relative with dementia (c).⁷⁶ Thus, an argument from therapeutic justice would support such a process, as long as the law is not compromised in the process.

The drawbacks of the adoption of such a model include the possibility that the focus shifts from the person who is the intended subject of the decision to other persons and their concerns (x). An individual-centric model maintains a focus on that individual; there is a risk that a shared model of decision making will detract attention from the very person the decision concerns. A second corresponds to (b) above – the formalities of the current system maximise transparency. There

is a risk that, where these formalities are done away with, other concerns and issues, peripheral or even irrelevant to the person's well-being, 'slip' into the dialogue. If there are no designated and formal boundaries to the decision-making process, it may be hijacked by these other concerns, therefore compromising the outcome (y). Finally, a focus upon grief management may facilitate an attitude of appeasement of family members, which again may shift the focus away from the person's wishes (z).

While further research will need to explore the optimal methods of maximising these benefits and protecting against the potential drawbacks,⁷⁷ there are wider questions for policy makers and legislators to address. These questions arise from the particular perspective which this research engaged with: that of health professionals involved in the care of those with dementia. It is not suggested that this is a satisfactory basis from which to construct a complete critical overview of ACPs and dementia; this would require engagement with other perspectives (particularly people living with dementia, and their family members), as well as factoring in the legitimate self-interest of the health professionals.⁷⁸ With this caveat in mind, our research leads us to ask where efforts to improve ACPs in this context are best directed. Should we pursue the GAA model of autonomy-based ACPs, through greater efforts to support and promote the use of ACP earlier in the illness trajectory? Or would it be preferable to better support practitioner efforts to enable the most agreeable outcome approach that is currently evident in dementia care and endorsed by practitioners? And how might law makers respond to the challenges presented to ACPs in dementia care, in order to make progress towards the practical implementation of ethically and morally defensible approaches to end of life decision making in the context of this increasingly prevalent condition?

We would suggest that a continuing policy focus on promoting formally documented

AHDs, completed at a time when a person has full capacity, is unlikely to benefit those with dementia admitted to RACF, unless they have already completed such documents prior to admission. Admission to RACF late in the dementia trajectory, and a tendency to defer to 'in the moment' substitute decision making by family members in crisis situations (even when a resident's wishes are known) mean that formal AHDs are likely to have minimal uptake and impact in this context. Instead, the focus on AHDs could be supplemented by clearer guidance (i.e. decision-making principles) and training/support for RACF staff in the implementation of their already established approach of working collaboratively to achieve a 'most agreeable outcome'. Such a process might be supported by non-statutory forms that enable structured approaches to family case conferences. This pragmatic approach to law making might focus on programs that support the family case conferencing process (to optimise the ways in which resident preferences are taken into account), while working with policy makers and regulators in RACF settings, to ensure that staff are guided and supported with 'best-practice principles' to support their efforts at achieving 'most agreeable outcomes'.

Given the reported prevalence and impact of family conflict associated with care and treatment decisions, it may be that targeted programs, aimed at equipping key RACF staff with skills in mediation, conflict resolution and advocacy, could be a productive use of public money. Beyond this, there will always be a place for those with professional skills in mediation and conflict resolution, as well as more authoritative bodies (e.g. SAT) to make orders and enforce the law when required. However, given the growing prevalence of dementia, and concerns about overburdening the judicial system, adversarial processes must be seen as a method of last resort.

Moreover, given the extensive evidence from health professionals that family members make treatment decisions for their

dementia-affected relative, a number of specific legal questions arise. For example, there is evidence of health professionals being generally supportive of those family members/carers who are most involved with the person's care to be given authority as substitute decision makers when there is dispute over decisions. This preference for the 'most involved carer' does not necessarily fit with the hierarchy of decision makers specified in the WA GAA, Section 110ZJ. Although beyond the scope of this paper, it may well be beneficial to ascertain whether there is any evidence of SAT engaging with this issue and, if so, what, if any, guidance is provided by any relevant decisions. It is also evident that these family members of people with dementia in the RACF setting are engaging in forms of ACP on behalf of the resident. This is at odds with the GAA, in which ACP in the form of an execution of an AHD or an EPG concerns treatment decisions about one's own future treatment. It is important to note that these 'plans' do not coincide with the notion of a statutory AHD (indeed the residents in question were typically judged to lack the 'full legal capacity' to do this), and under the GAA 1990 (WA), the EPG or other substituted decision maker does not have the statutory authority to make general 'plans' for the person, only to make 'treatment decisions'. To the extent that the 'plan' may result in *contemporaneous* substitute decision making, such decisions may have legal force, but not necessarily. The term 'treatment' is restrictively defined to *mean* medical or surgical treatment which may not include some of the contemporaneous decisions made by substitute decision makers. For example, the interviews indicated that the question of transfer to hospital is one that is often deferred to relatives of those in RACF, but the decision to transfer in itself, recognised as significant for the person with dementia, arguably does not fall within the notion of 'medical treatment'. Family members are therefore exercising powers that are not present under the GAA, and this is a matter which

should be considered in any legal reform.⁷⁹ They are also making decisions which arguably do not constitute 'treatment' under the GAA.

The tendency to utilise alternative forms for ACPs, distinct from those provided under the GAA (one of which is a form developed by the Western Australian Health Department⁸⁰), raises another prevailing practice potentially at odds with the legislation. These forms have been created outside of the statutory scheme, and can constitute, at most, a common law anticipatory decision. As noted, the legal force of these decisions is retained under the GAA, but the existence of this alternative form does create potential difficulties in the event that a decision made by a guardian or person responsible, in the best interests of the incapacitated person, conflicts with the plan.

Finally, the prevalence of substituted decision making, and the 'most agreeable outcome', requires attention to be directed to the process and substance of substituted decision making. While the prescribed standard is that of 'best interests', there is clear potential for other (potentially irrelevant or 'improper') interests to inform this evolving view of the 'most agreeable outcome'. Such interests might include a family member's interest in a person's will, a family member's enjoyment of free accommodation while the person remains alive or administrative burden experienced by health professionals associated with 'adverse event reporting' that might arise if they strongly advocated for respect for a person's wishes. All of these factors could potentially derail the otherwise admirable efforts of health professionals in navigating risk and building consensus toward the 'most agreeable outcome'. It is important to consider established principles that should underpin decision making in the context of people with decision-making impairment, and to ensure that these principles are guiding decision making toward the 'most agreeable outcome'. Section 51 of the GAA gives some indication of factors relevant to the exercise

of the best interests' power, but these provisions are general in their wording and directed at largely lifestyle matters rather than specific decisions about treatment. In relation to consideration of the incapacitated person's preferences, there is no legal obligation in the GAA to have reference to these, the GAA stating that the guardian (either EPG- or SAT-appointed) or 'responsible person' should act 'as far as possible':

(e) in consultation with the represented person, taking into account, as far as possible, the wishes of that person as expressed, in whatever manner, or as gathered from the person's previous actions.

Substituted judgment, as a standard for decision making, has been the subject of considerable ethical and legal scholarship;⁸¹ theoretically, it is acknowledged as more explicitly supportive of the autonomy perspective than the best interests test.⁸² Substituted judgment is endorsed by the Australian Law Reform Commission Report on 'Equal recognition before the law and legal capacity for people with disability' (ALRCR)⁸³ as the preferable decision-making standard for substituted decision makers; Recommendation 3-3 of the National Decision-Making Principles clearly mandates the substituted judgment approach. Regardless of the approach taken, the substitute decision maker may well be limited by his or her inability to accurately discern the person's best interests, or to understand the person's wishes in order to apply a substituted judgment standard.⁸⁴ There is evidence that surrogates often refer to their own desires and needs to inform the treatment decision of the person on whose behalf they are acting, and that these may be inconsistent with that person's previously expressed wishes.⁸⁵ Social psychological research also notes the tendency for people to overestimate the degree to which their own values and choices are shared by others,⁸⁶ and this is evident within decisions about life-sustaining treatments.⁸⁷ It is therefore

submitted that resources be dedicated to providing substituted decision makers with the training and guidance needed to make treatment decisions for those lacking capacity.

The recognition of the value of a consensus-driven model of decision making for ACP for those with dementia should not detract from measures that can be taken to increase the uptake of the legislative options of AHDs and EPGs. Several of the interviewees made suggestions as to such measures including the pivotal role of GPs in initiating and continuing discussions with their patients about ACPs. The continuity of care provided by such professionals was noted as central to the ACP process; several of the professionals noted that their own interaction with those with dementia was limited to one or two meetings and did not provide the opportunity for detailed discussions. While the GP does appear to be best suited to have these discussions, the GPs themselves often referred to time pressures. Other interviewees made reference to key capture points where ACPs could be addressed. These included during hospital discharge, during transitional care and at the point of entry to RACF. With respect to the last of these, many respondents also felt that people being admitted to RACF are typically past the point of being able to satisfy the current legal requirements for executing ACPs at the point of admission, so this may not be a viable option.

The requirement for full legal capacity for ACPs under the GAA is clearly an issue for those with dementia, particularly those entering RACF. The capacity 'bright line' has implications far beyond the present context, and will not be the subject of commentary here.⁸⁸ Suffice to say that the focus on supported decision making resulting from the Convention on the Rights of Persons with Disabilities⁸⁹ and the subsequent ALRC Report may impact on the ability of those with dementia to engage in legal ACPs, even where they lack full legal capacity.⁹⁰ Many of the interviewees referred to difficulties in assessing the capacity of the person with

dementia, confirming the literature which has found that persons with dementia experience fluctuating cognition in a 'spontaneous, periodic, transient' manner, resulting in challenges assessing capacity.⁹¹ The timing of assessment of capacity is therefore crucial for those with dementia. Persons with dementia appear to be disproportionately disadvantaged by the current capacity requirements under the GAA.

Conclusion

This article has sought to compare the ethos and philosophy under the legal framework for ACP in Western Australia with the 'on the ground reality', as perceived by health professionals providing care for people with dementia. An examination of Hansard in the introduction of the legislative provisions, as well as the provisions themselves, indicates a clear nod to the value of personal autonomy. However, the interviews reveal that there are distinct contextual factors associated with the diagnosis, progression and ongoing care of people with dementia, which impacts on the implementation of ACPs. The evidence indicates that the particular context under examination is usually not amenable to legal requirements that emphasise individual capacity and decision making, and that a negotiated approach, which attempts to generate consensus around a 'most agreeable outcome' is preferred. This does not suggest that the legal framework is not generally appropriate; just that in this context, policy and law makers may need to make changes to facilitate and guide this shared decision-making model of ACP.

Acknowledgments

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Notes

1. S Ikonomidis and P Singer, 'Autonomy, Liberalism and Advance Care Planning' (1999) 25 *Journal of Medical Ethics* 523.

2. These limitations include the inability of an adult person to make health care decisions for another person who lacks capacity. The practical impediments associated with specific directives are outlined in the paper.
3. For example, in relation to Advance Health Directives note that the terminology in other jurisdictions has the same effect of allowing individuals to refuse consent to medical treatment. See Powers of Attorney Act 1998 (Qld) for advance health directives, the Advance Personal Planning Act 2013 (NT) for advance personal plans, the Medical Treatment Act 1988 (Vic) for a refusal of treatment certificate, Advance Care Directives Act 2013 (SA) for advance care directives, and Medical Treatment (Health Directions) Act 2006 (ACT) for health directions. The Guardianship Act 1987 (NSW) outlines the requirement of consent to treatment but there is no legislation for AHDs. Tasmania has no legislation for AHDs.
4. Western Australia, *Parliamentary Debates*, Legislative Council, 15 August 2007, 4071 (Helen Morton). Note: the Bill originally entered Parliament as the Acts Amendment (Advance Health Care Planning) Bill 2006 (WA) and the short title was changed to the Acts Amendment (Consent to Medical Treatment) Bill 2006. This article is based on Hansard analysis of both Bills.
5. See also Guardianship and Administration Act 1990 (WA) pt 9C where 'persons responsible' for treatment decisions were also inserted, whereby relatives and significant others can make treatment decisions where no other substitute decision maker or AHD exists.
6. Guardianship and Administration Act 1990 (WA) pt 9A.
7. Guardianship and Administration Act 1990 (WA) pt 5.
8. Office of the Public Advocate, Department of the Attorney General, Government of Western Australia, *A Guide to Enduring Power of Attorney in Western Australia* (December 2013) 7.
9. Western Australia, *Parliamentary Debates*, Legislative Assembly, 21 June 2006, 4061 (Jim McGinty – Minister for Health).
10. Guardianship and Administration Act 1990 (WA) s 110ZB. The common law often uses the term 'living will'.
11. Western Australia, *Parliamentary Debates*, Legislative Assembly, 21 June 2006, 4061 (Jim McGinty – Minister for Health).
12. Western Australia, *Parliamentary Debates*, Legislative Assembly, 21 June 2006, 4062 (Jim McGinty – Minister for Health).
13. For Canada, see *Malette v Shulman* (1990) 67 DLR (4th) 321; For United Kingdom, see *Re T (Adult: Refusal of Treatment)* [1993] Fam 95; For Australia, see *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84; *Hunter and New England Area Health Service v A* (2009) 72 NSWLR 88 (in which the court noted the need for the direction to be 'clear and unambiguous').
14. *Re T (Adult: Refusal of Treatment)* [1993] Fam 95.
15. *Schloendorff v Society of the New York Hospital*, 211 NY 125 (Ct App, 1914), 129–30; *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84.
16. Guardianship and Administration Act 1990 (WA) s 110P.
17. Guardianship and Administration Act 1990 (WA) s 110B.
18. Guardianship and Administration Act 1990 (WA) ss 110Q(1), 100E(1); Guardianship and Administration Regulations 2005 (WA) Sch 2.
19. Guardianship and Administration Act 1990 (WA) s 110ZB. Although note the decision in *Qumsieh v Guardianship and Administration Board* (1998) 14 VAR 46 at [18] in which the Victorian Court of Appeal held that the trial judge was not required to 'look over its shoulder' to ensure that all of the evidence (including a form purporting to refuse treatment) was before it. For commentary see Cameron Stewart, 'The Australian Experience of Advance Directives and Possible Future Directions', (2005) 24 *Australasian Journal on Ageing* S25–S29.
20. Guardianship and Administration Act 1990 (WA) s 110Q(1)(b), (2); s 110E(1)(b), (c), (d).
21. Guardianship and Administration Act 1990 (WA) s 110R(1)–(2).
22. *Hunter and New England Area Health Service v A* (2009) 72 NSWLR 88, 93–94.
23. It is not clear why there is no explicit reference to these three requirements for valid legal decision making in relation to EPGs, but it is assumed that they would apply in the execution of such a power.
24. Guardianship and Administration Act 1990 (WA) s 110S(1)(b)(ii).
25. Guardianship and Administration Act 1990 (WA) s 110S(2).
26. Guardianship and Administration Act 1990 (WA) s 110S(3).

27. Guardianship and Administration Act 1990 (WA) s 110S(4)–(5).
28. Guardianship and Administration Act 1990 (WA) s 110S(6).
29. Guardianship and Administration Act 1990 (WA) s 110P; Western Australia, Acts Amendment (Consent to Medical Treatment) Bill 2006: Standing Committee on Legislation, Parl Report No 10 (2007) 39.
30. Guardianship and Administration Act 1990 (WA) s 110U, 110ZJ.
31. Western Australia, *Parliamentary Debates*, Legislative Assembly, 21 June 2006, 4061 (Jim McGinty – Minister for Health).
32. S 110G.
33. GAA, pt 5, div 2. Note that the guardian is subject to constraints; for example, he/she cannot consent to the sterilisation of a represented person nor consent in relation to marriage.
34. GAA, s 110G(2), (3), (4).
35. GAA 1990 (WA) s 110P.
36. Guardianship and Administration Act 1990 (WA) s 110V, s 110J.
37. Guardianship and Administration Act 1990 (WA) s 110W, s 110K.
38. Guardianship and Administration Act 1990 (WA) s 110X, s 110L.
39. Guardianship and Administration Act 1990 (WA) s 110Y, s 110M.
40. Guardianship and Administration Act 1990 (WA) s 110Z, s 110N.
41. The GAA 1990 (WA) s 110ZK states that a health professional who relies on an AHD or a substitute decision maker in ‘good faith’ is protected. Note that other jurisdictions require the reliance to be formed on the basis of a reasonable belief that the person is unable to make a decision – see Guardianship and Management of Property Act 1991 (ACT) s 32L, Guardianship and Administration Act 2000 (Qld) s 77.
42. Satisfied if the health professional acts ‘honestly’ in relying on the treatment decision – s 110ZK(3).
43. GAA 1990 (WA) s 110ZK.
44. GAA 1990 (WA) s 110ZI.
45. Guardianship and Administration Act 1990 (WA) s 110S.
46. Western Australia, *Parliamentary Debates*, Legislative Council, 15 August 2007, 4071 (Helen Morton). Note: the Bill originally entered Parliament as the Acts Amendment (Advance Health Care Planning) Bill 2006 (WA) and the short title was changed to the Acts Amendment (Consent to Medical Treatment) Bill 2006. This article is based on Hansard analysis of both Bills.
47. Western Australia, *Parliamentary Debates*, Legislative Assembly, 21 June 2006, 4061 (Jim McGinty – Minister for Health); Western Australia, *Parliamentary Debates*, Legislative Assembly, 15 August 2006, 4697 (Sue Walker).
48. Guardianship and Administration Act 1990 (WA).
49. Guardianship and Administration Act 1990 (WA) s 4(3)(a). Note that the basis and the clinical utility of the legal presumption of capacity to consent/refuse medical treatment has been attacked by PDG Skegg in ‘Presuming Competence to Consent: Could Anything be Sillier?’, *University of Queensland Law Journal* (2011), vol 30(2), although his argument is largely confined to the refusal of treatment in circumstances where the refusal threatens the life of the person. He does note that a person’s age might be a ‘good reason for a clinician to pause and take steps to check whether the patient’s level of competence is adequate’ (at 180).
50. Western Australia, *Parliamentary Debates*, Legislative Assembly, 31 August 2006, 5606–607 (Jim McGinty).
51. Western Australia, *Parliamentary Debates*, Legislative Assembly, 31 August 2006, 5606 (Jim McGinty).
52. Western Australia, *Parliamentary Debates*, Legislative Assembly, 31 August 2006, 5611 (Jim McGinty).
53. *Wyong Shire Council v Shirt* (1980) 146 CLR 40, 42 (McHugh J).
54. *Re MB (An Adult: Medical Treatment)* [1997] 2 FCR 541, 553 (Butler-Sloss LJ), quoted in *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, 93 (McDougall J).
55. *F v R* (1983) 33 SASR 189, 193 (King CJ), quoted in *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, 90–91, cited in *Roger v Whitaker* (1992) 175 CLR 479, 487 (Mason CJ, Brennan, Dawson, Toohey, McHugh JJ).
56. (2009) 74 NSWLR 88.
57. (2009) 40 WAR 84.
58. *Hunter and New England Area Health Service v A* (2009) 72 NSWLR 88, 93.
59. *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84, 91, citing *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, 113 (Donaldson MR).
60. *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, 92.

61. *Re C (Adult: Refusal of Treatment)* (1994) 1 WLR 290, 295.
62. As there is no definition of 'means' in the Interpretation Act (WA), the term falls to be interpreted under general principles. In D Pearce and R Geddes, *Statutory Interpretation in Australia* (8th edn, Lexis Nexis Butterworths 2014) it is stated that 'The orthodox and, it is submitted, the correct approach to the understanding of the effect of these expressions is that "means" is used if the definition is intended to be exhaustive while "includes" is used if it is intended to enlarge the ordinary meaning of the word: *Sherritt Gordon Mines Ltd v Federal Commissioner of Taxation* [1977] VR 342 at 353' (at 309).
63. S 51(2)(c) GAA.
64. The Consent to Medical Treatment and Palliative Care Act 1995 (SA) s 14 and the Advance Care Directives Act 2013 (SA) s 10 (g).
65. Guardianship and Management of Property Act 1991 (ACT) s 4(2)(a); Medical Treatment Act 1988 (Vic) s 5C(3).
66. EK Vig, JS Taylor, H Starks, E Hopley and K Fryer-Edwards, 'Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-making' (2006) 54 *Journal of the American Geriatric Society* 1688, 1690–692.
67. Guardianship and Administration Act 1990 (WA) s 110S(6).
68. Guardianship and Administration Act 1990 (WA) s 110S(3).
69. Guardianship and Administration Act 1990 (WA) s 110S(5).
70. Western Australia, *Parliamentary Debates*, Legislative Assembly, 19 September 2006, 6254 (Max Trenorden, Jim McGinty); Western Australia, *Parliamentary Debates*, Legislative Council, 15 May 2008, 3104 (Sue Ellery).
71. D Thomas, 'A General Inductive Approach for Analysing Qualitative Evaluation Data' (2006) 27 *American Journal of Evaluation* 237.
72. Reported practices of the interviewees indicated that they believed/understood that these plans would not protect them if they went against the decision of the person responsible and the matter ended up at SAT for determination.
73. Note that a similar conclusion was reached in S Ikonomidis and P Singer, 'Autonomy, Liberalism and Advance Care Planning' (1999) 25 *Journal of Medical Ethics* 523–27. In that article the authors analyse four arguments against the neo-liberal autonomy basis for advance care planning. They deconstruct the first three, but admit that the fourth one – that individualist autonomy does not adequately account for the importance of personal family relationships in ACP, is important.
74. R Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (Harper Collins 1993) 233–37; E Pellegrino, *Humanism and the Physician* (University of Tennessee Press, Knoxville 1979) 6.
75. This is not to underestimate the difficulties associated with the value of dignity, insightfully explained in C Foster, *Human Dignity in Bioethics and the Law* (Hart, Oxford 2011).
76. Research has explored the complexity of grief experienced by relatives of terminally ill older persons – see B Kramer, M Kavanaugh, A Trentham-Dietz, M Walsh and J Yonker, 'Complicated Grief Symptoms in Caregivers of Persons with Lung Cancer: The Role of Family Conflict, Intrapsychic Strains and Hospice Utilization' (2011) 62 *OMEGA* 201–220.
77. See Cognitive Decline Partnership Centre, 'Future Planning and Advance Care Planning: Why it Needs to Be Different for People with Dementia and Other Forms of Cognitive Decline' Sydney, 2016 <http://sydney.edu.au/medicine/cdpc/documents/resources/J000606_CDPC_report2015Final_WEB.pdf> accessed 7 November 2016. The report makes recommendations to facilitate better ACP for those experiencing cognitive decline.
78. See K Denning, L Jones and E Sampson, 'Advance Care Planning for People with Dementia: A Review' (2011) 23 *International Psychogeriatrics* 1535–551.
79. This would also not constitute an anticipatory treatment decision under the common law, which does not recognise the existence of proxy decision makers for adults lacking capacity, outside of treatment carried out by health care professionals in emergency situations and which is in the best interests of such persons.
80. WA Health Department, 'My Advance Care Plan' <http://ww2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Advance%20care%20planning/PDF/ACP_form.ashx> accessed 7 November 2016.
81. T Hope, A Slowther and J Eccles, 'Best Interests, Dementia and the Mental Capacity Act (2005)' (2009) 35 *Journal of Medical*

- Ethics 733; D Degrazia, 'Value Theory and the Best Interests Standard' (1995) 9 *Bioethics* 50.
82. See, eg, HJ Taylor, 'What Are "Best Interests"? A Critical Evaluation of "Best Interests" Decision-making in Clinical Practice' (2016) 24 *Medical Law Review* 176–205.
 83. Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124, 2014).
 84. L Series, 'Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms' (2015) 40 *International Journal of Law and Psychiatry* 80, 86–87.
 85. JT Berger, EG DeRenzo and J Schwartz, 'Surrogate Decision-making: Reconciling Ethical Theory and Clinical Practice' (2008) 149 *Annals of Internal Medicine* 48–53.
 86. See Joachim Krueger, 'On the Perception of Social Consensus' in M Zanna (ed), *Advances in Experimental Social Psychology* (New York: Academic Press 1998, vol 30) 163–240.
 87. Angela Fagerlin, Peter Ditto, Joseph Danks, Renate Houts and William Smucker, 'Projection in Surrogate Decisions About Life-sustaining Treatments' (2001) 20 *Health Psychology* 166–75, 167.
 88. Meredith Blake, 'Dementia and Planning Death: The Challenge for Advance Directives: An Australian Perspective' in Braun International Law and Policy Conference (Vandeplas Publishing 2015); L Barry and J Lorie, 'Capacity, Dementia and Neuropsychology' (2014) 5 *Law Society of NSW Journal* 78, 79.
 89. <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>. The Convention came into force on 3 May 2008, and was ratified by Australia on 12 July 2008.
 90. Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124, 2014).
 91. Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124, 2014) 361.