

Dr Craig Sinclair and Associate Professor Meredith Blake

Point 1: Supported Decision-Making Principles

The Committee expressed an interest in knowing more about the principles we have proposed for law reform in the area of substitute decision-making, to incorporate supported decision-making and comply with the United Nations Convention on the Rights of Persons with Disabilities. These principles are based on the learnings that have emerged from our research with people living with dementia and their family members. We would also direct the Committee to the Australian Law Reform Commission's report and 'National Decision-Making Principles'.¹

- A person's ascertainable will and preference should always be given regard in decision-making.
- Presumption of decision-making capacity, and assessment that is sensitive, time- and decision-specific, mindful of relational contexts and 'strength-based' (geared towards understanding the person's need for support in decision-making, rather than identifying deficits).
- The principle of 'voluntariness' and addressing risk of undue influence in decision-making.
- Supportive interventions should be tailored for both the person with dementia and their 'relational decision-making unit' (family members, close friends and others in existing informal supporter roles).
- Supportive interventions should aim to maintain or develop the person's existing informal support networks.
- Any intervention (whether for supported or substitute decision-making) should be 'tailored', 'proportionate' and 'least restrictive' of the person's freedom.
- Where there is no ascertainable will and preference, a person's previously expressed will and preferences, historical decisions and overarching human rights should direct decision-making.

Point 2: Clarification of 'informal substitute decision-making'

CS: I would like to clarify my comments made in regard to the Chair's questions about 'informal substitute decision-making'. Informal supportive arrangements are very important, and supportive relationships between family members/carers and people living with disability are the basis for any system of supported decision-making. When a person is having difficulty in understanding information relating to a decision or making a decision, the responses of those around them become critical. In the context of dementia, family members, carers, service providers and health professionals can act in ways that promote a person's decision-making ability, by understanding their needs, dealing with one issue at a time, translating professional jargon into simple language, taking time and prompting the person's recall. If all reasonable efforts to support the person are unsuccessful, there is a framework for substitute decision-making, with the substitute decision-maker either *chosen* by the person (e.g. through an Enduring Power of Attorney or Enduring Guardianship) *assigned* to the person (e.g. the hierarchy of 'persons responsible' for medical treatment decisions in the GA Act or the criteria for 'representatives' in the Aged Care Act) or

appointed for the person (e.g. appointed by an administrative tribunal).² Problems can occur if professionals simply default to assigned substitute decision-makers without giving the person a chance to participate in the decision-making process. This often appears to occur due to. In these cases there is no 'formal authority' for the substitute decision-making. The person may well have decision-making capacity for the decision, if appropriately supported. Further problems arise when professionals and/or the assigned substitute decision-maker do not understand the principles that should guide their decisions, lack training and support in their role, and wrongly assume that they can make decisions in all domains from this point onwards, rather than assisting the person with individual decisions at individual moments in time.

Our project is developing resources to assist people in providing support with decision-making for people living with dementia.

Point 3: On the matter of advance directives, dementia and critical versus experiential interests in refusal of treatment or requests for assisted dying

In follow up to our comments about the possibility of advance directives for assisted dying, and in response to the Hon. Robin Chapple's question about "people with dementia... being unavailed of situations in terms of voluntary assisted dying." Advance directives for assisted dying (or for euthanasia in some jurisdictions) are not commonly used, and most of the research around their use comes from the Netherlands. While there is a very important thread of ethical debate about the importance of not simply following such directives blindly, these critiques also recognise how advance directives can facilitate communication about a person's wishes.³

The more common experience across the world is that of advance directives to refuse future medical treatment, given by people with dementia at a time where they have decision-making capacity, and being considered problematic to implement at a later time when the person is deemed to have lost decision-making capacity. Ethical debate on this point has been running for a significant period of time, with seminal arguments by Dworkin and Dresser.^{4,5} Part of the complication here is that care providers, health professionals and family members may have induced or adduced a conclusion that the person's preferences have now changed, and that "they would not want that now". They may appear happy in their current state, or their daily behaviour may be used to infer that they experience a good quality of life, and thus "would want treatment to continue". These examples illustrate the complexity of adopting a substituted judgement perspective, even in the context of an existing written advance directive.⁶ However closer analysis shows that such inductions or adductions by family members or health professionals can also be due to the assumptions or personal preferences of these people. Jongsma et al. helpfully analyse this situation, proposing that the purported "changed preferences" of people with dementia need to be interrogated closely, to determine whether or not these changes are actually associated with changes in their underlying values systems (reflecting a truly changed preference) or distortions associated with communication failures or a lack of supportive contexts.⁷ Such an approach can assist in the interpretation of advance directives where a person has lost decision-making capacity, and their current preferences appear to conflict with the directive. We must also always protect the right of a person with decision-making capacity to 'change their mind', withdraw consent and/or revoke advance directives.

Point 4: On the matter of potential difficulties in accessing the Voluntary Assisted Dying Act 2017 (VIC) among people with certain conditions

Professor Kathy Eagar's commentary on the Victorian Assisted Dying legislation being narrowly framed, and the broader social issues that underpin requests for assisted dying, can be accessed at <http://www.abc.net.au/news/2017-12-02/euthanasia-is-not-just-about-unbearable-pain/9214008>

References supporting our assertion that dementia has become 'the most feared' condition, and perhaps associated with broader fears about loss of control and independence.^{8, 9} These comments come in the light of broader research which has shown that it is typically more empowered and educated people whose requests for assisted dying are granted.¹⁰

Point 5: Comparative analysis of assisted dying models

We provide the reference to Penney Lewis's work on the comparative analysis of assisted dying models.^{11, 12}

Point 6: Section 259 and its' application to the cessation of life-sustaining medical treatment

We provide a reference to the article referred to in evidence discussing the case of *Rossiter* and the reasoning associated with sections 262 and 259 of the Criminal Code (WA).¹³

Response to Committee questions 20-25, not covered in verbal evidence

ADVANCE CARE PLANNING

20. Why do you think the uptake of formal advance care planning in WA is so low? In particular could you comment on:

a) the delay in implementing the recommendations arising out of the 1986 WA Law Reform Commission's Medical Treatment for the Dying reference, which reported in 1991, but was only legislated for in 2008 (much of it only going into effect in 2010)?

CS: I am not well placed to comment on this delay, given that my work in this field commenced in 2010, after the legislation was given Royal Assent.

MB: While I have been working in this field for many years, I was working in UK universities until 2005, and so was not engaged with the deliberative process. I do note, however, that very significant changes were made to the Criminal Code in 2008, following a Law Reform Commission Report in 2007, and that this may have assumed priority.

b) the still unproclaimed provision from the 2008 Consent for Medical Treatment legislation for a register for advance health directives?

CS: See my answer below to 21

c) the evidence before this Committee, that the Department of Health's Advance Care Planning section consists of one dedicated FTE?

CS: This is true to my understanding, and my anecdotal observations (based on regularly attending national advance care planning conferences and working on national advisory

groups) is that there is less activity 'on the ground' in WA compared to other states. I must presume that the Committee does not mean to imply that a portfolio based around direct advance care planning facilitation can be maintained within the Department of Health, even with a greatly increased FTE. Aside from the gross inadequacy of one dedicated FTE for such a role (see the estimates of clinical resource-use associated with advance care planning facilitation in our submission), advance care planning must be understood not as a 'one-off event' but instead as an ongoing process of discussion about evolving goals and values between patients and others whom they trust. This draws on healthcare professionals, social workers, spiritual advisers.

Our recommendation would be that for WA to achieve higher uptake of advance care planning, the Department of Health should continue to take a leadership role at the policy level, building capacity within its own clinical services in the public health system, but also providing resources and policy direction for the broader health and social care system in WA. Our suggestion would be that the Department of Health does this through:

- continuing their work on promoting advance care planning in the community and within clinical services, through education, provision of online training and community workshops;
- maintaining their commitment to working at a policy level towards greater inter-jurisdictional consistency in law, policy and clinical systems for advance care planning (across different states in Australia);
- taking leadership at a policy level for the development of more advanced systems for receiving, storing and communicating advance care planning documentation;
- maintaining and developing partnerships with non-government organisations in the delivery of community workshops and broader awareness raising (e.g. culturally and linguistically diverse service providers, aged care peak bodies, Aboriginal health services, legal advocacy services etc);
- providing guidance and advice for health professionals who are undertaking advance care planning as part of their role;
- encouraging greater participation in national work in advance care planning (e.g. national conferences, and a recent national project to understand advance care planning prevalence – which garnered participation from 51 clinical services across six Australian states/territories, but none from Western Australia)

Of course, resourcing the Department of Health's advance care planning portfolio to a greater extent would enable greater activity, particularly in regional, rural and remote areas and with specific populations in which particular issues might be prevalent (e.g. CaLD and Aboriginal and Torres Strait Islander communities).

d) the evidence before this Committee, that the GPs' manual on medical care of older persons in residential aged care facilities (the Silver Book) has not been updated since 2004?

Given that the aged care environment has changed dramatically since 2004 (due to changes in legislation, funding models and soon to be released changes in the Quality Standards) it would be advisable that this resource is reviewed. For more detailed observations on the interface between general practice and residential aged care facilities in the context of

advance care planning please see our recently published work,¹⁴ and we also suggest being aware of the work of Glenn Arendts on this topic.¹⁵⁻¹⁷

21. In 2013 the Department of Health made a submission to the statutory review of the Guardianship and Administration Act. Could you comment on whether you agree with the Department of Health in relation to the register?

CS: In promoting advance care planning across the Great Southern region, a key concern within the community is the extent to which a person's AHD will be accessible to the relevant clinicians (and/or paramedics) when required. People complete these documents because they are serious about their wishes, and because they want them to be adhered to. Our research group has responded to this concern by collaborating with WACHS Great Southern on the development and maintenance of a local register of Advance Health Directives (both statutory and non-statutory). For patients in the Great Southern region, Advance Health Directives were:

- lodged in the register by the delivery of a physical copy to the Medical Records Department. This could be delivered by the person, or on their behalf (commonly by their GP when the AHD was generated in the GP setting).
- Staff in the medical records department were trained to assess the validity of the AHD (i.e. that it was appropriately signed, dated and witnessed), and responded by sending a notification of successful receipt and lodging (or notification of problems requiring attention) to the maker of the AHD at the address stated in the AHD. (This notification stage was later removed from the process (we understand due to resourcing issues).
- AHD's determined to be valid were scanned and lodged electronically on a secure drive accessible to authorised staff within the Albany Health Campus. A 'flag' was also initiated on the patient's WebPAS, meaning that staff in other hospitals could be alerted that the person had completed an AHD, when the patient's WebPAS record was opened up. For staff in other hospitals across the region, if this alert required investigation (e.g. if a patient arrived in an emergency department at Mt Barker hospital and did not have capacity to give consent to medical treatment, but was noted to be in possession of an AHD), the system enabled staff to call through to Albany Health Campus medical records department by phone. Such a system was deemed necessary because the Albany Health Campus is the only hospital in the region with a medical records department that is staffed 24 hours a day 7 days a week.
- The system was supported with organizational endorsement, education of clinical staff and the provision and promotion of a 'quick reference booklet' on each ward of the Albany Health Campus.
- While the research team were not given access to detailed follow up data as to the process of developing and maintaining this system, we understand that it has been accepted within the local clinical community, and has met an important clinical need for local GP's, who now routinely send through completed AHD forms to the Albany Health Campus medical records department for lodging.
- This experience has told us that the maintenance of a (small-scale) register of AHDs is possible. We note that our team has always supported this system with advice to every clinician and patient that a completed AHD should be made along with at least three copies (one to the Albany Health Campus Medical Records, one to your GP,

one to a key family member or supporter and the original kept in a known location at home).

- We believe that a register of AHDs, combined with ongoing education of clinical staff and promotion of the importance of providing up to date copies of AHDs to family members/supporters (who can attend hospital and provide physical copies and advocacy where needed) is necessary as a means of supporting the intent of this legislation, which is to provide a mechanism by which an incapacitated patient might make their wishes known, through consenting or refusing consent to certain treatments in advance.
- It remains the job of the treating clinician to assess the document they receive (either physically or by a register) for its relevance to the current situation.
- Based on our reading of the legislation, we understand that a health professional acting in good faith and with reasonable care may presume that a valid AHD, relevant to the treatment situation at hand, can be followed. It is the responsibility of the maker (along with their family members and perhaps primary care doctor) to revoke any AHDs that are superseded by a change in treatment preference, although it can be disregarded under section 110S in certain cases.¹⁸

In terms of the arguments made by the Department of Health, that a register would only be beneficial if

- 1) Registration was compulsory
- 2) Patients were also required to ensure that the current AHD lodged on the register represented their current views
- 3) Access to the register could be provided on a 24 hour basis
- 4) Access to AHDs held on the register could be limited to appropriate members of staff

Our responses would be as follows:

- 1) Compulsory registration is conceptually problematic within the broader context of the statutory recognition of AHD's, and the fact that other common law AHD's are explicitly preserved within the legislation. While the Department of Health may be concerned that sporadic use of the register would then mean that clinicians would be unable to 'presume no AHD' from its absence on the register, this is a perennial problem, which is not overcome by simply having no register. Given that the public would likely find out about such a register through interactions with health professionals, it also potentially grates with a key component of the GA Act, which is that the maker of an AHD is advised to seek medical advice, but does not have to as part of completing their AHD.
- 2) Again a 'requirement to ensure that the current AHD lodged on the register represented their current views' is conceptually problematic if it leads to suspicion that a person's AHD 'is not valid unless confirmed by the patient'. The whole purpose of giving AHDs is that they will be understood to be adhered to in future, unless revoked. This is the issue of 'consenting for the future self' which patients grapple with when making AHDs. The fact that they make an AHD despite this concern demonstrates the strong views that many people in the community maintain about having their wishes respected. Such a requirement, if put in force, would arguably generate a similar responsibility to do the same for physical copies of AHDs, which leads to the disturbing conclusion of an approach of 'presumed invalid until proven current' ... by who? An incapacitated patient? This point potentially

subverts the intent of the legislation. See below our comments about a more pragmatic approach aimed at promoting the intent of the legislation.

- 3) The most resource-efficient and future-proof approach would be to establish such a register within an electronic system that would be accessible to all relevant clinical staff across hospitals in WA. Such a system would be accessible 24 hours a day.
- 4) Access to an appropriate electronic register could be provided in terms of 'access to view' (which should be broadly available to all relevant clinical staff) and 'access to modify' (which could be limited to appropriate administrative staff – and would be a capacity to upload revised versions of the signed/witnessed physical AHD, thus maintaining a history of the current and revoked documents, and capacity to automatically notify key people in the maker's support team/treating team when modifications occur).

Overall our response would be that in order to promote the intent of the legislation, a system for receiving, storing and communicating AHDs is very important. This may or may not be in the form of a register that is maintained within the Department of Health. This has been recognised at previous national advance care planning conferences (e.g. Karen Detering at the 2015 National Advance Care Planning Conference) and in the academic literature.¹⁹

The apparent inertia associated with establishing a register may be associated with the work associated with the current transition towards electronic records, integration with electronic discharge summaries and the gradual implementation of a Personally Controlled Electronic Health Record or 'MyHealthRecord' (which will eventually become an opt-out system).

The Department of Health have instituted an alert in the patient WebPAS system, which notifies clinicians in any public hospital that a person is known to have an AHD. This can trigger further attempts to locate the AHD, and is certainly better than nothing.

Concern about whether a patient has 'changed their mind' should not be allowed to erode the autonomy of the vast majority of patients who lodge AHDs with the strong expectation that they will be adhered to. A simple clinical process at the time of admission, associated with determining who the patient's 'person responsible' is, could also flag an AHD lodged in clinical systems, and trigger a process of checking whether the document is current. This could be undertaken by ward clerk's under oversight of the treating team, and would require liaison either with the patient or with their person responsible. Such processes should already be occurring to obtain relevant consent for treatments occurring during the person's admission, and hence are not resource intensive.²⁰

We note that other jurisdictions (e.g. NSW Ministry of Health) are pushing ahead with electronic systems for storing and communicating advance care planning documentation. In jurisdictions such as Wisconsin, where advance care planning is well developed, such systems are a core part of the electronic records system, and communicate across the public and private health care sectors.²¹

In our view, if there is no action on this matter in WA, the void will be filled by other emerging technologies, such as the MyHealthRecord (which already has the capacity to store electronic versions of a person's Advance Health Directive) or other third-party proprietary mechanisms (e.g. www.myvalues.org.au). Our recommendation would be that the Parliament, Department of Health and community stakeholders (including consumers of health services) consult and develop a clear strategy on this point, and then invest sustained resources in the preferred option. In the case of the MyHealthRecord this would align with ongoing activity to support health services in engaging with e-health records. Our preference for the MyHealthRecord is premised on it being

- i) a national system, enabling carriage of AHDs into other state jurisdictions;
- ii) resourced federally; and
- iii) controlled by the patient and/or their representative.

The MyHealthRecord of course relies on achieving a critical mass of participation from health services in WA, in order to achieve its aims.

22. Could you comment on whether you agree that such a legislative provision for revocation would be required in addition to s 110S(6) of the GA Act (which applies should the person change their mind)?

CS: This point is dealt with succinctly within the *Advance Care Directives Act 2014 (SA)* (Part 3 Division 1 s 17). As noted above, an electronic system would be effective in capturing a dated archive of a person's advance care directives, however it may not capture the full history of subsequent discussions that may have occurred with different treating teams, which would hopefully be captured in the medical notes, along with any concerns flagged as to whether the patient has 'changed their mind' about an existing AHD. In terms of the existing legislation in the GA Act, the wording of s 110S(6) must imply that the making of a new AHD must constitute evidence of the person 'changing their mind' (unless the new AHD is made under duress or undue influence). However I believe that this has to be read into the text. If the Committee's question on this point relates to concerns about revocation of AHDs stored in a register, then I believe that a clause similar to that used in the *Advance Care Directives Act 2014 (SA)* would be helpful. For our further comments on revocation of AHDs see section 1.3.4 of Blake et al 2017.¹⁴

23. Can you comment on whether you think doctors' reluctance to comply with patients' wishes or other institutional or cultural factors continue to inhibit the uptake of advance health directives (AHD) in Australia?

CS: With respect to the previous comments by A/Prof. Skene, I was not undertaking research in this field 20 years ago, so cannot give direct observations. However since commencing work in this field in 2010, I have noted a gradual culture change, which seems to have been triggered partly by the implementation of advance care planning programs, and particularly driven by the younger generation of health professionals, with increasing acceptance of the importance of advance care planning. Institutional factors (e.g. inability to communicate ACP documents effectively) or cultural factors may still constitute barriers in some settings.

24. Other than the advice included in the DoH advance care planning forms that these may not be legally binding treatment decisions, do you think there is any reason why a

directive included in that form, so long as the person completes it themselves, would not be legally binding in WA as a common law advance health directive?

CS: We believe that the main reason that some decisions in one of the DoH 'My Advance Care Plan' advance care planning forms would not be taken to be legally binding would be where they are dealing with decisions that are not 'treatment decisions' (e.g. place of care at end of life). However this is not necessarily a bad thing. Our experience is that a significant proportion of patients who are undertaking facilitated advance care planning, when given the choice, choose the non-legally binding option. This is often explained with reference to giving family members and health professionals 'leeway' in end-of-life decision-making, and typically occurs in situations of trusting family relationships.^{14, 22} In some cases it is also used as a 'pragmatic fallback' option, when an appropriate statutory witness cannot be found. Anecdotally, I (CS) have heard of this happening in remote areas, in which visiting health professionals have a conscientious objection to witnessing the document (feeling themselves to be in a conflicted position), and cannot find another appropriate statutory witness during their short visit. In other cases our research group have acted to challenge clinical managers to clarify their policy stance on registered nurses witnessing AHDs. We believe that this should be a matter for individual registered health professionals to assess as to whether they feel comfortable to witness the document, and if they conscientiously object to doing so in a certain case (e.g. due to being conflicted or having fears about potential legal repercussions) then they should act to engage an appropriate third party.

The risk inherent in the use of these non-statutory advance care planning forms is that they don't clearly delineate who has completed the form, in whose presence and how the preparatory discussions have been facilitated. Also, if organizations 'adopt' a particular form and use it preferentially over the official statutory Advance Health Directive, patient autonomy, and their right to choose how to document their wishes is eroded.

CS/MB: We have noted in our past research that there are a number of other non-statutory advance care planning forms that are in use in residential aged care facilities across Australia.¹⁴ We believe it is important that these forms clarify the extent to which the person was involved in the discussion and approving the plan. In some cases advance care planning forms are completed by family members on behalf of a person who has been judged to lack decision-making capacity. This is done with pragmatic intentions of optimizing care and providing a plan for health professionals to follow. However such a document should be treated as just a plan, and not a set of legally binding directives. Some aged care facilities respond to this issue by keeping these plans only for use on their premises, and not communicating them to other organizations (e.g. hospitals), except in the form of clinical handover discussions. We believe this is a prudent course of action.

END OF LIFE PRACTICES - DATA

25. Your submission recommends the establishment of an ongoing process of data collection relating to the full range of end of life practices. Could you elaborate on:

a) The state of data collection relating to end of life practices in WA currently?

CS: Little if anything (see answer above to 20(c)). Our research group have collected some data on practices within WA,^{14, 20, 23-32} and a current project led by Claire Johnson and colleagues aims to fill a gap in the collection of data on primary care (especially GP) involvement in end of life care, through a modified protocol based on the SENTI-MELC questionnaire used in the Netherlands. The nation-wide Palliative Care Outcomes Collaborative (PCOC) collects a range of data on palliative care, but this is limited in terms of 'end-of-life practices'.

b) The benefits of data collection in this area?

CS: Our recommendation here was made in the context of a potential future scenario in which end of life choices were broadened, potentially to include an option for assisted dying. The experience in Netherlands, Belgium and more recently in Canada has been one of the important value of data collection, relating to the *full* range of end of life practices, not just 'approved' requests for (in the European case) euthanasia. In the WA context an ongoing program of data collection would be beneficial in the following ways:

- providing security for the community about the current practices occurring, and that they are subject to oversight and regulation
- a chance to observe trends and respond at a policy level with adjustments to programs and/or training as required
- modelling of current and future trends in the need for different end of life care services (e.g. palliative care across rural areas of WA)
- detecting suspicious patterns of clinical activity

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