

Submissions to the Joint Select Committee on End of Life Choices

Dear committee members,

Thank you for the invitation to make submissions to this extremely important parliamentary inquiry. The authors respond on the basis of previous research, as well as observations from other jurisdictions, within and outside Australia. Some of this research is ongoing, and the committee are referred to various published or in press papers where relevant.

(a) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care

Based on the existing research, and discussions with practicing clinicians, the authors assert that the practices currently being utilised within the medical community relating to end of life fall into (one or more of) the following categories:

- i. Encouraging discussion with a person and their family members, about their goals, values and preferences in relation to future care and treatment (advance care planning). In the event that this is not possible (e.g. due to a person having severe cognitive impairment and being unable to participate in such discussions), such discussions are often undertaken with family members of the person. This appears to be a particularly prevalent practice among persons admitted to residential aged care facilities.¹
- ii. Continuing 'aggressive', curative-oriented treatment up until the time at which such treatments are deemed to be 'futile', at which point palliative care may or may not be introduced. This might include the use of intensive care, high dependency units, cardio-pulmonary resuscitation, intubation, artificial nutrition and hydration and/or other measures such as intravenous antibiotics. The continuation of these treatments late into the course of a terminal condition, and even to a point at which they 'prolong the dying process' is anecdotally seen to occur as a result of lack of any advance care planning discussion, family member 'demands' for continued aggressive treatment, or, in rarer cases, patient preference to continue aggressive treatment.
- iii. Referring patients to palliative care services at key points in their illness trajectory (e.g. diagnosis of a life-limiting illness, non-response to treatment, deterioration in an existing life-limiting illness, or in response to patient or family request).
- iv. Withdrawal or withholding of life sustaining treatment, either in consultation with a patient, in consultation with the person responsible for an incapacitated patient, or unilaterally, without consultation with the patient or person responsible. An example of this would be the completion of a 'not for cardio-pulmonary resuscitation' form for a patient in the hospital setting.
- v. The use of palliative care measures including 'terminal sedation', where this is motivated by the intention to relieve pain and/or other suffering, even where some hastening of death is foreseen as a possibility.

¹ Blake M, Sinclair C, Doray O. Advance care planning for people with dementia in Western Australia: An examination of the fit between the law and practice. *Psychiatry, Psychology and Law* (in press)

The authors are best placed to comment on the first of these practices (encouraging advance care planning), and note the relative lack of high quality data on broader end-of-life practices in Western Australia. In the absence of such data, the committee are referred to existing research in this area from researchers based in other Australian jurisdictions (e.g. Professors Ben White and Lindy Willmott).

1. Advance Care Planning

Research in Australia has shown that the uptake of formal advance care planning (ACP) instruments is low, (14% of the general adult community), with uptake in Western Australia being lower than other states (7.5%).² While significant investment has occurred at a national level in an attempt to increase awareness and uptake of ACP (e.g. Decision Assist, Advance Care Planning Australia), it is not yet clear the extent to which this has influenced uptake across the population. A pilot national prevalence study is currently being undertaken by a consortium of researchers and organisations from around Australia, with the first wave of data expected to be available during the first part of 2018. While one key trial has demonstrated the efficacy of ACP among hospitalised older patients,³ other research around Australia has indicated difficulties in the practical implementation of ACP documents,⁴ and low levels of knowledge of the relevant laws among clinicians.⁵

In Western Australia, the Department of Health (WA) funded a trial of a nurse-facilitated advance care planning intervention. This intervention, implemented among patients with serious lung disease in a metropolitan tertiary hospital and a rural primary and secondary healthcare system, demonstrated that such interventions are acceptable (no adverse events) and highly valued by many patients (approximately 40% of invited patients strongly preferred to receive the intervention, while the majority of others preferred to be randomly allocated, with 10% strongly preferring to avoid the intervention). The intervention was effective in increasing levels of ACP uptake (both formal ACP documents and informal discussions with clinicians and family members), with particular effectiveness for those with a pre-existing preference.⁶ While the clinical impacts of this intervention are still being analysed, we note that the intervention was not particularly costly to deliver, requiring nurse time to coordinate referrals, liaise with other clinicians, meet with patients and family members (sometimes on multiple occasions) and facilitate storage of ACP documents. This typically resulted in about 2 hours of nurse time per participating patient, with additional costs associated with clinical supervision (totalling approximately \$AUD350 per patient).

² White B, Tilse C, Wilson J, Rosenman L, Strub T, Feeney R, Silvester W. Prevalence and predictors of advance directives in Australia. *Internal Medicine Journal*, 2014, 44(10): 975-980. doi:10.1111/imj.12549

³ Detering KM, Hancock AD, Reade MC and Silvester W. The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *British Medical Journal*. 2010; 340.

⁴ Auret K, Sinclair C, Averill B and Evans S. Advance care planning and end-of-life care in a network of rural Western Australian hospitals. *Aust J Rural Health*. 2015; 23: 195-200.

⁵ White B, Willmott L, Cartwright C, Parker MH and Williams G. Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment. *Med J Aust*. 2014; 201: 229-32.

⁶ Sinclair C, Auret K, Evans SF, et al. Advance care planning uptake among patients with severe lung disease: A randomised patient preference trial of a nurse-led, facilitated advance care planning intervention. *BMJ Open*. 2017; 7: e013415.

Further work in Western Australia has included community forums organised by the WA Cancer and Palliative Care Network and Palliative Care WA. Other community-based organisations such as the Albany Death Café have also organised community awareness raising events, associated with National Palliative Care Week and 'Dying to Know Day'. These events appear to have been successful in raising awareness about issues relating to end of life care, with small effects commensurate with their low-level of funded support. In many cases they are organised and run by passionate volunteers, with contributions by clinicians, researchers and other community organisations. Related to this, research undertaken with the Noongar community in the Great Southern region of Western Australia found support for the use of 'whole of community' approaches to raising awareness, rather than health professionals broaching the topic with individual patients in clinical situations (which was seen by some as an intimidating way of broaching the initial discussion about advance care planning).⁷ This suggests the importance of supporting both community-based awareness raising, as well as clinical processes for facilitating tailored ACP discussions.

RECOMMENDATION: Research supports the benefits of advance care planning, when this is implemented in the context of supportive clinical services and/or community organisations. We recommend that there is an important role for community-based awareness raising, well-trained clinical facilitators (e.g. nurses, social workers and/or medical practitioners) and clinical systems to support the storage and communication of ACP documentation.

RECOMMENDATION: Noting the ongoing discussion about the potential for future legislation in the area of assisted dying, we highly recommend the establishment of an ongoing process of data collection relating to the full range of end-of-life practices. The experience in Belgium and Netherland has shown that such measures, when conducted rigorously and with assurances of clinician confidentiality, provide a critical measure to support community trust in the range of end-of-life practices supported under legislation, as well as providing a mechanism for responding to changing community views or demographic trends.

⁷ Sinclair C, Williams G, Knight A and Auret K. A public health approach to promoting advance care planning to Aboriginal people in regional communities. *Aust J Rural Health*. 2014; 22: 23-8.

(b) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions

The committee is referred to Chapters 5 and 9 from Allan and Blake, 'The Patient and the Practitioner: Health Law and Ethics in Australia' (2014, Lexis Nexis) for general information on criminal law and health care; and the legal landscape surrounding end-of-life decision-making in the clinical setting.

1. Terminology

No doubt the committee will receive other comments to this effect, but it is submitted that any use of the terms 'assisted dying', 'suicide', 'euthanasia', and 'futility' should be used with especial attention to the varied way in which these terms have been interpreted. In particular, 'euthanasia' has no settled meaning. For example, 'passive euthanasia' has been a term associated with the withdrawal of life-sustaining treatment from permanently incapacitated persons (for example, note the reaction to *Airedale National Health Trust v Bland* [1993], UK HL) (*Bland*). It should also be noted that assisted suicide is not regarded as a homicide offence as there is no necessity to prove a causal connection between the encouragement or assistance and the suicide.

2. Relevant WA criminal law

The spectre of possible prosecution for homicide offences is associated with any discussion about end-of-life decision-making, and therefore merits attention. The Criminal Code (WA) contains several provisions which are integral to the discussion about end of life choices.

2.1 The conduct element for homicide is that a person causes the death of another person.

Section 270 of the CC provides that causation may be direct or indirect. There needs to be both factual ('but for') and legal (normative) causation for liability to be established. In *Jemelita* (1995) 12 WAR 362 a prosecution for wilful murder was appealed on the basis that the drugs administered by the accused to his wife could not constitute a factual cause of her death.

Sections 271-275 of the Code identify situations where the accused will be 'deemed' to cause the outcome. Section 273 states that a person causes the death of another where he or she accelerates the death of another (for limited analysis see *Krakouer v Western Australia* (2006) 161 A Crim R 347)

Sections 262-269 of the CC create 'duty' provisions which, if applicable, will establish a causal link between the accused's action/inaction and the consequence. These sections do not create offences but facilitate proof of a causal link in cases where the accused has omitted to act when under a duty to do so.

2.2 A person fulfils the mental element of the first form of intentional murder (most relevant to this discussion) where he/she intends the death of another (s27991)(a)). Intention under the Qu CC (and implicitly WA CC) means purpose or aim (*Zabouroni*, [2016], HCA 12), and will be inferred in very limited circumstances (for example where there is evidence of malice – eg.

Reid [2007], Qu CCA). Foresight of the result, even of the highest level) does not equate to intention.

2.3 A person's consent to their own death is irrelevant under s261 CC

Observations on 1.1-1.3: Those involved in end of life care may be technically fulfilling the conduct and mental elements of murder under s279(1)(a) of the Criminal Code.

2.4 There is no separate defence of consent in the Criminal Code. While lack of consent needs to be proven for the crime of assault (sections 213 and 222), consent is not relevant in some circumstances (section 223), and is not an element of more serious offences (gbh, wounding). As noted above it is explicitly not relevant to homicide offences.

2.5 Section 259 states that there is no criminal responsibility where surgical or medical treatment (including palliative care) is administered or not administered in good faith and with reasonable care and skill, where that is reasonable having regard to the state of the patient and all of the circumstances. This section was amended with the changes to the Guardianship and Administration Act 1990 (WA) (GAA) which introduced advance care planning provisions and wider substitute decision-making powers over health care and lifestyle matters for incapacitated adults. Section 259 was applied in *Brightwater Care Group v Rossiter* [2009, WASC] (see below) and was also considered in *Queensland v Nolan* [2002] QSC which involved the separation of Siamese twins (in which one of the twins would necessarily die).

Observations on 1.4 and 1.5 – Section 259 (and its Queensland CC equivalent) was originally construed as applicable to treatment which resulted in the death of an unborn child out of necessity to save the mother. The interpretation in *Rossiter* situates the legality of (at least) withdrawal of life-sustaining treatment from those with capacity to make these decisions. It does, however, have potentially other applications to health professionals involved in other actions associated with end-of-life care (see below).

2.6 There is an offence of aiding suicide under section 288 of the Criminal Code. This is not technically a form of homicide as there is no requirement of a causal connection between the assistance and the victim's death – it is submitted that *AG v Able* [1984, HL] would apply on this point.

3. End of life choices and the general legal position in Australia: the 'Rubicon rule'

Lord Goff in *Bland*

"It is not lawful for a doctor to administer a drug to his patient to bring about his death, even though that course is prompted by a humanitarian desire to end his suffering, however great that suffering may be...So to act is to cross the Rubicon which runs between on the one hand the care of the living patient and on the other hand euthanasia – actively causing his death to avoid or to end his suffering. Euthanasia is not lawful at common law."

Lord Mustill:

“The conclusion that the declarations can be upheld depends crucially on a distinction drawn by the criminal law between acts and omissions, and carries with it inescapably a distinction between, on the one hand what is often caused “mercy killing”, where active steps are taken in a medical context to terminate the life of a suffering patient, and a situation such as the present, where the proposed conduct has the aim for equally humane reasons of terminating the life of Anthony Bland by withholding from him the basic necessities of life...The acute unease which I feel about adopting this way through the legal and ethical maze is I believe due in an important part to the sensation that however much the terminologies may differ the ethical status of the two courses of action is for all relevant purposes indistinguishable. By dismissing this appeal I fear that your Lordships’ House may only emphasise the distortions of a legal structure which is already both morally and intellectually misshapen’

The current legal framework surrounding ending-of-life decision-making is constrained by the act/omission distinction, a tool used in deontological theory to morally distinguish contributions of individuals to bad outcomes. In terms of ending-of-life decision-making, this has been incorporated into the common law so as to establish a ‘bright line’ between decisions which concern the non-administration or withdrawal of life-saving or life-sustaining treatment, and the active intervention which leads to a person’s death. This ‘bright line’ has been consistently challenged in Australian jurisdictions, but remains a solid barrier to legal change.

3.1 Withholding or withdrawing of life-saving/sustaining treatment

It is well established in Australian law that a person who has the capacity to make a decision to withhold or withdraw treatment which is needed to maintain survival has the ‘right’ to have this decision respected⁸. This accords with traditional principles in both criminal law and civil law in which treatment without consent constitutes both an assault (crime) and a trespass to the person (civil law). In Western Australia, the decision in *Brightwater Care Group v Rossiter* [2009, WASC 229] (*Brightwater*) confirms that this position is followed in Western Australia, and is consistent with the provisions of the Criminal Code (WA), specifically sections 262, 261 and 259 (for commentary see M Blake: ‘Doctors Liability for Homicide under the WA Criminal Code: Defining the Role of Defences’ UWALR (2011), Vol 35(2)). The question of whether a person who is seeking this is attempting suicide has been addressed by courts from overseas as well as in the case of *Hunter and New England Area Health Service v A* (2009, NSWSC). The issue is problematic as if this is the case, then health professionals involved in not administering or withdrawing such treatment could be regarded as assisting that person’s suicide (and therefore committing a section 288 offence)

There is also authority in Australian common law that the withdrawal of life-sustaining treatment from adults who lack capacity is lawful – for example see *BVW Re; Ex parte Gardner* [2003, VicSC].

⁸ Note that while in the UK it is accepted that this extends to the pregnant woman who refuses treatment and thereby endangers the life of her unborn child, that there has been some doubt cast over this following obiter dicta comments in *Hunter and New England Area Health Service v A* (2009, NSWSC 76).

This, again, is consistent with the law from other western jurisdictions which upholds the position that the withdrawal of such treatment may be in a person's best interests, generally on the grounds that this treatment is futile, and that the burden of the treatment outweighs any benefits it may be conferring (see Wilmott, White and Downie, 'Withholding and Withdrawal of 'Futile' Life-sustaining Treatment: Unilateral Decision-making in Australian and New Zealand' (2013) *Journal of Law and Medicine* 907). The compatibility of this position with the WA Criminal Code is not explicit, but it is probable that the withdrawal of such treatment would be permissible on the grounds that it is reasonable in the circumstances under section 259 (as Wayne Martin CJ found to be the case where Mr Rossiter, who had capacity, had asked for his request to withdraw ANH to be respected). Given that in Brightwater Martin CJ had regard to the imminent advance care planning provisions in construing section 259, it is suggested that decisions taken by an EPG/SAT appointed guardian/ 'person responsible' to refuse or discontinue life-saving or life-sustaining treatment on the basis of the incapacitated person's best interests under the GAA ('treatment decisions' specifically include a decision to treat or not to treat) would prompt a similarly consistent interpretation of section 259(2) – that the non-administration of the treatment is reasonable having regard to the state of the person and all other circumstances, as it is in the 'best interests' of that person as decided by the person with decisional authority.

ACTION REQUIRED: Clarification of the position regarding the withholding or withdrawal of life-saving/sustaining treatment. While it is assumed s259 covers this situation, it would be preferable to have this explicitly acknowledged within the Criminal Code. The inclusion of life-sustaining measures and palliative care within the meaning of 'treatment' under the GAA provides clarification for those lacking capacity, while the common law position regarding the person with capacity who refuses such treatment is well established. This should be explicitly recognised within the Criminal Code.

3.2 Pain relief for terminal conditions

Doctors provide pain relief to patients in an effort to relieve pain and suffering. This is most commonly associated with patients who are terminally ill and who are expected to die within days. The legal issues around this sort of therapy is complicated by the laws relating to criminal responsibility for the death of a person, specifically that a person will be held to have caused another person's death where his or her actions accelerates that death (section 273 Criminal Code).

The common law has relied on the Catholic doctrine of double effect, applied to justify self-defence and abortion. The law therefore regards the situation where a doctor's actions accelerate the death of a patient in these situations (through, eg., suppression of respiratory function) as being lawful as the death of the patient is not 'intended', although it is foreseen. It is the pain relief which is intended.

The issue of terminal pain relief which might have the incidental effect of hastening death was addressed in the *Rossiter* case. Martin CJ was not prepared to grant a declaration that any such relief administered to Mr Rossiter would be covered by section 259(1), on the grounds that the application of that provision 'will depend critically upon the particular facts and circumstances of the individual case' (at 55), however his judgment clearly contemplates that this defence if where the legal justification for such a practice would be situated.

ACTION REQUIRED: Section 259 seems an appropriate place to situate the justification for this practice, but it is suggested that the section be followed by examples of relevant situations so that its' function as a modern day defence to legitimate accepted practices is clear. Alternatively the committee may wish to explore the view that it is inappropriate to regard such practices as prima facie criminal and to instead remove these from the sphere of criminal liability altogether. The GAA could be an appropriate locale, but it does only apply to those who lack the capacity to make decisions for themselves.

3.3 Active intervention

The committee is encouraged to distinguish between the situation where a person seeks assistance to die and where the final death-causing act is of that person (reflected in the laws of the US states which have enacted Physician Assisted Dying (PAD) laws), and the action of another person is the most direct cause of death (for example the lethal injection). The importance of this distinction is that the final 'act' is that of the person seeking assistance and therefore reinforces that this is an autonomous course of action. The committee, however, needs to consider that persons who are terminally ill with terrible diseases such as motor neurone disease may be unable to take that 'final step' on their own. Those seeking to challenge laws which criminalise assisted death have used arguments based in the right to equal treatment to support their claims, although autonomy-based arguments remain the most common for such challenges.

Various Australian states have considered legislative bills seeking to legalise PAD and/or euthanasia (referring here to the situation where the 'last act' is that of another person, not the deceased). Apart from the Northern Territory legislation (which included both forms of assisted death within its scope), none of these attempts have been successful, although the Victorian Parliament is currently debating a bill which would legalise physician assisted suicide.

The committee is encouraged to consider the cultural differences between the countries and jurisdictions which have legalised forms of assisted dying. Allan and Blake, Chapter 9, explains that the Netherlands position was led by physicians and remains strongly supported by the medical profession, while human rights discourse (the emphasis being on the patient's choice, rather than providing a justification for the doctor's actions) is behind the US legislation in those states which have legalised PAS. The necessity defence found in the Criminal Codes of WA and Qu could arguably be applied to justify assisted death (see M Blake: 'Doctors Liability for Homicide under the WA Criminal Code: Defining the Role of Defences' UWALR (2011)). Australian states do not have the same legally enforceable human rights frameworks which have facilitated arguments supporting assisted dying in other jurisdictions (eg. US, UK); while Victoria and the ACT have human rights legislation this is largely regarded as aspirational. The distinction between a necessity-based model and one based on human rights has important implications for the permissible scope of actions.

The committee is alerted to the developments which have occurred since the publication of this book.

3.1 Quebec introduced physician assisted death under its health powers; while Canadian provinces have parliamentary powers over health, they do not over criminal law – see <http://www.cbc.ca/news/canada/montreal/medical-assisted-death-cases-first-year-1.4023851>

3.2 The Canadian Supreme Court decision in *Carter v Canada* [2015] SCC 5 has resulted in the Canadian Parliament legalising physician assisted dying in limited circumstances (June 2016). For a synopsis of the decision see M Blake, 'Seeking a proportionate response to choices about dying', <http://www.healthlawcentral.com/?s=Carter+>

3.3 The UK High Court has rejected a claim that the ban on assisted suicide was a violation of the applicant's Article 8 ECHR right to control the manner and timing of his own death – *Conway v The Secretary of State for Justice* [2017] EWHC 2447. This followed the defeat of the Assisted Dying (No 2) Bill in the House of Commons in September 2015 (330 to 118 votes).

3.4 Oregon, Washington, Montana, California, Colorado, Washington DC and Vermont have now legalised physician assisted suicide;

RECOMMENDATION: It is suggested that when considering the issue of assisted dying that the committee is fully aware of the implications of the different models which have been adopted in those jurisdictions which have legalised forms of assisted dying. For example, a 'defence' based model is different to a 'rights' based model, while a model which allows another person to directly bring about another person's death is significantly different to one which is limited to the provision of assistance. The former model would allow access by those persons who cannot administer to themselves the death-causing agent (and therefore meet arguments from the 'unequal treatment' principle) whereas the second, more limited form, has appeal in the reassurance provided by the fact that the 'last act' is that of the deceased (therefore strongly reflecting a 'physical autonomy' position). A further consideration which needs attention in the event that the 'assisted suicide' model is being contemplated is whether this be limited to physician assistance, or to familial assistance (note here the DPP Code in the UK).

The scope of the current bill before the Victorian model is regarded as narrow – assisted dying can only be accessed by those with a terminal illness who are expected to die within a year. The committee would be advised to consider whether setting time limitations is useful or practical. It should also consider whether there is justification for limiting access to those with terminal illnesses, and whether other chronic conditions could be included. Finally the Victorian bill specifically excludes access to assisted dying via advance directives, and it is important that the committee considers the rationale behind the 'contemporaneous request' (versus the 'anticipatory request') model given the strong support for end-of-life-planning in the legislation in many Australian jurisdictions. The authors note that this specific exclusion, along with the necessity that the person requesting assisted dying be in the final stages of a terminal illness, makes it unlikely that this legislation would be accessible by a person experiencing a neurodegenerative condition.

(d) Examine the role of Advance Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws and implications for individuals covered by these instruments in any proposed legislation

This part of our submission focuses on the operation of Advance Health Directives, Enduring Powers of Attorney and Enduring Powers of Guardianship within the *Guardianship and Administration Act 1990 (WA)*, and the *Mental Health Act 2014 (WA)*

1. The inclusion of section 110ZIA which allows disregard of AHDs and substituted decision-makers instructions where a health professional reasonably believes the patient to have attempted suicide seems inconsistent with the spirit of the provisions which emphasise the autonomy of the patient, and is not found in any other jurisdiction;

RECOMMENDATION: That the committee reconsiders the inclusion of this section. It is noted that this matter is addressed with a bit more nuance within the Mental Health Act 2014 (WA), where professionals still need to ‘give regard’ to the AHD even if the person is involuntarily admitted under the Mental Health Act (and report to the Office of the Chief Psychiatrist). Assuming that acts of suicide (or presumed suicide) do not always come under the Mental Health Act, it is suggested that this issue could be dealt with similarly in the GAA. Professionals should still ‘give regard’ to the AHD of a person who has attempted suicide, and, if the AHD is overridden that this should be reported to either to the Chief Medical Officer, or to SAT.

2. Section 110S(3) is arguably easily widely interpreted to permit the annulment of advance health directives, particularly given that it refers to the ‘reasonable person in the maker’s position’. The reference to ‘reasonable’ appears to impose a judgment assessing the rationality of the terms of the AHDs and again is inconsistent with the spirit of the legislative changes;

RECOMMENDATION: That the committee reconsiders the wording of this section so that it operates more restrictively and therefore more consistently with the right of the person to make choices about their end-of-life treatment. It is suggested that one way that this process could be given more rigour by requiring that clinicians who want to ignore an AHD should take the matter to SAT.⁹

3. It is submitted that, in line with the Convention on the Rights of Person with Disabilities, the committee reconsiders the inclusion of the best interests test as the basis for decision-making by all substituted decision-makers under the GAA (section 51). The Convention emphasises the centrality of the rights, will and preferences of the disabled person. The subsequent ALRC Report on Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124, 2014) is critical of the best interests test as the basis for substituted decision-

⁹ Although such a course of action does bring up the issue of potentially unwanted life sustaining treatment being applied ‘just in case’, while waiting for the outcome of the SAT hearing, which could be lengthy.

making and regards it as inconsistent with the Convention. Article 12 of the Convention, which requires persons with disability to be equal before the law, requires state parties to institute supported decision-making so as to facilitate the respect for the rights, will and preferences of these persons. The ALRC Report similarly supports the adoption of supported decision-making in appropriate circumstances.

RECOMMENDATION: That the committee reconsiders the basis for substituted decision-making under the GAA, and introduces a requirement to consider and implement supported decision-making where possible and to introduce a substituted judgment approach to substituted decision-making where it is not possible to apply supported decision-making. The best interests test should be applied only as a last resort. It is particularly important that the wishes and preferences of the incapacitated person are front and centre considerations when end-of-life treatment is the subject of the decision, as this is the best way to ensure that the treatment is a 'choice'. It is also suggested that training and counselling be available to guardians on how to prioritise the wishes and preferences of the incapacitated person in the decision-making process.

4. We suggest that the committee considers the research which the authors of this submission have carried out at a local level around advance care planning and people with dementia. The authors interviewed 19 professionals in health care and aged care to ascertain their responses to a number of questions focusing on decision-making around end-of-life care by and for those persons with dementia. The research has been written up and is shortly to be published.¹⁰ Key findings from these interviews were that:
 - There is a low take up of AHDs and EPGs, compared to Enduring Powers of Administration;
 - A person with dementia is often 'assumed' to lack the capacity to make decisions for him or herself, particularly once that person has been admitted to an aged care facility. The common law approach to functional tests of decision-making capacity referred to in *Hunter New England Health Service v A* [2009] NSWSC 761 is often not used in practice. People are often defined in 'black and white' terms as 'not having capacity', with little regard for the nature of the decision required, the time of the decision, or fluctuations in the impairment or condition which is leading to the decision-making impairment;
 - Decisions relating to transitions between health and care services, and end-of-life care, are often preceded by a 'crisis' which propels the decision in the absence of any care plan;
 - The combination of a relative with dementia and decisions regarding care near the end-of-life may well precipitate family conflict, often motivated by feelings of guilt, unresolved tensions and the arrival of a 'fly-in' relative who seeks treatment options contrary to what the long-term involved relative feels is appropriate;
 - Approaches to SAT are reserved for instances where care staff believe that the conflict cannot be resolved. Many of those interviewed identified 'the most agreeable outcome'

¹⁰ Blake M, Sinclair C and Doray O. Advance care planning for people with dementia in Western Australia: An examination of the fit between the law and practice. *Psychiatry Psychology and Law*. (in press).

as being the driving force behind treatment decisions, not the autonomy of the person with dementia. This suggests the importance of having access to staff with mediation skills, and having access to alternative dispute resolution mechanisms instead of going to SAT (a process which has been found to work well in South Australia);

- Several of the interviewees referred to the use of alternative, non-statutory advance planning forms completed by relatives for the person with dementia. These would appear to involve an unlawful exercise of power by guardians and persons responsible, in that this form amounts to an exercise of an advance health directive on behalf of another person, whereas the GAA requires that the person themselves execute the AHD. However it may be that supporting the existing alternative practices (e.g. the 'most agreeable outcome' approach) with greater guidance, will enable respect for the person's autonomy, within the broader context of their overarching dignity, while supporting the important emotional processes that family members may also be experiencing, with the chance to resolve conflict and disputes before they negatively impact on the person's care and/or autonomy. Further literature relating to mediation in end-of-life care are also available.¹¹

RECOMMENDATION: That the committee considers the findings of this research which indicates that there is a 'gap' between the letter and spirit of the advance planning provisions in the GAA and the on-the-ground practice surrounding end-of-life care for persons with dementia, and considers further implementation work or possible law reform to address this gap.

RECOMMENDATION: There is an opportunity to more clearly enunciate the best practice principles underpinning capacity assessment in legislation. In this regard we would recommend the provisions in the *Advance Care Directives Act 2013 (SA)*.¹²

5. The authors of this submission also suggest that the committee considers other research which has examined the extent to which supported decision-making features in the legislation in three Australian jurisdictions (WA, SA, NSW). As part of this work we also reviewed 35 recent tribunal decisions (WASAT and NCAT) involving people with dementia. This research is currently being written up, but several key findings are of relevance to the issues of capacity assessment and the appointment of guardians in connection with people with dementia. Specifically:
 - a. Western Australian has no formal mechanisms in place for supported decision-making under current legislation

¹¹ Sinclair C, Davidson C, Auret K. The role of mediation in advance care planning and end-of-life care. *Australian Family Physician*, 2016, 45(1-2), 69-73.

¹² *Advance Care Directives Act 2013 (SA)* Section 7. Note that the implementation of s7(1)(b) would be achievable within the current Advance Health Directive form, in which different 'Circumstances' under which the directive might be invoked could be nominated. This would however require further detailing in the preamble to the form, and would also necessitate further training of health professionals, along with the above considerations in respect of assessing decision-making capacity more generally.

- b. Circumstances leading to the application for guardianship typically involved family conflict/dispute and/or allegations of exploitation, abuse or improper care.
- c. In assessing decision-making capacity, tribunals relied predominantly on medical evidence (GPs and specialists) and nursing/allied health professionals. Additional evidence was sought from the person themselves, their family, friends and social workers.
- d. Several of the tribunal decisions articulated the point that the diagnosis of dementia should not pre-determine the outcome of a capacity assessment nor whether there is a need for a guardian
- e. Tribunals referred to the 'principle of necessity' in imposing a guardianship order. However, of the 35 relevant decisions, when it was determined that a person lacked decision-making capacity, guardianship order were avoided in only six cases. Family conflict was often the key factor precluding the use of existing informal supports.

What we can tell from this research is that the quality of the implementation of existing 'best practice' approaches to capacity assessment appears to be better at the Tribunal level, as opposed to everyday practice in health and care settings. This suggests the need for further education of health professionals and care staff, with respect to understanding the principles underpinning functional capacity assessment. As we have already suggested, this could also be facilitated through further clarification of best practice functional approaches to capacity assessment in existing legislation.

This research also shows how many of the cases coming before Tribunals are leading to the imposition of a guardianship order, driven predominantly by family conflict or dispute. The experience in South Australia has shown the positive impact of alternative dispute resolution mechanisms, to enable existing informal support arrangements to continue, rather than resorting to guardianship orders.

RECOMMENDATION: Consider establishing an alternative avenue for dispute resolution within the GAA. An approach such as that legislated in the *Advance Care Directives Act 2013 (SA)* is recommended.¹³

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¹³ *Advance Care Directives Act 2013 (SA)* Division 3 s47-51.