



GOVERNMENT OF  
WESTERN AUSTRALIA

# **Ministerial Expert Panel on Advance Health Directives**

**Final Report**  
August 2019

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## Chair's Foreword

As a community we are starting to pay more attention to the choices we will make as we approach end of life.

For a long time, conversations about death and dying, and about end of life have been difficult for us as a society. Recently, that pre-existing cultural scepticism has been replaced by an appreciation in parts of the community that a good death is possible.

People often fear death or loss of capacity on anticipation of a loss of control. As we embark on a discussion on voluntary assisted dying, elder abuse and investing in palliative care, it is worth remembering that Western Australians already have access to a very useful and worthwhile statutory instrument that not only assists those who may be approaching end of life, but others who are suffering from a neurodegenerative cognitive condition or other form of cognitive impairment.

This instrument is known as an Advance Health Directive (AHD) and provides for patients to outline in clear and unambiguous terms their treatment wishes.

For whatever reason the take up of these instruments in WA has been low compared to other jurisdictions. As the discussion around elder abuse, palliative care and voluntary assisted dying unfolds over the coming months, now is an opportune moment for us as a community to promote both awareness and uptake of AHDs.

The parliamentary Joint Select Committee into End of Life Choices appreciated this exact point and recommended to the WA Government the establishment of an expert panel to advise on AHDs.

This report is the culmination of that Panel's excellent efforts. This report contains a number of important recommendations including raising community awareness, amending the statutory form, creating an online register and considering the particular circumstances of people with dementia or neurocognitive impairment. I am hopeful that this report will provide a useful basis for government policy making, and action, in this important area.

This report would not have been possible without the outstanding work of all the panel members, to whom I express my sincere gratitude.

As a panel we were expertly supported by the tireless efforts of the Panel's secretariat. My heartfelt thanks for their tireless work, and extraordinary patience goes to Damien Parke and Liz Perkins, without whose efforts this report would not have been completed to such a high standard.

I commend the work of the Panel, and this Report, to the Minister and wish him well in his considerations of its contents, findings and recommendations.

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## List of findings and recommendations

### CHAPTER 2 Community awareness and education

#### **Recommendation 1 – The scope of a new approach**

- 1.1 A new approach to community awareness and education should encompass and coordinate measures promoting:
- The concept of ‘having the conversation’ about serious illness and death;
  - Advance care planning; and
  - The statutory instruments.

#### **Recommendation 2 – Strategic planning**

- 2.1 The State Government should mandate the Department of Health to lead the development and delivery of a community awareness and education strategy.
- 2.2 The Department of Health should co-design the proposed strategy with relevant government and non-government stakeholders.

#### **Recommendation 3 – Audiences**

- 3.1 The proposed community awareness and education strategy should incorporate initiatives:
- Addressed to the community as a whole;
  - Specifically targeting priority groups including older people, people in regional areas, people experiencing disadvantage, Aboriginal people and people from culturally and linguistically diverse communities; and
  - Targeting individuals at ‘key points’, including the 75-year-old health check and at diagnosis with a life-limiting condition or neurodegenerative disease.
- 3.2 Measures targeting priority groups should be developed and delivered in close collaboration with relevant stakeholders including carers, service providers, the Office of the Public Advocate and advocacy bodies.

#### **Recommendation 4 – Funding**

- 4.1 The proposed community awareness and education strategy should be:
- Supported by ongoing dedicated funding, to be sought and allocated in line with standard Government budgetary processes; and
  - Designed to leverage other resourcing opportunities, including those associated with the Commonwealth and the private sector.

## CHAPTER 3 Education for health professionals

### Finding 1

The ability of health professionals to support advance care planning and apply the treatment hierarchy is influenced by a number of structural factors that are not primarily related to education, but are addressed in the recommendations of the Joint Standing Committee's report, elsewhere in this report or both.

Health services can support individual health professionals to discharge their responsibilities in relation to advance care planning, including adherence to decisions documented in the statutory instruments, by examining relevant processes and policies, particularly in relation to clinical handover and discharge communication.

### Recommendation 5 – A new approach to the education of health professionals

- 5.1 The State Government should mandate the Department of Health to lead the development and delivery of a strategy for educating health professionals about advance care planning, the treatment hierarchy and the statutory instruments.
- 5.2 The Department of Health should develop and deliver the strategy in partnership with relevant stakeholders including professional bodies, tertiary institutions, aged care providers and Commonwealth agencies.
- 5.3 The strategy should focus on opportunities to embed consistent information within existing education and training systems including academic curricula and professional development processes.
- 5.4 The State Government should provide funding to support the development and delivery of the strategy.

### Recommendation 6 – Target audiences

- 6.1 Education for health professionals should:
  - Recognise the diversity of roles and educational requirements that exist under the broad umbrella of 'health professionals' and other relevant service providers; and
  - Give initial priority to general practitioners, acute sector health professionals and health professionals working with people with life-limiting conditions or neurodegenerative diseases including dementia and/or in aged care.

### Recommendation 7 – Structuring the content

- 7.1 The proposed education strategy for health professionals should consider educational needs across the following stages of the advance care planning process:
  - Initiating discussion about advance care planning;
  - Assisting patients to make advance care plans, including the statutory instruments; and
  - Applying the treatment hierarchy and implementing decisions documented in statutory instruments.

## CHAPTER 4 The advance health directive template

### **Recommendation 8 – Non-binding values statements**

- 8.1 The new advance health directive template should provide for the inclusion of a non-binding values statement.
- 8.2 Consideration should be given to enabling values to be expressed via a combination of tick-boxes and free text.
- 8.3 The new template should clearly distinguish the non-binding values statement from the binding treatment decisions.

### **Recommendation 9 – Tick boxes**

- 9.1 The new template should enable individuals to make certain common treatment decisions via a tick-box approach.
- 9.2 The conditions presented in this manner should be identified in consultation with relevant health professionals including emergency doctors, general practitioners, paramedics and geriatricians.
- 9.3 The new template should make it clear that the maker needn't complete both the tick-boxes and the free-text section unless they wish to do so.
- 9.4 The specific treatments listed in this part of the new template should be presented in language that is understood readily by health professionals yet minimises medical jargon.

### **Recommendation 10 – A user-friendly approach**

- 10.1 The new template should continue to be published as part of a booklet containing information about the purpose and nature of advance health directives and advance care planning generally.
- 10.2 The content of the booklet should be updated to:
  - Reflect changes to the template and any other reforms arising from the present report or other processes; and
  - Include a complete hand-written sample, similar to that contained in the South Australian booklet.
- 10.3 The new template should continue to include technical notes to assist the maker to complete the form correctly, but with the notes placed on the left margin to correspond with the relevant part of the form.
- 10.4 The new template should:
  - Be presented in plain English and have an inviting visual style;
  - Accord with relevant accessibility standards; and
  - Provide adequate space for treatment decisions, or at least make clear that further content may be attached.

### **Recommendation 11 – Combining different forms**

11.1 The advance health directive, enduring power of guardianship and enduring power of attorney templates should remain separate.

### **Recommendation 12 – Digitisation**

12.1 The new advance health directive template should be able to be completed electronically and then printed, with signatures to be completed in hard copy.

12.2 An electronic register of advance health directives should aim to eventually support the making and witnessing of advance health directives electronically.

### **Recommendation 13 – Medical advice or certification**

13.1 The advance health directive template should continue to encourage, but not require, the person completing the form to seek medical advice.

## **CHAPTER 5 Register of advance health directives**

### **Finding 2**

Recent reforms implemented by the Department of Health have improved the existing situation, but are not an adequate substitute for a dedicated register.

### **Finding 3**

There is no existing online platform, nationally or in Western Australia, that could effectively serve as a register of advance health directives.

### **Recommendation 14 – The need for a dedicated register**

14.1 The State Government should establish and maintain a register for advance health directives and provide funding for this purpose.

### **Recommendation 15 – The functionality of a register**

15.1 The functionality of the register should be determined with reference to a cost-benefit analysis comparing, at a minimum, the following models:

- A register that operates as a simple repository of PDFs.
- An online 'one-stop-shop' that guides the person through the entire process of considering, planning, making, witnessing and sharing an advance health directive.

### **Recommendation 16 – Access to a register**

16.1 To be effective, the advance health directive register should support differential access as follows:

- 24 hour access to:
  - a. Providers of emergency medical services (including ambulance services, Royal Flying Doctor Service);
  - b. Authorised staff in public and private hospitals;
  - c. Authorised staff in aged care providers; and
  - d. General Practitioners.
- Access must also be provided to individual records, as requested, for enduring guardians, guardians, the Public Advocate and the State Administrative Tribunal.

16.2 Serious consideration should be given to extending access to:

- Other medical practitioners;
- Relevant allied health practitioners; and
- Relevant community service providers.

16.3 The advance health directive register should distinguish between searchable access to all records (for example, as required by emergency medical services); and the right to access a specific individual's information (for example, as required by guardians) and the individual's right to access their own data.

### **Recommendation 17 – Registration**

17.1 The registration of advance health directives should be voluntary.

17.2 Where a person elects not to store their advance health directive on the register, the register should be capable of indicating the existence and location of the document.

17.3 Community education initiatives and resources should highlight the benefits of registration with a view to ensuring that individuals are able to make informed choices about, and be accountable for, their decision regarding registration.

### **Recommendation 18 – Vetting**

18.1 Advance health directives should be reviewed by a trained health professional and/or an appropriately skilled administrator before being uploaded to the register.

18.2 The purpose of the review should be to ensure that the advance health directive is legally valid and clear enough to be implemented, not to assess the advisability of the person's treatment decisions.

18.3 People who are seeking to upload an advance health directive to the register should be made aware of the vetting process before submitting the document.



### **Recommendation 19 – The scope of a register**

- 19.1 The register should be confined to advance health directives.
- 19.2 The register should accommodate all aspects of the advance health directive template, including whether a person has nominated an enduring guardian.

### **Recommendation 20 – Accommodating pre-existing and common law AHDs**

- 20.1 The design process for the register should include consideration of the needs of people who have existing advance health directives, common law advance health directives, and advance health directives made on outmoded templates.
- 20.2 In the event that these advance health directives cannot reasonably be included in the register, individuals should be able to use the register to flag the existence and location of the advance health directive.

### **Recommendation 21 – Obligation on health professionals**

- 21.1 The establishment of a register should be accompanied by a statutory obligation requiring that the register be searched before provision of treatment to a person without decision-making capacity.
- 21.2 Searching the advance health directive register should form part of the process for obtaining consent for medical treatment of a person without decision-making capacity.
- 21.3 The statutory obligation should be carefully calibrated so as to avoid placing an unreasonable burden on health services. For example, the obligation should:
- Apply only to non-urgent medical treatment decisions;
  - Not apply where the patient has not had the capacity to make, revoke or vary an advance health directive since a previous search;
  - Not apply where the health professional has reasonable grounds to believe that the treatment decision is not covered by an advance health directive;
  - Accommodate the fact that the treating health professional will not always be the responsible person for searching the register; and
  - Not apply in circumstances where the health professional is unable to access the register.
- 21.4 To ensure people who do not store their advance health directive on the register are not disadvantaged, the register should not fully replace other operational procedures in place to determine the existence and location of an advance health directive; however, these should not form part of the proposed statutory obligation.

## CHAPTER 6 Accommodating people with dementia and cognitive impairment

### **Finding 4**

Existing legal instruments already operate for the benefit of people with dementia and cognitive impairment, and will do so more effectively if the recommendations contained in this report are implemented.

The time-limited window for many people diagnosed with dementia or another neurodegenerative disease also presents a valuable opportunity to engage people in advance care planning discussions and decisions.

### **Recommendation 22 – Accommodating people with dementia**

22.1 Advance care planning, including advance health directives, should be promoted, funded and supported as part of an early intervention and education strategy for people diagnosed with dementia and other neurodegenerative diseases.

## APPENDIX A

### **Recommendation 23 – Voluntary assisted dying**

23.1 If, at a future point, voluntary assisted dying legislation is implemented in Western Australia, the State Government could consider establishing an Expert Panel to provide advice and recommendations on how to provide people with a neurodegenerative condition access to choice regarding voluntary assisted dying, in particular through the potential application of advance directives.

## **Glossary**

The following terms are used throughout this report:

### **Advance Care Planning**

A process that can include an ongoing discussion between a person and their enduring guardian/guardian, carers, family and health professionals about the person's values, beliefs, treatment and care options. It focuses in particular on the person's wishes for their future treatment and care should they no longer be able to make or communicate their decisions at the time they are needed.

### **Advance Care Plan**

A record of an advance care planning discussion and a way in which a person can inform others of their personal wishes.

### **Advance Health Directive (AHD)**

A legal document completed by an adult with full legal capacity that contains decisions regarding future treatment. It specifies the treatment(s) for which consent is provided or refused under specific circumstances.

### **Culturally and Linguistically Diverse (CALD)**

Groups and individuals who differ according to religion, race, language or ethnicity, except those whose ancestry is Anglo Saxon, Anglo Celtic, Aboriginal or Torres Strait Islander.

### **Dementia**

An umbrella term that covers a wide range of neurological conditions that lead to degenerative damage in the brain and impacts cognitive functioning such as memory, spatial perception and orientation, and personality changes.

### **Enduring Guardian**

A person appointed under an enduring power of guardianship to make personal, lifestyle and treatment decisions on behalf of the appointor.

### **Enduring Power of Attorney**

A legal document in which a person nominates someone (known as an attorney) to manage their financial affairs.

### **Enduring Power of Guardianship**

A legal document in which a person nominates someone (known as an enduring guardian) to make personal, lifestyle and treatment decisions on their behalf in the event they lose the capacity to do so themselves.

### **Guardian**

A person appointed by the State Administrative Tribunal to make personal, lifestyle and treatment decisions on behalf of a person with a decision-making disability.

### **Health professional**

A chiropractor, dentist (including dental therapist, dental hygienist and dental prosthetist), medical practitioner (including general practitioner and medical specialist), medical radiation technologist, midwife or nurse, occupational therapist, optometrist, osteopath, pharmaceutical chemist, physiotherapist, podiatrist, paramedic and psychologist.

### **The Joint Select Committee on End of Life Choices (JSC)**

A Parliamentary Committee established in August 2017 to inquire into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices. The JSC tabled its final report, *My Life, My Choice*, in Parliament on 23 August 2018.

### **Life-limiting condition**

A disease, condition or injury that is likely to result in death, but not restricted to the terminal stage when death is imminent.

### **Neurodegenerative disease**

An umbrella term for a range of conditions that primarily affect the neurons in the human brain. Neurodegenerative diseases are incurable and debilitating conditions that result in progressive degeneration and/or death of nerve cells. Examples of neurodegenerative diseases include Parkinson's, Alzheimer's, and Huntington's disease.

### **State Administrative Tribunal**

The primary place for the review of decisions made by Government agencies, public officials and local governments. The Tribunal also considers disciplinary matters and makes a wide variety of original decisions, dealing with a range of administrative, commercial and personal matters, including guardianship and administration, and matters about the operation of advance health directives, enduring powers of guardianship and enduring powers of attorney.

### **Terminal illness**

An illness or condition that is likely to result in death. The terminal phase of a terminal illness means the phase of the illness reached when there is no real prospect of recovery or remission of symptoms (on either a permanent or temporary basis).

### **Treatment**

Defined in section 3 of the *Guardianship and Administration Act 1990 (WA)* to mean medical or surgical treatment (including a life-sustaining measures and palliative care), or dental treatment or other health care.

### **Treatment decision**

Defined in section 3 of the *Guardianship and Administration Act 1990 (WA)* to mean a decision to consent or refuse consent to the commencement or continuation of any treatment.

### **Treatment hierarchy**

The order of priority of potential substitute treatment decision-makers established under sections 110ZJ and 110ZD of the *Guardianship and Administration Act 1990 (WA)* and reproduced on page 32 of this report.

### **Urgent treatment**

Defined in section 110ZH of the *Guardianship and Administration Act 1990 (WA)* to mean treatment urgently needed by an individual to:

- (i) Save the individual's life; or
- (ii) Prevent serious damage to the individual's health; or
- (iii) Prevent the individual from suffering or continuing to suffer significant pain or distress.

## CHAPTER 1: Background

The Joint Select Committee on End of Life Choices (the JSC) was established in August 2017 to inquire into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices. The Terms of Reference of the JSC were to:

- 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;
- b) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions;
- c) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation; and
- d) examine the role of Advance Health Directives (AHDs), Enduring Power of Attorney and Enduring Power of Guardianship laws and the implications for individuals covered by these instruments in any proposed legislation.

The JSC received more than 730 submissions and held 81 hearings involving more than 130 witnesses. The JSC's final report, *My Life, My Choice*, was tabled in Parliament on 23 August 2018, and contained 24 recommendations for consideration by the Government.

Recommendations 1 – 6 of the JSC's final report related to advance care planning. The first three recommendations were addressed to the Attorney General and specifically concerned AHDs.

The JSC recommended the establishment of an expert panel to review the current law and health policy and practice around AHDs and provide recommendations in relation to an electronic register for AHDs, amendments to the Western Australian template for AHDs, and how people diagnosed with dementia can have their advance care planning decisions acknowledged and implemented when they have lost capacity (JSC Recommendation 1).

### **Joint Select Committee Recommendation 1**

*The Attorney General, in consultation with the Minister for Health, appoint an expert panel to review the relevant law and health policy and practice – and provide recommendations in relation to the following matters:*

- *the establishment of a purpose-built central electronic register for advance health directives that is accessible by health professionals 24 hours per day and a mechanism for reporting to Parliament annually the number of advance health directives in Western Australia.*
- *a requirement that health professionals must search the register for a patient's advance health directives, except in cases of emergency where it is not practicable to do so.*
- *amendments to the current Western Australian template for advance health directives in order to match, as a minimum, the leading example across Australia, taking into account Finding 7 (see page 48).*
- *consider how the increasing numbers of people diagnosed with dementia can have their health care wishes, end of life planning decisions and advance health directives acknowledged and implemented once they have lost capacity.*

The JSC also recommended an immediate and extensive education program for health professionals (JSC Recommendation 2), and greater education for the wider community (JSC Recommendation 3).

#### **Joint Select Committee Recommendation 2**

*The Attorney General, in consultation with WA Health, and relevant health professional bodies, undertake an immediate and extensive program to educate health professionals about:*

- *the nature, purpose and effect of advance health directives and enduring powers of guardianship;*
- *how to identify a valid advance health directive; and*
- *how to identify the lawful substitute treatment decision-maker.*

#### **Joint Select Committee Recommendation 3**

*The Attorney General, in consultation with WA Health, provide greater education for the wider community about:*

- *advance health directives;*
- *enduring guardians; and*
- *the hierarchy of medical treatment decision-makers.*

The State Government tabled its response to the JSC's report on 27 November 2018. In response to Recommendations 1-3, the State Government announced that:

- *The Attorney General will appoint an Expert Panel (the Panel) in accordance with Recommendation 1. The Panel will be comprised of health and legal experts as well as members of the community and care sector with an interest in the operation of AHDs. The Panel will review the relevant law and health policy and practice and provide recommendations in relation to each of the matters outlined in Recommendation 1.*
- *The Panel will also make recommendations on how best to meet outstanding education needs and in doing so work to address recommendations 2 and 3.*

#### **The Expert Panel on Advance Health Directives**

The membership of the Expert Panel on Advance Health Directives (the Panel) comprised:

- Mr Simon Millman MLA, Member for Mt Lawley – Chair.
- Dr Jacquie Garton-Smith, General Practitioner.
- Ms Janet Wagland, General Manager, Brightwater Care.
- Ms Lana Glogowski, Chief Executive Officer, Palliative Care WA.
- Ms Carol Conley, Senior Assistant State Solicitor, State Solicitor's Office.
- Ms Rhonda Parker, Alzheimer's WA, Chief Executive Officer.
- Mr Nigel Haines, Consumer Advocate.
- Ms Pauline Bagdonavicius, Public Advocate.
- Dr Audrey Koay, Executive Director, Patient Safety and Clinical Quality, Department of Health, WA.

Secretariat support was provided by the Department of Justice.

## **The Panel's approach**

The Panel held a total of 10 meetings between February and June 2019. The discussions at the meetings were informed by a number of expressly invited experts from across the health sector, including representatives from the Department of Health, St John Ambulance, the Royal Australian College of General Practitioners, the Western Australian Primary Health Alliance and St John of God Hospital Group. The Chair of the Panel also held targeted consultations with stakeholders.

In line with the approach contemplated by the JSC, the Panel's deliberations were informed by an extensive cross-jurisdictional analysis prepared for the Department of Justice. Representatives from the Department of Health also provided detailed information on aspects of AHDs and current practices within the public health sector.

## **Guiding principles**

The Panel was cognisant of the work and consultation carried out by the Ministerial Expert Panel on Voluntary Assisted Dying to advise the WA Government on the development of voluntary assisted dying legislation. The following Guiding Principles articulated as part of that process informed the work of the Panel:

- Every human life has intrinsic value.
- A person's autonomy should be respected.
- People have the right to be supported in making informed decisions about their medical treatment.
- A therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and promoted.
- People should be encouraged to openly discuss death and dying and their preferences and values should be encouraged and promoted.
- People should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences.
- People are entitled to genuine choices regarding their treatment and care.
- People should be supported in their right to privacy and confidentiality regarding their choices about treatment and care preferences.
- People who may be vulnerable should be protected from coercion and abuse in relation to their medical treatment decisions.
- All people have the right to be shown respect for their culture, beliefs, values and personal characteristics.

The Panel strongly believes that all relevant stakeholders (community, medical, legal, end users) should be actively involved in implementing many of its recommendations to ensure the end result meets the needs identified in the report.

## CHAPTER 2: Community awareness and education

### **Joint Standing Committee Finding 3**

*There is widespread evidence that the community... does not understand advance care planning*

### **Joint Standing Committee Recommendation 3**

*The Attorney General, in consultation with WA Health, provide greater education for the wider community about:*

- *Advance health directives;*
- *Enduring guardians; and*
- *The hierarchy of medical treatment decision-makers.*

The JSC identified an “obvious lack of knowledge and understanding about advance care planning for end of life, particularly in relation to the legally binding instruments” and characterised existing community education initiatives as constituting an “inadequate” “patchwork approach”.

The Panel’s inquiries support the JSC’s findings. Existing community education initiatives (see information on page 17) are well received but only reach a relatively small proportion of the community. Particular gaps exist in relation to people in rural and remote areas of the State and vulnerable members of our community. Opportunities to provide information to individuals at certain critical junctures – such as the point of diagnosis with a life-limiting condition – are not being realised in a systematic way.

The reasons behind these issues are clear. First, government funding for dedicated education and training initiatives is minimal. The Office of the Public Advocate received funding to support the initial roll-out of the legal instruments, but this expired in 2013-14 and was not renewed. Palliative Care WA relies on small, short-term grants from a range of sources to deliver its community education programs. Second, there is no overarching state strategy or plan to ensure that community education is effectively coordinated and targeted.

It is apparent that an appetite exists for a more comprehensive, cohesive approach in this area. This is evidenced by the growing momentum of the WA Advance Care Planning Consortium, a joint initiative of Palliative Care WA and the Department of Health that brings together senior representatives of Government and non-Government organisations to share knowledge and coordinate activities. This existing collaboration provides a strong platform for further progress. It should also provide assurance that any new State Government investment in this area will be matched by an investment in energy and enterprise by a range of partner agencies.

What follows is a roadmap for how the State Government can effectively educate the community about the importance of planning for a future that involves serious illness and loss of capacity, and the legal instruments available to ensure that individual choices are respected.



## **Existing community education initiatives**

### Office of the Public Advocate

The Public Advocate has a statutory responsibility to promote public awareness of the human rights of adults with a decision-making disability under the provisions of the *Guardianship and Administration Act 1990* (WA), which includes community education about the guardianship and administration system, enduring powers of attorney, AHDs, enduring powers of guardianship and the treatment hierarchy for non-urgent treatment decisions.

The initial roll-out of statutory AHDs and enduring powers of guardianship was accompanied by a funding allocation of \$1 million over the four year period concluding on 30 June 2013. The Office of the Public Advocate used this funding to prepare and print a range of resources, including guides and kits for enduring powers of guardianship and enduring powers of attorney, and to deliver nearly 350 presentations across the State. The Department of Health had the lead role for the preparation and printing of AHDs.

Since the expiration of that funding, resourcing constraints have resulted in a significant reduction in awareness raising activities by the Office of the Public Advocate. Only a small portion of its resources remain in print, and the number of presentations delivered per annum has declined from a peak of 101 in the 2011/12 financial year to 22 in the 2017/18 financial year. Increased pressures in all other areas of its work continue to erode its capacity to deliver education and training sessions, despite high demand from community groups and service providers.

The Office of the Public Advocate continues to offer a suite of resources on its website and an Advisory Service via telephone, email, mail and in person. Recorded information on guardianship, administration, enduring powers of guardianship and enduring powers of attorney is also available.

### Department of Health

While the Office of the Public Advocate is mandated to – and does – raise awareness of all of the statutory instruments, in practice the Department of Health, and specifically the WA Palliative Care and Cancer Network (WAPCCN), has lead responsibility for providing education about AHDs. In the two years following the commencement of the statutory instruments, the WAPCCN worked with the Office of the Public Advocate to promote the uptake of, and compliance with, AHDs and enduring powers of guardianship.

From 2012, WAPCCN broadened its focus to advance care planning generally. Between 2015 and 2017, the WAPCCN delivered community education sessions in partnership with Palliative Care WA. Since 2017, as part of a broader reorientation of the functions of the Department of Health, the WAPCCN has reduced its role in the delivery of advance care planning education and focused instead on system management responsibilities such as policy and strategy development. In this capacity, the WAPCCN continues to fund Palliative Care WA to deliver community workshops on advance care planning and to convene the WA Advance Care Planning Consortium.

The WAPCCN hosts a suite of publications about advance care planning and the statutory instruments online, and provides these materials in hard copy on request. WAPCCN also provides an ACP advisory service for both community and health professionals, which is accessible by telephone or email. The advisory line received over 4,200 contacts in 2017, up from approximately 3,600 in 2016.

### The non-government sector

A range of non-government agencies play a role in promoting awareness of advance care planning and the statutory instruments. The most active organisation in this regard is Palliative Care WA.

Palliative Care WA's role in raising community awareness of advance care planning commenced in 2015 when the agency identified a gap in existing initiatives. Since then, Palliative Care WA has delivered 65 community presentations to a total of 2088 attendees. This has been enabled by grants from Lotterywest, the Department of Health, and the Peel Development Commission totalling \$354,000.

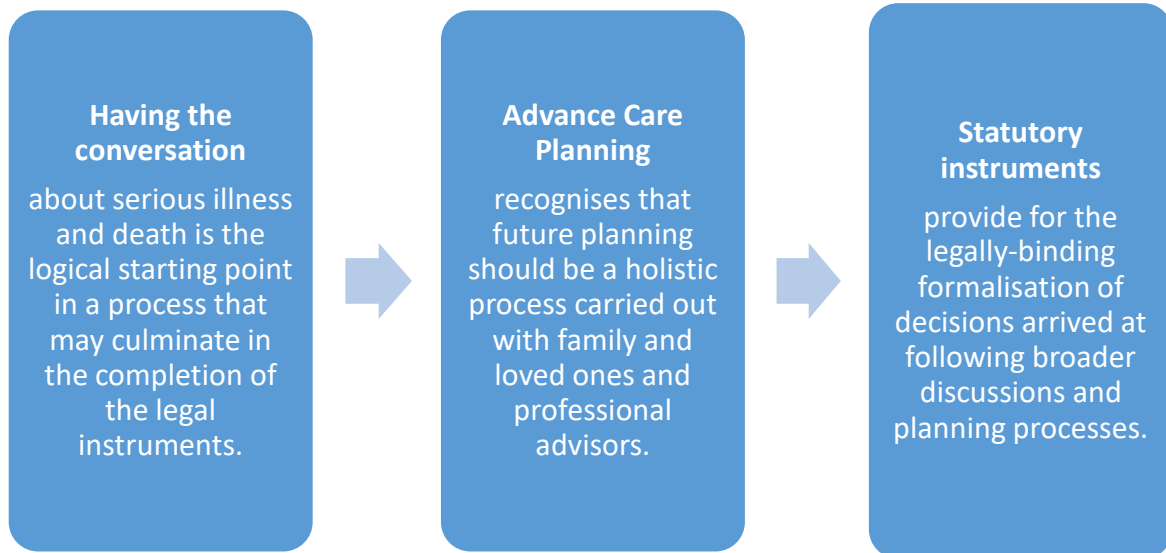
In addition to delivering presentations on advance care planning, Palliative Care WA convenes the WA Advance Care Planning Consortium bringing together over 20 government and non-government agencies with an interest in promoting advance care planning. The Consortium provides a forum for information sharing and the development of collaborative initiatives.

Alzheimer's WA is another non-government agency that actively promotes awareness about advance care planning and the statutory instruments. Information on these subjects is integrated into Alzheimer's WA's program offerings for people diagnosed with dementia and their families and carers, as well as the organisation's general public awareness activities.

Other community sector organisations that play a role in educating their clients and stakeholders about advance care planning include the Cancer Council and the Council on the Aging.

### The scope of a new approach

The JSC's recommendation calls for community education to focus on the statutory instruments and the treatment hierarchy. However, these statutory arrangements don't exist in a vacuum; they form part of the broader concept of advance care planning, which in turn is situated within a societal culture around disability, serious illness and death.



To be effective, a new approach to community awareness and education should incorporate and coordinate measures promoting each of these concepts. Such measures are likely to be mutually reinforcing:

- Measures to reduce the stigma surrounding conversations about serious illness and death address a barrier to the uptake of the statutory instruments.
- The process of advance care planning can generate decisions and desired outcomes that can be formalised via the statutory instruments.
- Understanding of the availability, nature and effect of the statutory instruments can encourage individuals to engage in planning for the future, confident in the knowledge that there are mechanisms available to ensure that their decisions will be honoured.

Of course, different aspects of the overall message should be emphasised depending on the messenger and audience. For example, initiatives of the Office of the Public Advocate will continue to reflect the Public Advocate's statutory obligation to educate the community about the statutory instruments and the treatment hierarchy. In addition, community members may wish to make a specific treatment decision because of their religious beliefs or because they

have ongoing mental health conditions which results in them having fluctuating capacity to make treatment decisions. The proposed new approach must accommodate these specific requirements.

### **Recommendation 1**

- 1.1 A new approach to community awareness and education should encompass and coordinate measures promoting:
- The concept of ‘having the conversation’ about serious illness and death;
  - Advance care planning; and
  - The statutory instruments.

### **Strategic planning**

Community education in this area involves a variety of potential audiences, messages, media and collaborators. Reaching these audiences, developing these messages, harnessing the media and engaging with these collaborators will all require a methodical approach.

To ensure that such an approach is adopted, the Government should mandate the Department of Health to lead the development and delivery of an overarching community awareness and education strategy. The Department of Health should not seek to control the agenda, but rather to encourage and integrate contributions from a broad range of government and non-government stakeholders. These should include:

- The Office of the Public Advocate;
- Relevant non-government agencies, including but not limited to Palliative Care WA, Alzheimer’s WA, the Cancer Council and the Council on the Aging;
- Representatives of the mental health, disability, aged care and legal sectors;
- Aboriginal stakeholders; and
- CALD stakeholders.

An ancillary benefit of this proposal is that a rigorous strategic process will offer assurance to Government that new investment will deliver the best possible outcomes. Consistent with Recommendation 1 above, the strategy should encompass measures promoting the concept of ‘having the conversation’; advance care planning; and the statutory instruments.

### **Recommendation 2**

- 2.1 The State Government should mandate the Department of Health to lead the development and delivery of a community awareness and education strategy.
- 2.2 The Department of Health should co-design the proposed strategy with relevant government and non-government stakeholders.

### **Who are the audiences?**

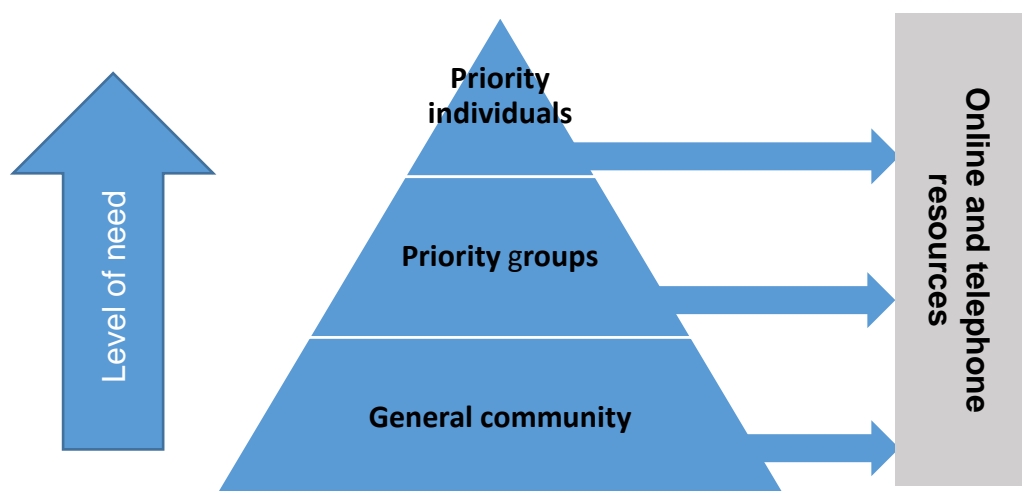
The strategy should cater for the different educational requirements of different segments of the community. Three key ‘tiers’ can be identified:

**Tier 1:** The general community.

**Tier 2:** Priority groups, notably older people and vulnerable people.

**Tier 3:** Individuals at ‘key points’; service interactions at which end of life planning assumes critical importance (such as diagnosis with a terminal illness).

In addition to measures designed to reach each of these groups, information should continue to be made available online and via telephone services.



#### Tier 1 – the general community

Awareness of end of life choices is a matter of importance for every member of our community, not just those approaching death. Even young, healthy people play a role by encouraging their parents and grandparents to consider and communicate their end of life choices.

Messaging for the general community should aim to accelerate the normalisation of conversations about the end of life. This messaging should not incorporate specific information about the legal instruments, but should provide guidance on where such information can be obtained (eg online). Community messages will also reach health professionals, complementing strategies that target these groups.

Such messages could be communicated via paid media, including social media, and through high-profile community ambassadors. It would be unrealistic to expect face-to-face presentations to reach, or even be relevant to, a high proportion of the general population.

#### Tier 2 – priority groups

The new approach should specifically target groups for whom special measures are required to ensure equity of access to relevant information and support, or for whom advance care planning has elevated importance. These groups include:

- Older people;
- Potentially vulnerable members of the community, including those with disability and those with mental health issues;
- Aboriginal people;
- People from CALD communities; and
- People in regional areas.

It is critical that messages and modalities be tailored to each of these groups. This can be achieved by involving relevant advocacy groups, peak agencies and professional bodies in the design and delivery of relevant materials. Encouragingly, many such organisations have already demonstrated a specific interest in this subject and a willingness to collaborate with other agencies.

Considerations specific to each identified target group are provided below.

- **Older people:** It is natural and desirable for people to start considering how to put their affairs in order as they approach their senior years, before the point at which loss of capacity is imminent. Relative to younger people, those entering this stage of life are more likely to engage with, and act in response to, education about end of life choices. This is supported by data showing that most attendees at Palliative Care WA's advance care planning presentations are over the age of 60.

In-person presentations, which are currently the dominant mode of community education, are likely to be particularly relevant for this cohort. This is because;

- a relatively high proportion of older people are not computer literate;
  - people who have retired from the paid workforce are more likely to have the time available to attend a presentation in person; and
  - it is relatively easy to reach older people in person via community groups – which are often searching for relevant and engaging presentations on matters of community importance – and retirement villages and other accommodation services for older people.
- **Vulnerable members of the community:** Existing community education initiatives are not well adapted to the needs of disadvantaged members of our community, including people experiencing homelessness, people with a disability and people with mental health issues. People in these groups are considered less likely to attend face-to-face presentations and access online resources. A more effective approach would be to embed relevant messages and support within the services that individuals in these groups access and, in some cases, depend upon. It follows that carers, disability service providers, mental health service providers and social service agencies should be key partners in the development and delivery of the strategy, as well as recipients of community education themselves.
  - **Aboriginal and CALD communities:** The proposed strategy should respect the reality that different cultures have different attitudes towards death. In developing the strategy, the Department of Health should work with representatives of Aboriginal and CALD communities to identify culturally appropriate messages and modes of communication. Consideration should also be given to translating and otherwise adapting hard copy and online resources to meet the diverse communication needs.
  - **Regional areas:** Existing community education initiatives are metro-centric. The Office of the Public Advocate does deliver presentations in some regional areas, but these are becoming less frequent due to resourcing limitations. Palliative Care WA's community education program is confined to the metropolitan area. The communications strategy should include measures aimed at achieving parity of access for people in regional areas. Potential measures include identifying and training 'champions' within regional communities who could play a lead role in sharing relevant information with community groups and other service providers; and making increased use of telehealth opportunities.

### Tier 3 – priority individuals

In some service interactions, end of life planning is so plainly relevant that it should be discussed as a matter of course. Key examples include:

- The period immediately following diagnosis with a life-limiting or neurodegenerative disease, and subsequent stages of change in the management of that disease;
- Older age-related health checks;
- Admission to an aged care facility; and
- Hospitalisation for a life-threatening condition.

Ideally, people who find themselves in these circumstances will have already considered and documented their end of life choices. The reality is that this will not always be the case. Embedding education at these critical service interactions will provide a 'backstop' in such circumstances.

Targeted interventions are particularly important for persons diagnosed with a neurodegenerative disease, who may have a limited window of opportunity in which to exercise decision-making capacity before this is rendered impossible by the effects of the illness.

Embedding relevant messages within particular service interactions will require 'buy-in' from relevant service providers and professional bodies. For example, a general practitioner (GP) or specialist who diagnoses a person as having dementia must be aware of:

- The need to raise the subject of advance care planning;
- How the person can obtain further information; and
- Which service providers can directly assist the person with their advance care planning requirements.

Accordingly, this proposal overlaps with the new approach to educating health professionals discussed in Chapter 3.

### Accessible resources (online and telephone)

It is essential that the community have ready access to specific information about the statutory instruments. Providing this information is a statutory function of the Public Advocate. The Office of the Public Advocate website already contains a number of easy-to-read resources, as well as the official forms themselves. The Department of Health hosts information on advance care planning and AHDs on its website. Both the Office of the Public Advocate and the Department of Health operate dedicated phone services, though the majority of the contacts to the Office of the Public Advocate's service are in relation to guardianship and administration, enduring powers of attorney and enduring powers of guardianship rather than AHDs. The development of the strategy should include consideration of whether the location and configuration of these resources is optimal, or whether there is a need for further integration.

### **Recommendation 3**

- 3.1 The proposed community awareness and education strategy should incorporate initiatives:
- Addressed to the community as a whole;
  - Specifically targeting priority groups including older people, people in regional areas, people experiencing disadvantage, Aboriginal people and people from culturally and linguistically diverse communities; and
  - Targeting individuals at 'key points', including the 75-year-old health check and at diagnosis with a life-limiting condition or neurodegenerative disease.
- 3.2 Measures targeting priority groups should be developed and delivered in close collaboration with relevant stakeholders including carers, service providers, the Office of the Public Advocate and advocacy bodies.

### **Funding**

Delivering a new approach to community education will have unavoidable resourcing implications. However, improved education is likely to deliver returns by enabling more person-centred care at the end of life and reducing the provision of unwanted health services. The development of an overarching state strategy should provide government with assurance that any further investment will be effectively targeted.

In considering this issue, Government should be mindful of the importance of providing security of funding. The need to educate the community about advance care planning is ongoing – as are the benefits that can be expected to flow from such education. Care should be taken to avoid the situation that arose in 2013-14, when the expiry of funding allocated to the Office of the Public Advocate resulted in a significant reduction in relevant activity.

Continuity of funding is especially important for non-government agencies. To date, Palliative Care WA's community education initiatives have relied on four distinct short-term grants from three separate sources, each with specific requirements and reporting obligations. This uncertain funding environment helps to account for the 'patchwork approach' to community education identified by the JSC.

The State Government is not the only funding body with a vital interest in promoting community capacity around advance care planning. With its responsibilities in relation to aged care and primary health, the Commonwealth should be regarded as a potential partner in the delivery of relevant initiatives. Opportunities to leverage private sector investment, including through the insurance industry, should also be examined.

### **Recommendation 4**

- 4.1 The proposed community awareness and education strategy should be:
- Supported by ongoing dedicated funding, to be sought and allocated in line with standard Government budgetary processes; and
  - Designed to leverage other resourcing opportunities, including those associated with the Commonwealth and the private sector.

## CHAPTER 3: Education for health professionals

### **Joint Select Committee Finding 3**

*There is widespread evidence that the community and health professionals do not understand advance care planning, particularly the legally binding instruments.*

### **Joint Select Committee Recommendation 2**

*The Attorney General, in consultation with WA Health, and relevant health professional bodies, undertake an immediate and extensive program to educate health professionals about:*

- *the nature, purpose and effect of advance health directives and enduring powers of guardianship;*
- *how to identify a valid advance health directive; and*
- *how to identify the lawful substitute treatment decision maker.*

Health professionals play a critical and multi-faceted role in the advance care planning process.

First, health professionals are at the front-line of community awareness raising. This means identifying patients for whom the conversation is needed, initiating the discussion about advance care planning with patients – particularly at key points such as diagnosis with, or a change in the course of, a life-limiting illness.

Second, health professionals support patients through the advance care planning process itself. This includes explaining the nature and effect of the statutory instruments, helping to ensure that treatment decisions in AHDs are expressed in a way that is comprehensible to treating health professionals, and recommending measures to ensure that relevant documentation can be accessed when required.

Finally, health professionals, and medical practitioners in particular, are directly responsible for applying the treatment hierarchy and giving effect to decisions documented in the statutory instruments.

The JSC identified a general lack of understanding of advance care planning among health professionals and, in some quarters, a possible reticence around promoting and applying the statutory instruments.

The JSC's recommendations imply, and the Panel's enquiries confirm, that this state of affairs is not solely a matter of inadequate education, but also influenced by a range of structural and service design factors that are beyond the control of individual health professionals.

Some of these broader issues are the subject of recommendations contained in the JSC's report, elsewhere in this report or both. For example:

- The issue of timely access to AHDs is addressed in the recommendations relating to the creation of an electronic register.
- Issues regarding the capacity of health professionals to interpret and apply decisions contained in AHDs are addressed through the proposed changes to the AHD template and the creation of a manual vetting system linked to the establishment of an electronic register.



- Barriers associated with the lack of clinical time are the subject of Recommendation 5 of the JSC report, which calls on the Minister for Health to recommend to the Council of Australian Governments amendment to the Medicare rebate schedule to include preparation of AHDs with GPs. In addition, adding descriptors to older-age checks to ensure that the need for advance care planning and/or AHDs are explored could further assist uptake.

Service design and policy can also play a role. For example, the Panel heard that:

- Sub-optimal discharge communication and clinical handover between acute and aged care services can result in the outcomes of advance care planning processes being lost or duplicated;
- The lack of an employment relationship between private hospitals and the medical practitioners that work within them can complicate the widespread adoption of relevant policies and processes; and
- A lack of clear role responsibilities – and associated accountability – within health services can impede the uptake of advance care planning.

The remedies to these service design issues are primarily within the purview of the services involved. Nevertheless, as the overall system administrator, the Department of Health has a role to play in encouraging health services to adopt policies, processes, role definitions and organisational structures that give due prominence to advance care planning.

#### **Finding 1**

The ability of health professionals to support advance care planning and apply the treatment hierarchy is influenced by a number of structural factors that are not primarily related to education, but are addressed in the recommendations of the Joint Standing Committee's report, elsewhere in this report or both.

Health services can support individual health professionals to discharge their responsibilities in relation to advance care planning, including adherence to decisions documented in the statutory instruments, by examining relevant processes and policies, particularly in relation to clinical handover and discharge communication.

#### **Education for health professionals – the current situation**

A number of education and training opportunities are already available for health professionals. Overarching responsibility in this area lies with the Department of Health. Since the introduction of the legal instruments in 2010, the Department of Health's education campaign for health professionals has included the provision of AHD/advance care planning education sessions for:

- Regional and metropolitan public and private health service providers and GPs;
- Medicare Locals/Primary Health Networks;
- Mental health sector;
- Corrective services;
- Aged care services;
- Disability services; and
- Tertiary and higher education providers.

Materials available to health professions include an e-learning website, a step by step guide to advance care planning for staff working with patients with chronic conditions and a guide to the use of the statutory AHD template.

The Department of Health also operates an advance care planning information line for health professionals (and health consumers), and is in the process of developing an advance care planning policy for internal use. Many public hospitals have implemented 'Goals of Patient Care', although these processes do not currently engage the patient's GP.

In addition to the activities of the Department of Health, various academic curricula touch on medico-legal issues around the end of life, albeit in a limited way. Peak bodies such as the Royal Australian College of General Practitioners and the Western Australian Primary Health Alliance make training available as part of professional development and capacity building initiatives. Major private sector health services – such as St John of God Hospitals – have internal policies and protocols in place for promoting and implementing end of life decision-making. Palliative Care WA offers training to health professionals as part of its broader community education program.

In spite of these endeavours, it is clear that there is scope for further improvement. The reasons for this are varied and include:

- Self-selection, whereby educational opportunities tend to be accessed by those health professionals who already have an interest in, and some knowledge of, this area of practice.
- A perception that some existing educational opportunities are excessively legalistic or otherwise ill-adapted to clinical realities.
- Possible gaps in training for health professionals who graduated prior to the commencement of the relevant legislation.
- Uncertainty as to the role of certain health professionals, such as those working in allied health, in advance care planning.
- Insufficient emphasis on the clinical techniques involved in initiating and guiding the advance care planning process.
- The sheer volume of educational subjects and materials that are available for health professionals.

### **A new approach to the education of health professionals**

To a significant extent, the general approach to community education set out in the preceding chapter is also applicable to clinical education. In particular, a new approach should:

- Be led by the Department of Health;
- Involve systematic mapping of needs and opportunities;
- Be developed and delivered in close collaboration with relevant stakeholders;
- Adopt modalities and messages that are tailored to the needs of target audiences; and
- Be supported by dedicated funding from Government.

Community education without a parallel effort to engage with and educate health professionals could lead to motivated and informed individuals seeking support from poorly informed health professionals, who may discourage use of AHDs. The question of whether clinical education should be an element of the broader community education strategy recommended in the preceding chapter is an implementation matter for the Department of Health. What is important is that the new approach recognises the particular importance and educational requirements of health professionals – and is resourced accordingly.

Whatever implementation model is adopted, it is critically important that education *for* health professionals is designed and delivered in partnership *with* health professionals. Resources that are not attuned to clinical realities are likely to be ineffective. This insight applies to both the substance content of education, and the modes used to deliver it; for example, the Panel heard that education for GPs may be better attended if delivered on-site at GP clinics.

Where possible, the new approach should avoid adding an extra layer of educational resources to what already exists. However, it is noted that if the State Government makes changes to the AHD template (Chapter 4) and/or implements an AHD register (Chapter 5), then existing education resources, including those produced by the Office of the Public Advocate and the Department of Health, will require significant updating.

The Panel heard that there is no shortage of material available for health professionals; the key issues lie in coordination, targeting and accessibility. These issues can be addressed by:

- Further embedding information about advance care planning, including the legal instruments, within academic curricula (including medical, paramedic, nursing and allied health).
- Partnering with professional bodies (including but not limited to the Royal Australian College of General Practitioners) to ensure that relevant training is available through existing professional development channels.
- Partnering with the WA Primary Health Alliance with a view to aligning substantive messages, avoiding gaps and duplication, and embedding relevant messages within existing capacity building initiatives.
- Encouraging health services to integrate advance care planning processes with related processes that currently exist, such as expanding the 'Goals of Patient Care' to explicitly encourage conversations about advance care planning and AHDs during and/or after discharge, provide information to patients and to communicate the recommendations to the patient's GP.

#### **Recommendation 5**

- 5.1 The State Government should mandate the Department of Health to lead the development and delivery of a strategy for educating health professionals about advance care planning, the treatment hierarchy and the statutory instruments.
- 5.2 The Department of Health should develop and deliver the strategy in partnership with relevant stakeholders including professional bodies, tertiary institutions, aged care providers and Commonwealth agencies.
- 5.3 The strategy should focus on opportunities to embed consistent information within existing education and training systems including academic curricula and professional development processes.
- 5.4 The State Government should provide funding to support the development and delivery of the strategy.

#### **Target audiences**

The new approach should reflect the diverse roles and educational needs that exist under the broad umbrella of 'health professional' and extend to other relevant service providers not captured under the traditional health professional definition. For example, ambulance services are often called upon to access and apply AHDs, but do not play a role in assisting in the preparation of advance care planning documents. Conversely, community health services play a critical role in encouraging their clients to consider advance care planning, but are not responsible for implementing treatment decisions in acute clinical settings. Other health professionals, such as GPs, have both 'front-end' and 'back-end' responsibilities.

A long-list of target groups would include:

- GPs (including locum medical services and after hours GP services).
- Nurse Practitioners.

- Community Based Specialist Medical Practitioners.
- Practice Nurses.
- Allied Health Professionals.
- Pharmacists.
- Aboriginal Health Workers.
- Paramedics and retrieval services (for example, St John's Ambulance and Royal Flying Doctor Services).
- Other care providers (for example, Aged Care Facilities, Silver Chain and others).
- Acute Sector Health Professionals both in the public and private sector, recognising that public and private sectors may need different strategies due to employment arrangements/contract agreements. This will include (but is not limited to):
  - Specialists and Specialist Medical Practitioners.
  - Junior Medical Officers.
  - Nurses.
  - Allied Health Professionals.

Priority groups in the first tranche should include GPs, acute sector health professionals and health professionals working with people with life-limiting conditions or neurodegenerative diseases including dementia and/or in aged care.

It is important that professionals working in residential and community-based aged care services are included in initiatives aimed at educating health professionals. There is potential in community aged care, and on admission to residential care, to provide individuals who are ageing with the opportunity to express their care wishes, both informally through advance care planning, and then more formally, where they have capacity, through the completion of an AHD. Interface with aged care providers can also offer opportunity for the provider to raise the advantages of appointing a key substitute decision maker through an enduring power of guardianship.

This diversity of educational requirements points to the feasibility of a 'module' based approach, whereby information packages can be 'mixed and matched' depending on the needs of each audience. Such packages could combine generic modules on key concepts (such as the importance of having the conversation and the legal effect of the treatment hierarchy) with modules addressing the specific information requirements of certain classes of health professional (eg ambulance officers).

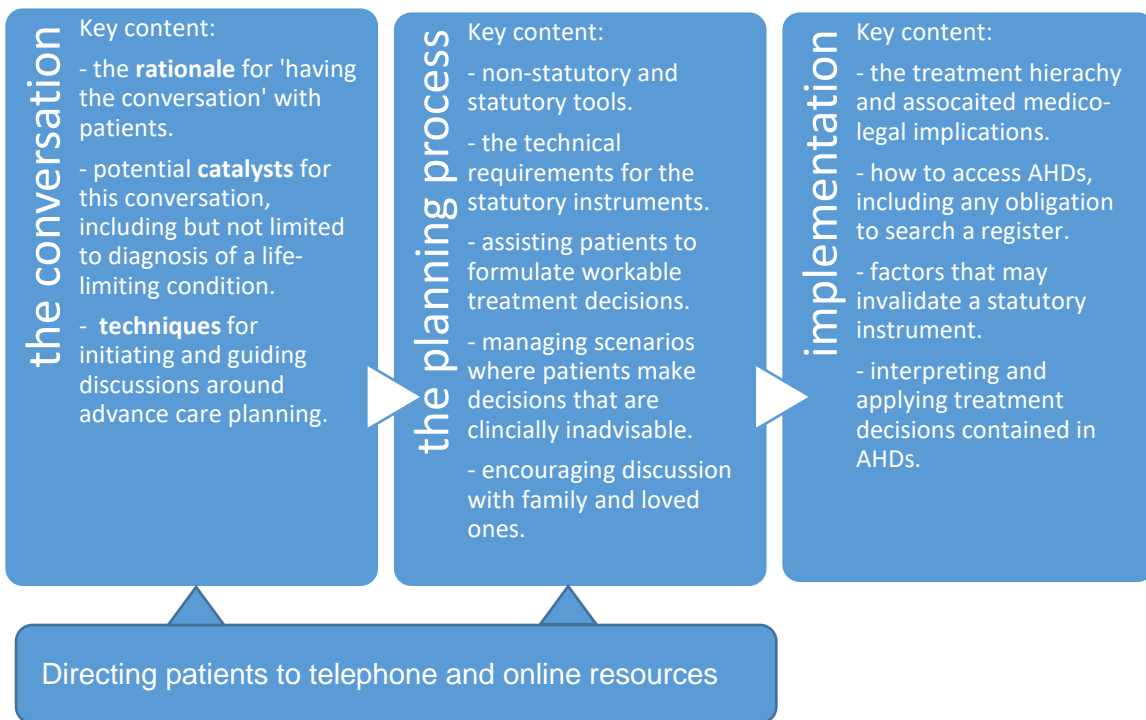
### **Recommendation 6**

6.1 Education for health professionals should:

- Recognise the diversity of roles and educational requirements that exist under the broad umbrella of 'health professionals' and other relevant service providers; and
- Give initial priority to general practitioners, acute sector health professionals and health professionals working with people with life-limiting conditions or neurodegenerative diseases including dementia and/or in aged care.

### **Structuring the content**

It has already been recommended that the content of educational initiatives be developed in collaboration with relevant clinical stakeholders. To give structure to this process, it is suggested that messages be developed across three distinct stages of the advance care planning process: the initial discussion; the planning process (including supporting patients to complete relevant instruments); and implementation.



### Recommendation 7

7.1 The proposed education strategy for health professionals should consider educational needs across the following stages of the advance care planning process:

- Initiating discussion about advance care planning;
- Assisting patients to make advance care plans, including the statutory instruments; and
- Applying the treatment hierarchy and implementing decisions documented in statutory instruments.

## CHAPTER 4: The advance health directive template

In Western Australia, if an individual chooses to make a statutory AHD, it must be in the form, or substantially in the form, prescribed in the Guardianship and Administration Regulations 2005, and the signature of the maker must be witnessed and signed. The form expressly encourages, but does not require, the maker to seek legal and medical advice.

The JSC made the following finding and recommendation in relation to the current template.

### **Joint Select Committee Finding 7**

*The current template suffers from a lack of guidance for people completing it. In other jurisdictions, examples are provided. Some of these medical conditions and treatments include but are not limited to:*

- *dialysis, antibiotics to treat infections (such as pneumonia and UTIs); blood transfusions; chemotherapy; radiation therapy; intensive care; intubation; invasive and non-invasive ventilator support; the activation (and de-activation) of electronic device implantation for heart failure; transplantation; nasogastric or PEG feeding; CPR and lifesaving surgery; receiving pain relieving medication which may also have significant sedating effects and receiving only comfort care.*

### **Joint Select Committee Recommendation 1**

*That the Expert Panel make recommendations for: amendments to the current Western Australian template for advance health directives in order to match, as a minimum, the leading example across Australia, taking into account Finding 7.*

In line with the approach proposed by the JSC in Recommendation 1, the Panel undertook an extensive cross-jurisdictional analysis of templates used in other Australian jurisdictions. This process led to the identification of the following potential enhancements to the Western Australian template:

- Making provision for non-binding values statements;
- Enabling common treatment decisions to be expressed via ‘tick-boxes’;
- Presenting the form in a more user-friendly manner;
- Combining different forms;
- Digitisation; and
- Requiring medical certification.

These options are discussed in more detail below.

### **Non-binding value statements**

The existing Western Australian AHD template records treatment decisions that would apply under identified circumstances. The template does not provide any opportunity for a person to record information about their underlying values and preferences, or what would be important considerations for the person in making treatment decisions.

A values section is currently included in the Tasmanian, Victorian, South Australian, Northern Territory, New South Wales and Queensland forms. In Victoria, ‘values directives’ have a statutory basis and are clearly distinguished from binding ‘instructional directives’ on the form. The NSW form provides for values to be expressed via both ‘tick-boxes’ and free text.

Including a values statement in the AHD template would offer three key benefits:

1. It would aid the development of AHDs by prompting the person to consider their underlying values;
2. It may assist health professionals to make appropriate treatment decisions in urgent treatment scenarios not covered by the AHD; and
3. It would assist guardians and substitute decision makers to make appropriate treatment decisions in non-urgent scenarios not covered by the AHD.

Care would need to be taken to ensure that making provision for values statements does not diminish the status, or influence the interpretation, of AHDs. In the interests of certainty, AHDs must remain at the pinnacle of the treatment hierarchy and continue to be interpreted and implemented without reference to extrinsic materials such as values statements.

The flowchart on page 32 demonstrates how a non-binding values statement would operate alongside AHDs.

### **Recommendation 8**

- 8.1 The new advance health directive template should provide for the inclusion of a non-binding values statement.
- 8.2 Consideration should be given to enabling values to be expressed via a combination of tick-boxes and free text.
- 8.3 The new template should clearly distinguish the non-binding values statement from the binding treatment decisions.

### **Tick-boxes**

The JSC found that the Western Australian template suffers from a lack of guidance for people completing it, and noted that other jurisdictions enable common treatment decisions to be made via a tick-box approach.

The Western Australian template merely invites the person completing the form to 'consent/refuse consent to the following treatment' in 'the following circumstances'. It is left to the person, with the assistance of any support person such as a GP, to decide how to define these treatments and the circumstances.

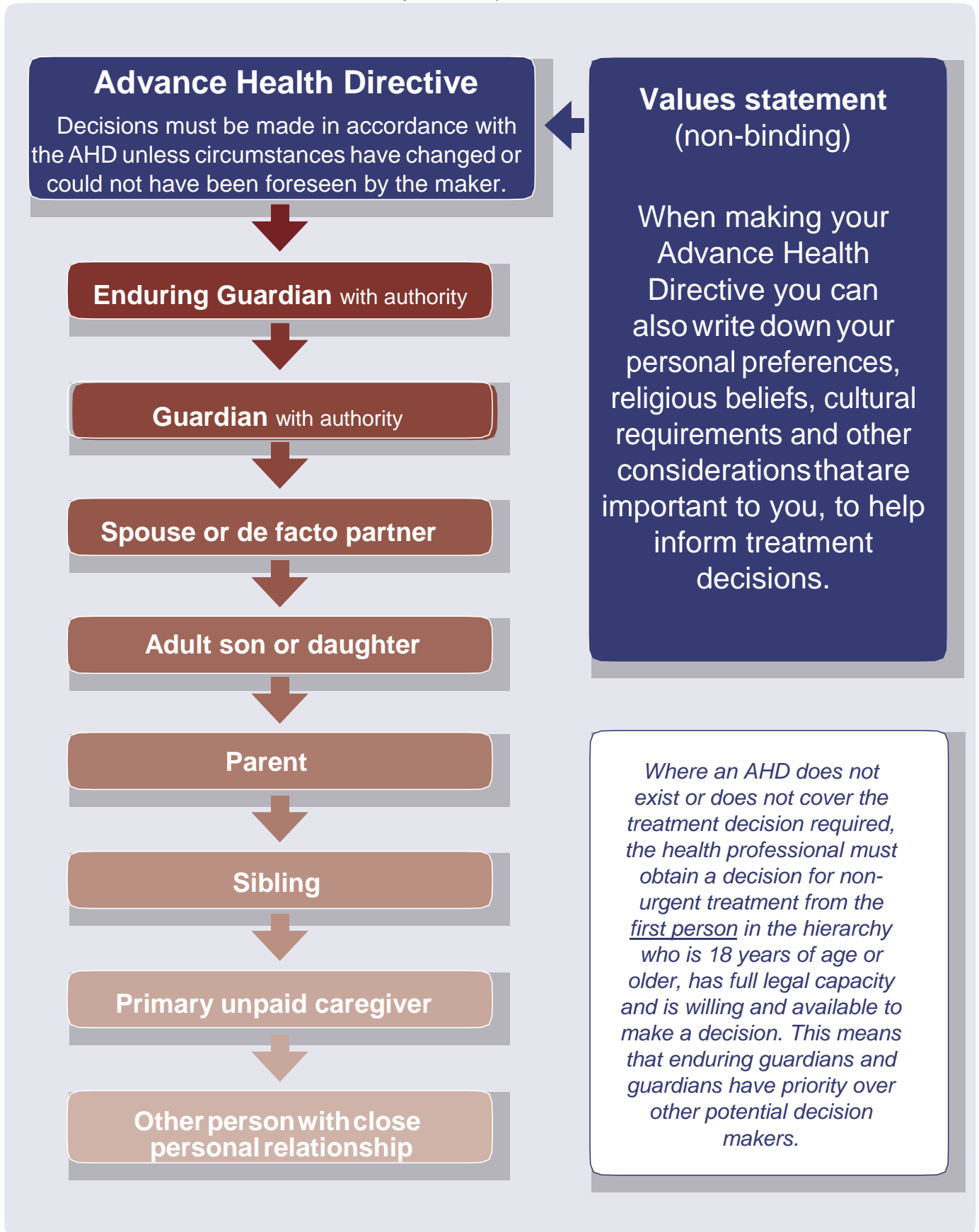
The Queensland template offers an illuminating contrast. The template has two pages of 'tick boxes' that can be used to give directions that will apply when a person is in the following conditions:

- Terminal, incurable or irreversible illness or condition;
- A persistent vegetative state;
- Permanently unconscious; or
- So seriously ill or injured that they are unlikely to recover to the extent that they can survive without the continued use of life-sustaining measures.

For each condition, a person can then identify if they do or do not want treatment such as assisted ventilation, artificial nutrition, cardiopulmonary resuscitation and antibiotics.

## Hierarchy of treatment decision-makers

To be read in conjunction with ss.110ZD and 110ZJ of the Guardianship and Administration Act 1990. Note, in the flowchart below, an AHD may be in the prescribed form, or a common law directive.





Including tick-boxes in the Western Australian template would offer significant advantages, both for people making AHDs and the health professionals responsible for implementing them, namely:

- It would relieve people of the burden of identifying which treatment may be relevant, and describing these treatments in a way that is understood by clinicians. This is particularly important for people with limited literacy, among whom, in the Panel's experience, uptake of AHDs is particularly low.
- It would encourage the person to think about how they would like to be treated in various common scenarios that may otherwise be overlooked.
- For health professionals, it would help to ensure that common treatment decisions are conveyed in terms that are easy to understand and apply. This is particularly important in view of feedback from clinical services indicating that difficulties in interpreting treatment decisions is a barrier to compliance.

It is not suggested that the 'tick-box' approach should replace the ability to express treatment decisions via free-text. AHDs can be used for any treatment decision, not just the common decisions that would be addressed via the tick-box approach. The template should make clear that the person completing the template may complete the tick box section, the free text section or both.

A potential downside of including tick-boxes is that the greater ease of completion may lead to people making certain treatment decisions without fully considering or understanding the implications. This risk can be mitigated by expressing the treatment decisions with a minimum of jargon and by continuing to encourage persons completing the template to consult a medical practitioner. A further potential drawback is that a static list of conditions and treatments would be unresponsive to medical advances. This risk can be mitigated by periodic expert review of the template.

#### **Recommendation 9**

- 9.1 The new template should enable individuals to make certain common treatment decisions via a tick-box approach.
- 9.2 The conditions presented in this manner should be identified in consultation with relevant health professionals including emergency doctors, general practitioners, paramedics and geriatricians.
- 9.3 The new template should make it clear that the maker needn't complete both the tick-boxes and the free-text section unless they wish to do so.
- 9.4 The specific treatments listed in this part of the new template should be presented in language that is understood readily by health professionals yet minimises medical jargon.

#### **A user-friendly approach**

All jurisdictions provide explanatory guidance to assist individuals to complete the form in accordance with the legal requirements and in a way that clearly reflects their intent. This explanatory guidance is provided in different ways.

- Victoria and South Australia have published separate guides that are cross-referenced in the form itself. In both cases, the form contains boxes on the left margin of the page directing the maker to refer to specific sections of the instructions (Victoria) or guide (South Australia).

- The New South Wales, Western Australian and Queensland forms are published as part of booklets also containing statements, FAQs and glossaries that explain the purpose and legal standing of the instrument. Among other things, this information contextualises the instrument within the broader concept of advance care planning.
- The Queensland, Victoria, New South Wales and Northern Territory forms – and the Victorian Instructions and South Australian Guide – include examples of the sorts of statements that can be included in each part of the form. The South Australian Guide includes an example of a completed handwritten form.
- All of the forms (including the Western Australian form) contain technical notes aimed at assisting the maker to complete the form correctly.

The information booklet within which the Western Australian template is published is a strength of the current approach and should be retained (with updated content). Consideration should be given to updating the booklet to include a complete handwritten sample similar to that contained in the South Australian booklet.

Similarly, the Western Australian template should continue to include technical notes to assist the person completing the form to do so correctly. Consideration should be given to moving the explanatory notes to the left margin so as to directly align with the relevant part of the form.

Practical limitations of the current template should be remedied by

- Enabling the person completing the form to consent to some treatments and refuse others in the same treatment decision (noting that the current form requires the person to *either* refuse *or* consent to the specified treatment in the specified circumstances); and
- Providing space for additional treatment decisions beyond the two currently provided for or, at a minimum, providing clear guidance as to how further decisions can be appended to the AHD.

It is imperative that the new form be designed with the end-user in mind. To this end, a draft of the new form should be 'road-tested' with members of target groups before being finalised. In addition, the new template should be prepared in line with relevant accessibility standards.

### **Recommendation 10**

10.1 The new template should continue to be published as part of a booklet containing information about the purpose and nature of advance health directives and advance care planning generally.

10.2 The content of the booklet should be updated to:

- Reflect changes to the template and any other reforms arising from the present report or other processes; and
- Include a complete hand-written sample, similar to that contained in the South Australian booklet.

10.3 The new template should continue to include technical notes to assist the maker to complete the form correctly, but with the notes placed on the left margin to correspond with the relevant part of the form.

10.4 The new template should:

- Be presented in plain English and have an inviting visual style;
- Accord with relevant accessibility standards; and
- Provide adequate space for treatment decisions, or at least make clear that further content may be attached.

### **Combining different forms**

Some jurisdictions provide a single form bringing together AHDs, enduring powers of guardianship and enduring powers of attorney. In Western Australia, each of these instruments is the subject of a separate form.

Combining the forms could better reflect the holistic nature of advance care planning and, arguably, promote ease of access. However, these potential benefits are outweighed by the following drawbacks:

- Complexity would arise where a person has sufficient decision-making capacity to make one instrument but not another (for example where the person has the capacity to make an enduring power of guardianship but not an AHD);
- The development of a national register for enduring powers of attorney would be further complicated by the combining of these instruments with AHDs and enduring powers of guardianship;
- There is a risk that people will think they need to complete both or all forms, whereas practically they may only need to complete one;
- The size and complexity of a combined form may be daunting; and
- The forms are published by different government agencies.

### **Recommendation 11**

11.1 The advance health directive, enduring power of guardianship and enduring power of attorney templates should remain separate.

## Digitisation

At present, AHDs can be drafted electronically but must be signed and witnessed in hard copy. Enabling the entire process to be completed electronically – and potentially via a mobile phone application – may encourage uptake by eliminating inconvenient printing requirements.

Any such development should be subject to the following conditions:

1. Individuals should retain the option of completing the template in hard copy (this is particularly important for some older people); and
2. The integrity of existing witnessing requirements must be preserved in full.

The question of digitisation is inextricably linked with the development and design of a register of AHDs, which is discussed in the following chapter.

### Recommendation 12

- 12.1 The new advance health directive template should be able to be completed electronically and then printed, with signatures to be completed in hard copy.
- 12.2 An electronic register of advance health directives should aim to eventually support the making and witnessing of advance health directives electronically.

## Medical advice or certification

The Western Australian template expressly encourages the person making the AHD to seek medical advice before documenting their treatment decisions. This is not mandatory; an AHD will still be valid even if there has been no medical involvement.

This contrasts with the position in some other jurisdictions. For example:

- In Victoria, one of the two witnesses to an AHD must be a registered medical practitioner. Among other requirements, the witness must certify that, at the time of signing, the person appeared to have decision-making capacity and to understand the nature and effect of each statement in their directive.
- In Queensland, an AHD is only valid if a medical practitioner certifies that the person making the directive is not suffering from any condition that would affect the person's capacity, and understands the nature and likely effect of the health care decisions in the document.

Mandating the involvement of a medical practitioner would offer benefits by:

- Increasing the likelihood that treatment decisions are framed in a manner that is implementable;
- Ensuring treatment decisions are made in view of medical advice;
- Providing assurance that the person completing the AHD has the necessary decision-making capacity; and
- Giving medical practitioners greater confidence in implementing AHDs.

However, these benefits would come with significant drawbacks. The potential cost and inconvenience of visiting a GP could deter some people from making an AHD. This is particularly true of people who are economically disadvantaged and those who live in rural areas. In addition, medical practitioners may feel conflicted in witnessing or certifying treatment decisions they consider to be clinically inappropriate or that are made by persons

with whom they don't have a pre-existing clinical relationship. This could create a further barrier to the completion of AHDs.

The Panel ultimately concluded that the existing position in Western Australia, in which the involvement of a medical practitioner is actively encouraged but not mandated, offers the optimal balance between these competing considerations. The recommendations of Chapter 3 dealing with education and training for health professionals are intended to help increase the proportion of AHDs that are made with the benefit of medical advice.

**Recommendation 13**

13.1 The advance health directive template should continue to encourage, but not require, the person completing the form to seek medical advice.

## CHAPTER 5: Register of advance health directives

### Joint Select Committee Finding 8

*Lawful advance health directives are not stored centrally and are not readily accessible to health professionals when required.*

### Joint Select Committee Recommendation 1

*That the Expert Panel provide recommendations in relation to:*

- *The establishment of a purpose-built central electronic register for advance health directives that is accessible by health professionals 24 hours per day and a mechanism for reporting to Parliament annually the number of advance health directives in Western Australia.*
- *A requirement that health professionals must search the register for a patient's advance health directives, except in cases of emergency where it is not practicable to do so.*

The JSC's finding and resulting recommendation were made in response to evidence from individuals and health care providers expressing support for the creation of a register. The JSC identified several issues that would need to be considered in the development of a register, including whether registration should be compulsory.

Amendments to the *Guardianship and Administration Act 1990* (WA) providing for a register of AHDs were included in sections 11 and 12 of the *Acts Amendment (Consent to Medical Treatment) Act 2008* (WA) but have not been proclaimed. Specifically: section 110RA provides that an AHD may be registered in the register; section 110ZAA provides for the establishment and maintenance of a register; section 110ZAB outlines the details and applicable penalties relating to the disclosure of information on the register; and section 110ZAC makes provision for regulations to facilitate a national register.

Queensland is the only Australian jurisdiction that operates a register akin to that contemplated by the JSC. The Northern Territory Office of the Public Trustee offers a registration service, but this does not provide 24/7 electronic access for health professionals.

### The Queensland model

The Queensland register is a state-wide electronic storage system that can be accessed 24/7 by public hospitals, ambulance services and GPs who have registered for access. The register was established in 2018 with a dedicated budget of \$4 million over four years and is administered by the Office of Advance Care Planning, South Metropolitan Health Service. The Queensland register provides a statewide, standardised clinical approach which receives, reviews and uploads advance care planning documents

The register contains both advance directives (binding) and values statements (non-binding). Most of the instruments uploaded to date are non-binding values statements. Instruments submitted for registration are reviewed by a clinician before being uploaded to ensure that the formal requirements have been met. In approximately 30% of cases, the vetting process leads to the individual being contacted to remedy or clarify identified issues.

The register has been positively received, with uptake growing at a rapid rate. There are approximately 20,000 instruments registered at present.

## **Is a dedicated register needed?**

The Panel is of the view that a dedicated electronic register is the only viable means of ensuring that AHDs are accessible to the people who need them, when they need them. In reaching this view, the Panel considered whether equivalent outcomes could be achieved with greater efficiency through operational changes within health services or the utilisation of an existing online platform.

### Existing systems in the Department of Health

There are multiple local examples of health services implementing measures to make AHDs more accessible. Most significantly, the Department of Health has amended its electronic patient administration system to notify hospital staff of the existence and location of an AHD. This will soon be supported by an overarching advance care planning policy aimed at ensuring a consistent approach across the Department of Health. At a more localised level, storage and retrieval processes introduced by health services in Albany are understood to have contributed to increased uptake and implementation of AHDs in that community.

While such measures represent a significant advance on previous practice, they are not an adequate substitute for a register. The clinical alerts that have been created operate only within the public health system, and only in circumstances where a patient has previously provided the AHD to a public health service. Moreover, AHDs are not immediately accessible in digital form; they are stored in a patient's medical record and must be manually retrieved. Bespoke processes such as those established in Albany are not well suited to metropolitan Perth, where patients can move between a broader range of health services. They are also of little utility where a patient receives treatment in a locality that is not their usual place of residence.

The Queensland register leverages a pre-existing Queensland Health IT system that enables patient health records to be shared within the public health system and viewer functionality allowing access to multiple Queensland Health systems by registered private providers. Western Australia does not have an equivalent system and there are no plans to introduce such a system in the foreseeable future. It follows that any Western Australian register will need to be constructed 'from the ground up'.

### **Finding 2**

Recent reforms implemented by WA Health have improved the existing situation, but are not an adequate substitute for a dedicated register.

### My Health Record

The Commonwealth My Health Record system provides a potential alternative to the creation of a dedicated State-based register. My Health Record is a national platform that enables health information to be viewed online from any location on a 24/7 basis. Established in 2012 as an opt-in service, it has operated on an opt-out basis since July 2018. Approximately 10% of Australians have opted-out to date.

The Commonwealth Government promotes My Health Record as a platform for storing and providing access to advance care plans. Individuals can upload their advance planning instruments (including AHDs) or the details of whom to contact in order to obtain these instruments. My Health Record is a platform for viewing and storing a range of medical information and is not a register.

There have been no formal plans to transition My Health Record to a health register and, as it stands, the platform does not offer enough functionality to operate as a register. The 10% opt-out rate from the system is of concern and presents issues with accessibility and availability of information.

My Health Record operates under strict access rules, so only authorised individuals from registered healthcare providers who are involved in a person's care are allowed to access My Health Records. Consequently, its use as a register is limited, as many organisations who, on a practical level, would benefit from access (for example, workers in aged care facilities) are not authorised to see an individual's health information.

Nominated representatives may be given either 'read only' or 'full access' to a person's My Health Record, however, this access is limited to individuals only. Privacy concerns mean establishing secure access can be quite onerous and also prevents such access from being granted to a 'body' (such as the Office of the Public Advocate) as it is limited to individual access only.

### **Finding 3**

There is no existing online platform, nationally or in Western Australia, that could effectively serve as a register of advance health directives.

### **Recommendation 14**

14.1 The State Government should establish and maintain a register for advance health directives and provide funding for this purpose.

## **Principles for a register**

In line with the model contemplated by the JSC, the register should be accessible by health professionals 24 hours per day and facilitate annual reporting to Parliament of the number of AHDs in Western Australia.

The creation of a register raises a number of policy questions, including:

- What functionality should the register offer?
- Who should have access to the register?
- Should AHDs be vetted before being uploaded to the register?
- Should registration be compulsory?
- Which types of instruments should be included?
- How should common law directives be accommodated?
- How can a register accommodate the revocation or variation of an AHD?
- Should health professionals have an obligation to search the register?
- Ability to indicate AHDs, or treatment decisions within an AHD, that are subject to proceedings before, or a decision of, the State Administrative Tribunal.



In considering these issues, the Panel identified and applied the following basic principles:

1. Individuals should have control over, and be accountable for, their own personal information;
2. Individuals should be able to use the register knowing that their AHD, where valid, can and will be accessed and applied in accordance with the law;
3. Health professionals should have the legal and clinical authority to treat the register as the 'source of truth' for AHDs in Western Australia; and
4. Health professionals, health services and relevant others must have the ability to access the register when needed.

#### The functionality of a register

A fundamental question about the design of a standalone register is, what functions should it perform? There are two main models that could be considered.

Under the first, the register would function solely as a repository of AHDs. Individuals would make an AHD independently of the register, and then upload the completed document, most likely in PDF form, to make it available to authorised persons.

An alternative model would see the register serve as an enabler of the entire AHD work flow. Under this more comprehensive approach, the 'register' would actually be a 'one-stop-shop' that would guide the individual through the process of considering, making and sharing an AHD. This type of functionality is demonstrated by the Victorian 'My Values' website

#### **The Victorian 'MyValues' website**

The Victorian 'MyValues' website is an example of how an online register can facilitate advance care planning. Funded by the Victorian Department of Health, MyValues invites users to interact with a set of specially constructed statements which help to identify personal wishes about medical treatment and intervention in the later stages of life.

MyValues is a form of advance care planning and supplements any other advance care plans that may be available (such as instruction relating to specific treatments that may be rejected or requested). While MyValues provides significant information that should be taken into account in medical treatment, medical practitioners are not legally bound to act in accordance with a patient's MyValues Report.

The first model (simple database) is a minimalist approach that would do little to alter the way that AHDs are made. This would avoid complications around online witnessing and verification processes, and better cater for people who prefer to work on paper rather than online. In addition, a simple database would be relatively quick and inexpensive to design.

The second model has greater transformative potential. A register that functions as a 'one-stop-shop' would likely become a centrepiece in any new community education strategy (see Chapter 2). This potential brings with it the risk of increased cost and complexity. In addition, the benefits would not extend to those who prefer to work on paper.

## **Recommendation 15**

15.1 The functionality of the register should be determined with reference to a cost-benefit analysis comparing, at a minimum, the following models:

- A register that operates as a simple repository of PDFs.
- An online 'one-stop-shop' that guides the person through the entire process of considering, planning, making, witnessing and sharing an advance health directive.

### Source of truth

As noted above, one of the fundamental principles in establishing a register is that health professionals and health services must treat the register as the 'source of truth' for AHDs in Western Australia.

AHDs stored on the register will be presumed to be the most current document, and consequently, the register must support a simple means by which AHDs can be amended, revoked and replaced as required. Recognising that people can have more than one AHD, the register must have the ability to store multiple entries, and to archive superseded documents.

In addition, there must be the capacity to flag entries on the register to indicate where an AHD, or a specific treatment decision within an AHD, is the subject of proceedings in the State Administrative Tribunal or has been declared to be invalid by the Tribunal.

### Access to a register

The purpose of establishing a register is to ensure that AHDs are accessible to those who need it, when they need it. The need for accessibility must be balanced with the need to respect the personal nature of the material contained in AHDs.

As previously noted, the Queensland register can be accessed by authorised hospital services, ambulance services and those GPs who register for access. Access by GPs is provided through a pre-existing Queensland Health Information Technology system that enables GPs to view data stored by multiple Queensland Health systems.

The Panel's view is that for the register to be effective, differential access is needed. At a minimum, 24-hour access should be afforded to ambulance services, the Royal Flying Doctor Service, aged care providers, public and private hospital staff, and GPs. In addition, access should be provided to enduring guardians, guardians, the Public Advocate and the State Administrative Tribunal.

To address privacy concerns, differential access would ensure that authorised persons can only access specific records. For example, whilst universal access would be required for ambulance services, the Royal Flying Doctor Service, authorised public and private hospital staff, and GPs; more individualised, restricted access must be supported for other parties.

Individuals must be able to view and edit their own AHD, but not have unauthorised access to any other person's information stored on the register.

In addition, serious consideration should be given to the viability of extending access to other medical specialists, relevant allied health practitioners and relevant community service providers. It would be beneficial to work with all identified groups in the implementation of the register, with the expectation that access will be provided at some point in the future.

## **Recommendation 16**

16.1 To be effective, the advance health directive register should support differential access as follows:

- 24 hour access to:
  - a. Providers of emergency medical services (including ambulance services, Royal Flying Doctor Service);
  - b. Authorised staff in public and private hospitals;
  - c. Authorised staff in aged care providers; and
  - d. General Practitioners.
- Access must also be provided to individual records, as requested, for enduring guardians, guardians, the Public Advocate and the State Administrative Tribunal.

16.2 Serious consideration should be given to extending access to:

- Other medical practitioners;
- Relevant allied health practitioners; and
- Relevant community service providers.

16.3 The advance health directive register should distinguish between searchable access to all records (for example, as required by emergency medical services); and the right to access a specific individual's information (for example, as required by guardians) and the individual's right to access their own data.

### Should registration be compulsory?

A register is only useful if people use it. However, use should be encouraged rather than mandated. Compulsory registration may reduce uptake of AHDs by deterring people who have misgivings about sharing private information on a register or who are unfamiliar with the technology involved. It is noted that the unproclaimed section 110RA of the *Guardianship and Administration Act 1990* (WA) does not make the registration of AHDs compulsory.

The establishment of a register should also not foreclose other effective options for sharing an AHD, such as ensuring a person's partner is aware of the AHD and has a readily accessible copy. Manual circulation may also be effective in regional areas that have a small number of health service providers.

In lieu of compulsory registration, community education (see Chapter 2) should emphasise the benefits associated with registration – in particular, that registration is the best way of ensuring that the AHD is followed. Individuals can then make an informed choice about whether to use the register.

People who do not wish to upload their AHD to the register on account of privacy concerns should have the option of using the register to record only the existence and location of their AHD, recognising that this may compromise the ability of health professionals to obtain the instrument in a timely manner.

### **Recommendation 17**

- 17.1 The registration of advance health directives should be voluntary.
- 17.2 Where a person elects not to store their advance health directive on the register, the register should be capable of indicating the existence and location of the document.
- 17.3 Community education initiatives and resources should highlight the benefits of registration with a view to ensuring that individuals are able to make informed choices about, and be accountable for, their decision regarding registration.

#### Should AHDs be vetted before being uploaded to the register?

As the register will be accessed by health professionals, and assumed to be the source of truth for AHDs, it is vital that documents stored on the register are valid. This will require some form of vetting process. This vetting could occur manually or through an automated process.

Under a manual vetting process, AHDs submitted to the register would be reviewed by an experienced health professional and/or trained administrator before being uploaded to the register. The purpose of the review is to ensure that:

- The AHD meets the formal requirements stipulated by the legislation; and
- The treatment decisions contained in the AHD are capable of being understood and applied.

If the review reveals concerns about the legal validity or clarity of the AHD, the person who made the instrument can be asked to remedy the identified issue. The review would not consider the advisability of the person's treatment decisions.

#### **Manual vetting under the Queensland register**

Manual vetting is used by the Queensland Advance Care Planning Register. In that jurisdiction, responsibility for reviewing AHDs proposed for inclusion on the register rests with specialist clinicians employed by the Office of Advance Care Planning. The review process involves the application of a checklist identifying the formal requirements established under Queensland legislation. In approximately 30% of cases, the review process identifies issues that require follow-up with the person who made the instrument.

An automated vetting process would only be an option for AHDs completed and submitted using an online system. It would work by preventing the registration of an AHD that is missing one or more mandatory fields.

This form of vetting would have severe limitations. It would not be able to accommodate hard copy AHDs, common law AHDs or AHDs from other jurisdictions; nor would it be an effective mechanism for determining the overall validity of an AHD and whether it is able to be implemented by health professionals.

In contrast, manual vetting would have a significant positive effect on the utility of a register. Health professionals would be able to use the register confident in the knowledge that the instruments it contains comply with the statutory requirements of the *Guardianship and Administration Act 1990* (at the time they were made), and have been reviewed from a clinical perspective to ensure the treatment decisions are able to be implemented. Manual vetting will ensure that the register supports health professionals, and does not represent a waste of time or a source of legal complexity. Similarly, patients will have confidence that their AHD will operate as intended, an understanding that will ultimately have a positive effect on the uptake of AHDs.

A manual vetting process may be seen to invade the privacy of the person submitting the AHD. However, this in itself should not be a significant concern given that the whole purpose of uploading an AHD to the register – a voluntary act – is to make it accessible to health professionals. Any residual privacy concerns could be mitigated by ensuring that people seeking to upload an AHD to the register are made aware of the vetting process.

A manual vetting process would inevitably involve staffing costs, particularly at the set up phase of the register. The Panel is strongly of the view that these costs would be outweighed by the significant benefits that would flow from a manual vetting process.

#### **Recommendation 18**

- 18.1 Advance health directives should be reviewed by a trained health professional and/or an appropriately skilled administrator before being uploaded to the register.
- 18.2 The purpose of the review should be to ensure that the advance health directive is legally valid and clear enough to be implemented, not to assess the advisability of the person's treatment decisions.
- 18.3 People who are seeking to upload an advance health directive to the register should be made aware of the vetting process before submitting the document.

#### Should other types of instruments be included?

AHDs are only one of a suite of advance care planning tools that are available to individuals in Western Australia. The Panel considered whether an online register of AHDs should be extended to incorporate other relevant instruments such as advance care plans, enduring powers of guardianship and enduring powers of attorney.

Advance care plans are often completed in preference to an AHD and indicate a person's values and preferences for future healthcare. While advance care plans are valuable, they do not have the same legal standing as an AHD. The Panel heard evidence that many people complete an advance care plan but not an AHD. Indeed, data from the Queensland register demonstrates that considerably more people have registered a Statement of Choices (14,716 at April 2019) than an AHD (1,946 at April 2019).

That said, the purpose of a Western Australian register is to encourage and support the making, storage and accessibility of AHDs, and to facilitate their use by health professionals. In this respect, it was not considered necessary to extend the scope of the register to include non-statutory documents such as advance care plans. Including advance care plans could potentially create confusion in terms of the interpretation and application of a person's 'wishes', particularly as such documents are non-binding. If subject to the same proposed vetting process as AHDs, the inclusion of advance care plans would also add considerable work (and cost) to the establishment and maintenance of a register.

As outlined in Chapter 4, it is proposed that the new AHD template include a section for a non-binding values statement. Assuming an individual elects to complete this additional section and registers their AHD, then by nature of the new template, the register will have the capacity to record personal preferences, religious beliefs, cultural requirements and other considerations that are important to an individual. Uploading the non-binding values statements within the AHD to the register would require the document to be witnessed to the same requirements as the binding wishes, even if the binding wishes section has been left blank, so that health professionals, guardians and substitute decision-makers can be assured these genuinely represent the individual's wishes.

In terms of other advance care planning tools, enduring powers of guardianship and enduring powers of attorney were considered out of scope due to their complexity and the fact that they often focus on matters outside of health care. In addition, work is underway to develop a national register of financial enduring powers of attorney, which would be separate to an AHD register. In light of all these reasons, the Panel determined that the Western Australian register should be confined to AHDs.

As explained in Chapter 4, it is proposed that the new AHD form retain a checkbox indicating whether the person making the AHD has also made an enduring power of guardianship. It follows that this information will be available on the register in the same way as other information contained in an AHD. This information will be of assistance to health professionals where the AHD does not yield a relevant treatment decision and the assistance of a substitute decision-maker is required.

### **Recommendation 19**

19.1 The register should be confined to advance health directives.

19.2 The register should accommodate all aspects of the advance health directive template, including whether a person has nominated an enduring guardian.

### Accommodating pre-existing and common law AHDs

If the register relies on online completion and submission, an issue will arise as to how other types of AHDs can be accommodated. This includes all AHDs made prior to the creation of the register, common law AHDs, and AHDs made in hard copy.

Any exclusion of common law AHDs would create equity issues and may impact disproportionately on particular population groups, such as those Jehovah's Witnesses who may use a common law AHD to indicate their acceptance or refusal of medical treatments that use transfusion of blood products or blood fractions, or people who may have lost capacity between making a common law AHD and the establishment of a register.

If the register cannot store such AHDs, it should at least be able to flag their existence and location.

### **Recommendation 20**

20.1 The design process for the register should include consideration of the needs of people who have existing advance health directives, common law advance health directives, and advance health directives made on outmoded templates.

20.2 In the event that these advance health directives cannot reasonably be included in the register, individuals should be able to use the register to flag the existence and location of the advance health directive.

### **Obligation on health professionals**

The JSC canvassed the option of placing a legal obligation on health professionals to search the register before providing treatment to a person without decision-making capacity. The Panel agreed with this suggestion. Public confidence in the register will be undermined if it is

not used routinely, and the most direct means of ensuring routine use is by way of a statutory mandate.

However, any such obligation must be carefully calibrated so as to avoid placing an unreasonable burden on health services. In particular, the obligation should not apply:

- In urgent treatment scenarios. Although the register should be accessible for health professionals responding to an emergency, there should be no obligation to search the register in emergency situations. This is consistent with the existing urgent treatment provisions of the *Guardianship and Administration Act 1990 (WA)*, which recognise that in urgent situations the need for timely treatment can outweigh the importance of securing consent in the usual way.
- Where the register has previously been searched and the patient has not had capacity at all times since that prior search; by definition, such a patient could not have updated their AHD and the search would be fruitless.
- Where the register is not accessible when required (for example, because a health professional doesn't have access; or due to particular circumstances such as an outage).

The obligation will need to accommodate the reality that it will often be an administrative officer, not the treating health professional, who searches the register. For example, in an ambulance service, the search will generally be conducted by call centre staff rather than the attending paramedics.

Concerns were raised about liability that may arise where a health professional acts on information contained in the register that proves to be outdated or invalid; or on the outcomes of a search that doesn't reveal relevant information. It is important that health professionals be empowered to act on information contained in the register – even if the information later proves to be incorrect. This is compatible with the overarching principle that the register is to function as the source of truth for AHDs.

Non-compliance with the searching requirement, or failure to implement a treatment decision specified in an AHD obtained via the register, could result in a number of consequences such as criminal charges, a civil suit and/or professional misconduct complaints. Consequently, it was determined that there is no need to create a new offence and penalty as non-compliance fits within the existing obligation to obtain consent.

The recommendation that registration of AHDs be optional raises the question of whether health professionals should have any obligation to enquire into the existence of an AHD beyond searching the register. Circumstances are likely to arise in which it is appropriate for clinical services to make such further enquiries – particularly in the initial period following the creation of the register when many existing AHDs will not have been uploaded.

It is important that the register not replace current operational practice in this regard. Hospitals and emergency services already have systems to determine, to the best of their ability, whether an AHD has been prepared (and its location), and these systems should remain in place. However, as the need for, and nature of, further enquiries into the existence of an AHD will vary on a case-by-case basis, this should remain a matter for operational policy.

## **Recommendation 21**

- 21.1 The establishment of a register should be accompanied by a statutory obligation requiring that the register be searched before provision of treatment to a person without decision-making capacity.
- 21.2 Searching the advance health directive register should form part of the process for obtaining consent for medical treatment of a person without decision-making capacity.
- 21.3 The statutory obligation should be carefully calibrated so as to avoid placing an unreasonable burden on health services. For example, the obligation should:
- Apply only to non-urgent medical treatment decisions;
  - Not apply where the patient has not had the capacity to make, revoke or vary an advance health directive since a previous search;
  - Not apply where the health professional has reasonable grounds to believe that the treatment decision is not covered by an advance health directive;
  - Accommodate the fact that the treating health professional will not always be the responsible person for searching the register; and
  - Not apply in circumstances where the health professional is unable to access the register.
- 21.4 To ensure people who do not store their advance health directive on the register are not disadvantaged, the register should not fully replace other operational procedures in place to determine the existence and location of an advance health directive; however, these should not form part of the proposed statutory obligation.

## **Implementation considerations**

The development of a register should be overseen by a strong governance committee (including health consumer representatives) charged with providing policy direction. The scope of the project must be tightly controlled, with minimum requirements distinguished from 'nice-to-have' extras. The governance structure for the Queensland register should be examined as it may provide guidance for Western Australia.

The operational model for the register should be determined by the State Government, with consideration given to the functionality that best meets the needs identified in this Report and the JSC Report. To ensure ease-of-use with existing systems and workflows, the register must be designed with user input from the earliest stages.



## CHAPTER 6: Accommodating people with dementia and cognitive impairment

According to the Australian Bureau of Statistics (ABS), it is highly likely that dementia will soon overtake heart disease as Australia's leading cause of death. Advanced cognitive impairment compromises decision-making capacity. The combination of prevalence and qualitative impact makes dementia, in the words of the Chair of the JSC, a “challenge of monumental proportions for policy makers and governments”.

The JSC recommended that the Panel consider *how the increasing numbers of people diagnosed with dementia can have their health care wishes, end of life planning decisions and advance health directives acknowledged and implemented once they have lost capacity.*

Whilst the JSC recommendation was aimed at accommodating the health care wishes of people with dementia, the Panel recognised that many people with other neurodegenerative diseases (with resulting cognitive impairment) are in a similar situation. The increasing numbers of people diagnosed with dementia has highlighted the issues with advance care planning for people with cognitive impairment.

Consequently, the issues that were discussed and considered by the AHD Panel apply to all people with cognitive impairment, and not just people diagnosed with dementia.

AHDs can already be used to make treatment decisions that will apply after loss of capacity resulting from dementia and other neurodegenerative diseases. Similarly, enduring powers of guardianship and the treatment hierarchy operate in the usual way in the context of cognitive impairment. It follows that all of the recommendations contained in this report will, if implemented, operate for the benefit of persons with dementia. Health professionals will also benefit as the treatment decisions of their clients will be clearly outlined and known which, in turn, reduces the decision-making burden on medical staff and family members.

Of particular relevance is the recommended focus on promoting advance care planning at the point of diagnosis, where capacity still exists (Recommendation 3). Persons diagnosed with dementia or another neurodegenerative disease may have a limited window of opportunity in which they can complete an AHD before loss of decision-making capacity, so starting the conversation about advance care planning at or soon after the point of diagnosis will help ensure more individuals engage actively in planning for their future health treatment.

### **Finding 4**

Existing legal instruments already operate for the benefit of people with dementia and cognitive impairment, and will do so more effectively if the recommendations contained in this report are implemented.

The time-limited window for many people diagnosed with dementia or another neurodegenerative disease also presents a valuable opportunity to engage people in advance care planning discussions and decisions.

## **Recommendation 22**

22.1 Advance care planning, including advance health directives, should be promoted, funded and supported as part of an early intervention and education strategy for people diagnosed with dementia and other neurodegenerative diseases.

In line with the terms of reference, the Panel considered opportunities to 'increase the number of people with dementia who have their end of life choices implemented' that are not already catered for under existing legislation.

Any discussion of how AHDs can best accommodate people with neurodegenerative diseases and cognitive impairment, including dementia, would be incomplete without acknowledgement of the advance wishes of some people to access voluntary assisted dying should they lose capacity. However, the Panel was also mindful of three other considerations:

1. The Panel's Terms of Reference require it to consider the law, policy and operational practice with regard to AHDs.
2. AHDs are concerned with treatment decisions. A person's preference, or otherwise, to seek voluntary assisted dying is not a treatment decision.
3. An AHD can be made without a clinical assessment of the person's decision-making capacity, and implemented by an individual health professional without independent oversight. These are suitable arrangements for treatment decisions, but not for a process that results in the proactive ending of life.

The consideration and discussion of voluntary assisted dying was also complicated as, at the time of the AHD Panel's operation, the parameters of the proposed legislation were still under debate and development. In addition, even if the workings of the proposed legislation were known, it remains up to the Parliament of Western Australia to make the decision on whether voluntary assisted dying will be introduced in this state. Accordingly, the discussions and considerations of the AHD Panel with regard to voluntary assisted dying decisions for people with cognitive impairment have been detailed in Appendix A to this report.

## APPENDIX A

The voluntary assisted dying model under contemplation in Western Australia will be inaccessible to the overwhelming majority of people with cognitive impairment due to dementia. This is the result of the interaction between two aspects of the eligibility requirements that are likely to be included in the proposed scheme:

- That the person has decision-making capacity at all stages of the process; *and*
- That the person is experiencing suffering as a result of the condition that cannot be relieved in a manner that the person considers tolerable, and his or her death is reasonably foreseeable within a period of 12 months.

Because of the degenerative nature of the condition, a person with dementia who meets the first requirement (decision-making capacity) is unlikely to meet the second requirement (suffering and proximity to death). The reverse is also true: persons who meet the second criteria as a result of dementia are unlikely to have decision-making capacity.

For a voluntary assisted dying scheme to accommodate people with dementia, the temporal link between these two requirements would need to be broken. The affected person would need to be able to request an assisted death *prior* to his or her condition deteriorating to the extent that the decision needs to be implemented. That is, via an advance directive.

Any discussion of how AHDs can best accommodate people with dementia would therefore be incomplete without acknowledgement of the potential role of advance directives in the voluntary assisted dying scheme. However, the Panel does not consider it appropriate for an AHD to contain a directive in respect of voluntary assisted dying. This is because a directive in respect of voluntary assisted dying is not a ‘treatment decision’ within the meaning of that term in section 3 of the *Guardianship and Administration Act 1990 (WA)*, namely a decision to consent or refuse consent to the commencement or continuation of any treatment of the person. The definition of ‘treatment’ in the *Guardianship and Administration Act 1990 (WA)* does not include voluntary assisted dying.

From a practical perspective, AHDs are not a suitable or appropriate vehicle for advance voluntary assisted dying decisions. An AHD can be made without a clinical assessment of the person’s decision-making capacity, and implemented by an individual health professional without independent oversight. These are suitable arrangements for treatment decisions, but not for a process that results in the proactive ending of life.

The question of whether a voluntary assisted dying scheme should accommodate advance decision-making for people with neurodegenerative diseases, including dementia, is a significant topic, but one that was beyond the remit of the AHD Panel. The State Government established a separate Ministerial Expert Panel chaired by Malcolm McCusker AC QC, to guide the development of voluntary assisted dying legislation. The Final Report of the Ministerial Expert Panel on Voluntary Assisted Dying was tabled in Parliament on 27 June 2019. While the Ministerial Panel acknowledged “the perspective of those that indicated preference for a system that would allow for advance request of assisted dying”, they concluded that the proposal raises “myriad concerns” and was “beyond the scope of this Panel to consider at this point in time” (at page 106).

Given that voluntary assisted dying legislation has not been enacted in Western Australia, this Panel is not in a position to make any findings or recommendations about advance directives, voluntary assisted dying and persons with dementia and other neurodegenerative conditions. Nevertheless, community concern about dementia means that the role of advance planning under the voluntary assisted dying scheme is likely to remain a live issue.

The Panel has identified guiding principles that should be applied, and further questions that should be considered, should this issue arise in the future. These are set out below:

The guiding principles that should be applied are as follows:

1. *Rejection of prejudicial assumptions:* any scheme must guard against the assumption that a diagnosis of dementia, or loss of capacity as a result of dementia, automatically makes life unbearable. People with dementia can and do adapt to their new reality and retain joy and purpose in life; and their human right to do so should be supported by the health and care system.
2. *Parity of safeguards:* Subject to any necessary adaptations, assisted dying enabled through an advance directive should be subject to safeguards of at least the same stringency as applies to voluntary assisted dying generally.

The questions that should be considered relate to the front-end (time of making) and back-end (time of implementation) safeguards that would be needed to ensure the integrity and legal validity of the decision at both stages of the process. They include:

- (i) Should the making of an advance voluntary assisted dying directive be subject to the same decision-making capacity requirements as other voluntary assisted dying decisions?
- (ii) Should there be a 'cooling off' period before the advance voluntary assisted dying directive takes effect?
- (iii) What information would need to be given to the person making an advance voluntary assisted dying directive?
- (iv) When should an advance voluntary assisted dying directive be implemented (for example, when the person has lost capacity and meets the eligibility criteria for access to voluntary assisted dying)?
- (v) Who should be responsible for determining that the person meets the eligibility criteria and has lost capacity, and that their advance voluntary assisted dying directive should be given effect (for example, a substitute decision-maker or an independent tribunal)? How would that person or body decide whether or not that person is, for example, experiencing suffering that cannot be relieved in a manner the person considers tolerable?
- (vi) How are the protections going to be implemented, and by whom?
- (vii) What happens if a person, having made an advance voluntary assisted dying directive and having lost capacity, makes it clear that they do not wish to die?

### **Recommendation 23**

23.1 If, at a future point, voluntary assisted dying legislation is implemented in Western Australia, the State Government could consider establishing an Expert Panel to provide advice and recommendations on how to provide people with a neurodegenerative condition access to choice regarding voluntary assisted dying, in particular through the potential application of advance directives.