



Advance Directives Review

Planning ahead: your health, your money, your life

Second Report of the Review of South Australia's Advance Directives

Stage 2 Proposals for implementation and communication strategies

Advance Directives Review Committee

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This report incorporates extracts from the unpublished work of doctoral candidate, Jean Murray.

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Letter of transmittal

To the Attorney-General, the Minister for Health and the Minister for Families and Communities

I am pleased to present to you the second and final Report of the Review of South Australia's Advance Directives. The first report addressed the need for changes to law and policy in accordance with the first requirement placed on the Advance Directives Review Committee to make recommendations for a simpler, more consistent and accessible system of advance directives.

This report addresses the second requirement in the Terms of Reference :

To make recommendations for informing and educating families, individuals, lawyers and service providers to ensure they have a shared and better understanding about advance directives; and for establishing a single advisory access point on advance directives for families, and a single public information booklet.

This report supports the principles and recommendations in the first report, and adds further recommendations to enable their effective implementation. It provides a broad framework for implementation, recommending what needs to be included or considered to support the recommended policy and legislative changes.

The Review Committee strongly advocates for agency and choice, so that advance directives are understood by the community as a means of personal empowerment rather than as 'handing over power' to others. The terminology and language used in forms and guidelines is critical to accomplishing this shift in focus so that advance directives are seen as accessible and relevant to South Australians.

One impetus for the Advance Directives Review was criticism that the Guardianship Act is perceived to treat loss of capacity as black and white – a single event whereby all decision-making rights are lost completely and irrevocably. This also came through in submissions. The Review Committee considered in depth how best to assess and respect residual capacity, but recognised that issues with capacity assessment are broader than advance directives, and needs a national approach. The Review Committee supports efforts by NSW Health that offer an opportunity for a nationally consistent approach to assessing capacity.

In developing this report, the Review Committee examined current practice as well as practical issues. Members focussed on developing processes to ensure the decision-making pathway set out in the first report could be applied across the various sectors, while being mindful that it is not the role of the Review Committee to write the guidelines or design the forms. In developing these recommendations, the Review Committee consulted with the health and aged care sectors and sought advice from the financial sector. The recommendations were checked with the relevant government agencies to ensure they will work in practice and appropriately allocate responsibilities for the provision of information and advice, mediation services, and dispute resolution.

The public must be adequately informed to complete advance directives, and encouraged to advise others that they have completed one. Making it easier to access and complete advance directives electronically is likely to foster greater uptake. Effective guidelines and well designed forms will be critical for engaging public interest and increasing understanding and acceptance.

Some of the Review Committee's recommendations will reduce the work of the Office of the Public Advocate and the Guardianship Board, while others may broaden their responsibilities and increase the demand for some of their services and those of the Legal Services Commission. For example, the appointment of monitors and the gate-keeping role attributed to the Public Advocate will reduce the load on the Guardianship Board to

some extent. However, an increase in the take-up of ADs is likely to generate an overall increase in the need for resources, advice and information. It is recommended that these three agencies be properly resourced through increased funding and staff to fulfil their net additional roles and duties.

The Review Committee closely examined the advantages and disadvantages of various recording systems to ensure advance directives are known about so the person's wishes can be respected after decision-making capacity is lost or diminished. The Review Committee determined that the closer the recording and retrieval system is to the person and their agent, the more likely it will be used, and used effectively. The current South Australian register, managed by MedicAlert, has had minimal use by the public and the health sector, therefore rather than create another form of register it is recommended that the person completing the form and their agents are encouraged to alert others to the existence of their advance directive.

The Review Committee recognises that the impact of Parliament's laws is proportional to the effectiveness of their implementation. Many of the difficulties with advance directives (or the lack of them) are attributable not to problems with the law and policy but rather to poor knowledge and understanding. However the Review Committee is also concerned about the level of misunderstanding of and misinformation about advance directives in the health, aged care, legal and financial sectors, and the consequent risk of their misapplication.

Even when people are aware of the benefits for them personally, at present only a small proportion actually complete an advance directive. They are uncommon in the aged care sector and rare in the health sector, making them the exception rather than the rule. Turning this around requires behavioural change on a community-wide scale. It requires public awareness and professional education programs supported by comprehensive guidelines and training to ensure individuals, families, lawyers and professional practitioners have a shared and better understanding about advance directives and their application. Effective implementation of new advance directives will be the key to increasing their uptake and their usefulness for South Australians.

The Review Committee recommends that regular public awareness campaigns and professional education programs are established and continued into the future.

I commend this second report to you.



Martyn J Evans
Chair
Advance Directives Review Committee

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Advance Directives Review Committee Terms of Reference

The South Australian Government recognises that statutory advance directives:

- allow people to put in place clear legal arrangements, before capacity is lost or diminished, that will respect and protect their right to make their own health care, lifestyle and financial decisions
- are important to families and communities and have implications for health and well-being, especially for older people
- contain legal requirements that can seem confusing and complex in situations where families may already be distressed and
- should enable a person appointed to make decisions on another's behalf to do so in a manner that best addresses that other person's circumstances.

The Government also recognises that in South Australia:

- health and lifestyle advance directives are not well understood or optimally used by the community or by service providers, such as hospitals and aged care facilities, that are required to comply with their directions
- financial, health and lifestyle advance directives each have different forms, different requirements and different appeal provisions which can make them difficult to access and use and
- when a family member loses the ability to make his or her own decisions, families often find it difficult to make appropriate arrangements for the person's health, lifestyle and financial matters because, although linked, each matter must be dealt with by a separate and distinct legal process.

To increase the use of advance directives in South Australia, and to prevent their abuse, the South Australian Government has established an Advance Directives Review, supported by three Government Departments – Health, Families & Communities and Justice.

The review will provide opportunities for individuals, families, community groups and key stakeholders to contribute to the development of any amending legislation.

The Advance Directives Review will be conducted by a committee with an independent chairperson, departmental and external stakeholder and expert membership. The Review Committee will report to the Attorney-General. It will be supported by an expert advisory panel with members from community and stakeholder groups, and by a cross-departmental steering committee.

The Review Committee will:

- consider the provisions of
 - the Consent to Medical Treatment and Palliative Care Act 1995 that establishes Medical Powers of Attorney and Anticipatory Directions (SA's 'living will') for health decisions
 - the Guardianship and Administration Act 1993 that establishes Enduring Powers of Guardianship for health and lifestyle decisions
 - the Powers of Attorney and Agency Act 1984 that establishes Enduring Powers of Attorney for financial decisions
- assess the reasons for: the current low take-up of health and lifestyle advance directives; how advance directives currently operate in SA; and in what circumstances they are useful to families and service providers
- consider the appropriateness of: current appeal mechanisms and provisions to prevent abuse; schemes of competence certification; registrations; and recognition of advance directives created in other Australian jurisdictions
- investigate how advance directives deal with fluctuating or partial competence and their capacity to authorise actions after death, such as autopsy and organ donation
- take account of imposts on families including cost, accessibility, the capacity for agents to act jointly and requirements for witnessing and for legal advice
- consider privacy, cultural and indigenous perspectives and
- be encouraged to consult with their constituencies.

To achieve this, the Committee will obtain information by:

- considering public submissions to the issues paper prepared by the cross-departmental steering committee
- conducting targeted consultations, and broader public consultations if indicated by the submissions
- consulting key groups with knowledge and understanding of the policy issues
- referring to Parliamentary debate on advance directive legislation, to legal advice (including Crown Law advice), to government guidelines, education materials and policy advice, and to other national and international schemes and legislative reviews and
- building on the knowledge and experience of Departmental officers.

The Committee will then make recommendations to the Attorney-General for:

- a simpler, more consistent and accessible system of advance directives that will
 - ensure the proper protection of citizens whose mental capacity becomes compromised and
 - increase people's capacity to direct how they want their finances managed, where and how they want to live and what treatment they want to be offered when they are unable to speak for themselves
- informing and educating families, individuals, lawyers and service providers to ensure they have a shared and better understanding about advance directives and
- establishing a single advisory access point on advance directives for families, and a single public information booklet.

Acronyms

AD	Advance directive
EPA	Enduring Power of Attorney (for financial decisions)
EPG	Enduring Power of Guardianship (for health and residential decisions)
MPA	Medical Power of Attorney (for medical decisions)
OPA	Office of the Public Advocate
GB	Guardianship Board

Glossary

Legislation

Consent Act	<i>Consent to Medical Treatment and Palliative Care Act 1995</i>
Guardianship Act	<i>Guardianship and Administration Act 1993</i>
Powers Act	<i>Powers of Attorney and Agency Act 1984</i>

Advance directives and advance care plans

Advance directives	a general term for statutory instruments that enable a competent adult to personally ensure their wishes, instructions or decisions about health, life-management or financial affairs are known and acted upon to the degree possible when they no longer have sufficient capacity to make such decisions personally
Agent	a general term for a person legally appointed by an individual as their substitute decision-maker for health, life-management or financial decisions
Agent advance directive	an advance directive that appoints an agent to make decisions during times when capacity is lost or diminished
Personal advance directive	an advance directive that does not appoint an agent, but records instructions and wishes about health care and life-management for future times of lost or diminished capacity
Advance care plans	advance care planning is a process whereby individuals, in consultation with health care providers and relatives, describe their personal values and life goals and put in place advance care plans for their future health care, in case they become incapable of making such decisions personally at a later time
Capacity	the measure of a person's ability to make personal decisions or to make a particular personal decision
Competence	a legal term used to describe the mental ability required for an adult to sign a legal document while understanding the consequences of his or her decisions
Health care	the World Health Organisation (WHO) defines health as a state of complete physical, social and mental well-being, and recognises that health care is more than medical care
Health professionals	health professionals include medical, dental, nursing, social work, ambulance paramedics and allied health staff; these are often called clinicians.

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
Life-management decisions	decisions about personal matters such as residential arrangements, employment, holidays, visitors and care of pets; these are separate from health care and financial decisions
Life-sustaining measures	treatment that sustains or prolongs the operation of vital bodily functions that are incapable of independent operation, including treatment such as assisted ventilation, cardiopulmonary resuscitation, and artificial hydration and nutrition
Medical treatment	administration of therapy by either physical, surgical or psychological means, or administration of medications to prevent disease, to restore or replace body function in the face of disease or injury, or to improve the comfort and quality of life. Medical treatment can be administered by a range of health professionals
Palliative care	an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems eg physical, psychosocial and spiritual. Palliative care intends neither to hasten nor postpone death, but provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process
PVS or persistent vegetative state	PVS was recently redefined by the National Health & Medical Research Council as post-coma unresponsiveness to differentiate persistent vegetative state from minimally responsive state
PCU or post-coma unresponsiveness	PCU is defined as a state or condition in which a person has emerged from coma to the extent that he or she has sleep/wake cycles but with no observable, purposeful responses to stimuli
Prescribed treatments	procedures that currently require Guardianship Board approval when provided to adults lacking capacity; limited to ECT (electroconvulsive therapy), sterilisation, termination of pregnancy and neurosurgery for mental illness
Relatives	used broadly to include close family members of the person as well as someone overseeing the ongoing day-to-day care and well-being of the person (but not a paid carer)
Representatives	legally appointed decision-makers, including agents appointed by the person and guardians and administrators appointed by the Guardianship Board
Terminal phase of a terminal illness	terminal illness means an illness or condition that is likely to result in death; and 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)

**Ulysses
Agreement**

a record of an agreement between a patient, their psychiatrist, relatives and others, about treatment to be provided and arrangements to be made during future episodes of mental illness

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Summary of recommendations

Recommendation 1

THAT expert advice and support is engaged for the development of forms and guidelines to support the new advance directives

THAT all materials be properly tested and evaluated to ensure they meet the needs of their intended audiences

Recommendation 2

THAT the Legal Services Commission, the Office of the Public Advocate and the Guardianship Board be properly resourced through increased funding and staff appointments to effectively fulfil their additional roles and duties

Recommendation 3

THAT the forms and guidelines be drafted in consultation with a range of people from different communities and professional sectors to ensure they meet the needs of those who complete them and those who will be required to abide by them

Recommendation 4

THAT the take-up rate of the new advance directives be monitored

THAT an evaluation of the guidelines and forms be undertaken when they have been in use for between one and two years, depending on the rate of take-up

Recommendation 5

THAT an advance directives web site be established and maintained

THAT the guidelines and forms be made available in a range of formats including hard copy, downloadable and online versions,

THAT the guidelines use scenarios and stories to illustrate and clarify how advance directives can be used and applied

Recommendation 6

THAT legislation, information and forms be written in simple, easily-understood, non-legal language

THAT the guidelines and forms refer to impaired decision-making ability rather than incapacity

Recommendation 7

THAT the guidelines for the general public be broadly targeted to the population, and complement other detailed guidelines developed specifically for the health, aged care and financial sectors

THAT the guidelines offer practical advice about the roles and responsibilities of the person completing the advance directive, any agents being appointed, the witness, and professionals required to abide by advance directives once the person's decision-making capacity is diminished or lost

Recommendation 8

THAT the guidelines include example outcome statements that have been tested through focus groups of lay people and experts to ensure a wide and common understanding of their meaning and intent

THAT the guidelines also provide advice to those who want to specify refusals of certain treatments in advance

Recommendation 9

THAT guidelines advise that where instructions or conditions are recorded in advance directives, the person clearly designates when or under what circumstances they are intended to apply and whether they are intended to be binding or advisory

Recommendation 10

THAT guidelines advise that instructions intended to be followed after death may be written in an advance directive, but also point out more appropriate mechanisms for communicating such wishes to families eg organ donor register

Recommendation 11

THAT the guidelines provide a checklist for agent decision-making based upon the pathway outlined in the Advance Directives Review Stage 1 Report

Recommendation 12

THAT advance directive forms and guidelines be readily available and free

THAT the Legal Services Commission be resourced to manage the web site

THAT the Legal Services Commission and Service SA be resourced to manage the printing and distribution of printed copies of forms and guidelines

Recommendation 13

THAT a single recognisable design be applied to advance directive forms, guidelines and promotional materials

THAT only forms in a design and format approved by the Attorney-General be recognised as South Australia's statutory advance directives

Recommendation 14

THAT it be made clear in guidelines that advance directives are personal rather than private documents, which must be readily available when needed

THAT form design allow for financial sections to be separate from health and other personal sections so that copies can be distributed appropriately

Recommendation 15

THAT witnesses be required to sign a witness statement attesting that they are satisfied the person and their agent/s meet the criteria for validity

Recommendation 16

THAT witnesses be limited to registered professionals and JPs who have completed an accredited training course, and notaries practicing interstate and overseas

THAT consideration be given to allowing retired registered professionals who undertake ongoing or refresher training to continue to be witnesses

THAT witnesses not be permitted to charge a fee for simply witnessing an advance directive

Recommendation 17

THAT those completing advance directives be encouraged to provide copies to relevant people

THAT wallet cards be provided and fridge magnets be promoted to help ensure that the existence of advance directives is better known, and contact details of agents can be readily retrieved

THAT an ongoing program encouraging the public to discuss their future wishes be implemented, and that Ministers work towards a national program in the longer term

Recommendation 18

THAT the Minister for Health propose to the Australian Health Ministers' Conference that accreditation standards for hospital and aged care facilities require that advance directives be checked on admission, are filed with the person's record and can be easily located

THAT resources be available to ensure that hospital information systems can record the existence and contents of the health-related sections of advance directives, and these be made accessible across the broader South Australian health system

THAT the use of a 'green sleeve' in the front of a hospital medical record to hold advance directives be promoted and encouraged

THAT lodgement of financial advance directives with the Lands Titles Office continue under current arrangements for people with real estate

Recommendation 19

THAT South Australia not establish a State register of advance directives

Recommendation 20

THAT the guidelines recommend advance directives be regularly reviewed and updated

THAT there be a public reminder program, such as a 'life in order' day, to encourage annual review of completed advance directives and to prompt professionals to remind their clients about the need to review their advance directives

Recommendation 21

THAT the guidelines include general advice for agents about assessing the capacity of the person to make the decision in question

THAT the Attorney-General proposes to the Standing Committee of Attorneys-General that the NSW Capacity Toolkit be adapted so it applies generally across Australian states and territories

Recommendation 22

THAT the guidelines for the public include advice for relatives to assist them to follow the decision-making pathway when the person has completed a personal advance directive but not appointed an agent

THAT guidelines for both the public and professionals explain that health and aged care professionals must consult with relatives if circumstances permit, and that if no relatives are available, such professionals are bound to follow the same decision-making pathway as relatives

THAT a concise stand-alone pamphlet explaining the pathways for decision-making by relatives and agents be developed and made available in health and aged care settings

Recommendation 23

THAT guidelines for agents include advice about

- discussing intentions when an agent advance directive is being completed
- following the decision-making pathway when using the advance directive
- any obligations to report to or consult with others and
- how to seek help with dispute resolution

Recommendation 24

THAT a professional education program be developed for managers and staff of banks and other financial institutions to be delivered through risk managers or their equivalents that explains

- the statutory nature of advance directives in South Australia
- the requirements for completing and revoking an advance directive and
- the protections offered for compliance with an advance directive that appears to be validly completed and witnessed

Recommendation 25

THAT a person be able to appoint a trusted individual as a monitor for financial and other decisions

THAT the appointment of monitors for both financial and other decision-making be actively encouraged

THAT guidelines recommend specific reporting arrangements for the agent are documented in the advance directive when a person appoints a monitor

THAT a person be able to appoint a company such as a law firm or a financial institution as a monitor to oversee their agent's financial management

Recommendation 26

THAT a program of community engagement and information dissemination be implemented through effective use of the media and of existing community-based forums

THAT the Legal Services Commission be resourced to produce a training kit including electronic and printed materials for use by community agencies providing presentations to the public

THAT the Aboriginal Legal Rights Movement be funded and resourced to communicate and promote the value of advance directives to remote Aboriginal communities

Recommendation 27

THAT printed information explaining the value and role of advance directives be developed and distributed to a range of country and metropolitan access points

THAT the advance directive web site provide materials and simple advice for people considering whether to complete an advance directive

THAT advice on completing, using and abiding by Ulysses Agreements be prepared with expert input and distributed through the mental health sector

Recommendation 28

THAT a free public advice service be implemented for people completing advance directives that provides one-on-one advice either in person, via email or over the phone

THAT advisers located in community centres and local council offices, and GP practice nurses, be trained to assist people who need extra assistance to complete their advance directives

THAT the Legal Services Commission be resourced to coordinate training for these roles to ensure consistency

Recommendation 29

THAT the Office of the Public Advocate be resourced to advise

- agents about their decision-making role
- families and health professionals about making decisions when there is a personal advance directive in place but no agent appointed

Recommendation 30

THAT when disagreements arise about the application and interpretation of advance directives, the advance directive guidelines encourage discussion and advise agents and families when to seek advice from the treating clinical team, the Office of the Public Advocate, the Legal Services Commission or community mediation officers

THAT where the person has already appointed an agent, the Guardianship Board's role should be to assess the person's capacity to make the particular decision in question and authorise the agent to make that decision if appropriate

Recommendation 31

THAT guidelines for professionals be comprehensive, tailored to different sectors, and offer protocols to follow in a range of commonly-encountered situations

THAT a standard training module be developed that can be adapted to different professions and circumstances and that is accredited and qualifies for professional development points

THAT participation in formal training programs be required for health and aged care professionals, and this requirement be incorporated into accreditation standards and service agreements

THAT the Respecting Patient Choices Program, along with other evidence-based advance care planning programs, should continue to be supported in the future to complement the implementation of the new advance directives across health, hospital and aged care settings

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Introduction

Summary : the Review so far

The Terms of Reference

This is the second of two reports prepared by the Advance Directives Review Committee, which reflect the two challenges spelt out in the Advance Directives Review Committee's Terms of Reference: to improve advance directives and to communicate those improvements to provide a better system for South Australians.

The first report recommends changes needed to law and policy to create a simpler, more consistent and accessible system of advance directives. This second report addresses implementation and practice issues, including proposals aimed at ensuring advance directives work effectively for those who complete them, their agents, and those who are required to abide by them. These include mechanisms and programs to increase awareness and understanding, improve access to forms and guidance, provide advice and assistance, and help to resolve disputes.

Stage 1 : Law and policy

The Review Committee's Stage 1 Report lists 23 principles and 36 recommendations that seek changes to law and policy regulating advance directives, including:

- combining the advance directives into a single Act, and incorporating Ulysses Agreements for episodic mental illness
- retaining both a personal advance directive recording health and life-management decisions and an agent advance directive appointing a trusted person or persons to make health, financial and other life-management decisions
- building in flexibility so that agent advance directives can be completed as a whole or in part, record both binding instructions and guiding wishes, and set a personal trigger for their operation
- requiring agents to make decisions that they believe the person would make if they were competent and aware of the advice and information that is available to the agent by applying contemporaneous substituted judgement
- recognising that relatives, broadly defined, can make health decisions in the absence of an appointed agent or guardian, and proposing that relatives also be required to apply contemporaneous substituted judgement to their decision-making
- encouraging instructions in health advance directives to be recorded in outcome terms, so that the person's values and life goals are known and it is clear what circumstances they wanted to avoid when decisions are being made on their behalf, whether by their appointed agents or by guardians, relatives and professionals.

The Stage 1 Report highlights where the Review Committee's recommendations require implementation strategies.

Stage 2 : Implementation and practice

The stage 1 proposals need to be underpinned by comprehensive guidelines, forms with flexible formats, and mechanisms to ensure these are available when needed. Effective implementation also requires a communication strategy that takes account of the different information needs of the public, appointed agents, and professionals working in the health, aged care, financial and legal sectors.

Throughout Stage 1, the Review Committee kept in mind the implementation processes its recommendations would require in order to be effective. These were discussed with the Expert Advisory Panel at a workshop in March 2008, and the collated feedback examined. This report presents the fruits of the Review Committee's deliberations.

Implementation issues

Guidelines and forms

The Review Committee's recommendations depend upon

- a flexible form that accommodates the needs of those who simply want to appoint one agent to make all their future decisions without writing instructions but also of others who prefer to appoint separate agents for different types of decisions and set separate conditions and instructions on their decision-making, and all possibilities between these extremes
- comprehensive guidelines that inform and guide the completion of the form, providing advice and suggestions along the way for those completing them, guidance for agents being appointed, criteria for witnesses to follow, and information about what to expect when their advance directive is needed for decision-making down the track.

These are addressed in Section B of this report.

Utilising one form for medical, health, lifestyle and financial ADs would seem the way to go as the 3 situations would be brought to one's attention when say...considering finance and could be in a book form provided it is not so complication that costly legal advice will be necessary to have the forms understood [by the public] 74l

The Review Committee recognises that developing such materials requires specialist knowledge and expertise, and that drafting such documentation will require consultation and focus-group testing to ensure they meet the needs of their respective audiences. The Review Committee is gratified by the enthusiasm expressed by a number of community groups and professional bodies to be engaged in such consultations to ensure that South Australia's new ADs will work effectively – not only for those who complete them, but also for those whose work requires them to apply and abide by them.

Recommendation 1

THAT expert advice and support is engaged for the development of forms and guidelines to support the new advance directives

THAT all materials be properly tested and evaluated to ensure they meet the needs of their intended audiences

Making it work

New laws and policies can engage the public and induce behavioural change which may in this case increase the uptake of ADs. The implementation of the Patient Self-Determination Act in the USA in the 1990s significantly increased public interest in, and acceptance of, ADs, and raised awareness across the health and aged care sectors of the duties and roles of professionals in respecting the wishes of those for whom they provided care.

The Review Committee acknowledges the importance of putting systems in place to ensure:

- ready access to the forms and guidelines when individuals want to complete one
- means of knowing if an AD is in place
- means of retrieving completed ADs when they are needed for decision-making

- reliable and accessible sources of advice for those completing ADs, their agents and witnesses
- access to advice and support for professionals, especially health and aged care professionals, when decision-making is required to abide by ADs
- advice for the legal and financial sectors about applying ADs when decisions need to be made on behalf of clients who have lost the capacity to manage their own affairs
- availability of mediation and advocacy services when disagreements arise about decisions to be made
- fair and timely dispute resolution procedures that are easily understood and accessible, but only as a last resort.

These points are addressed in Section C of this report.

Communication strategy

The Review Committee recognises that many of the difficulties with ADs (or the lack of ADs) brought to the Review's attention through submissions and consultations are attributable not to problems with the law and policy but rather to poor knowledge and understanding. Submissions and consultations attested to limited public awareness of ADs and significant confusion about their application.

However the Review Committee is also concerned about the level of misunderstanding of and misinformation about ADs in the health, aged care, legal and financial sectors, and the consequent risk of misapplication of ADs.

Awareness of the provisions of the AD legislation is limited in the medical profession and in the general community, with the exception of people who have a particular interest in it
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ADs are completed by only a fraction of the population. Even when people understand what ADs are and are aware of their benefits for them personally, local, national and international studies and surveys indicate only a proportion actually complete them. Those who do complete an AD need to be informed and encouraged to advise family members and professionals they deal with of their existence. Financial ADs are more common so the banking and finance industry has mechanisms that encourage staff and clients to ask about them. However, ADs are still uncommon in the aged care sector and rare in the health sector. Although many aged care facilities actively ask about ADs, this is not the culture in hospitals where ADs are the exception rather than the rule.

This requires behavioural change on a community-wide scale. It requires public awareness and professional education programs supported by guidelines and training to ensure individuals, families, lawyers and professional practitioners have a shared and better understanding about advance directives and their application.

It is therefore important that regular public awareness campaigns and professional education programs are established and continue into the future to ensure:

- the public is aware of ADs and their useful role in planning ahead, and how decisions will be made on their behalf if they choose not to complete one
- individuals know where to access forms and guidelines about how to complete them and make use of them when making decisions
- witnesses understand their role and are trained to carry it out
- health, aged care and financial professionals recognise ADs when they come across them and understand their legal status and when they apply

- professionals understand their duties and roles in complying with the terms of ADs
- lawyers have a comprehensive understanding of ADs when they advise their clients
- health and aged care professionals understand what decisions relatives can make in the absence of an AD
- banks and financial institutions understand the requirements of, and protections offered by, legislation regulating South Australian ADs
- information on mediation and dispute resolution procedures is readily available when required.

The Review Committee makes recommendations for an initial communication strategy and ongoing public awareness and professional education programs in Section D of this report.

Funding implications

The Review Committee is aware that many of its recommendations have funding implications for the South Australian Government.

Adequate investment in the development of forms and guidelines and a widely-targeted ongoing communication strategy is the most effective means of ensuring that ADs are properly understood, completed and applied. Submissions to the Review raised concerns about inadequacies with the current forms and guidelines, and about the haphazard and incomplete dissemination of information. The lack of public awareness and professional understanding of the Medical Power of Attorney and Anticipatory Direction testifies to the inadequate investment of resources and time in their implementation when the Consent Act became law in 1995. It is time to learn from earlier mistakes and take a more enlightened approach, recognising that the impact of Parliament's laws is proportional to the effectiveness of their implementation.

The Review Committee's recommendations place duties on the Legal Services Commission, the Office of the Public Advocate and the Guardianship Board that may increase the demand on some of their services. Some recommendations, such as the appointment of monitors and the gate-keeping role attributed to the Public Advocate, will reduce the load on the Guardianship Board to some extent. However, an increase in the take-up of ADs is likely to generate an overall increase in the need for staff, facilities, education services, web site establishment and maintenance, and production of forms, guidelines and other materials. It is recommended that these three agencies, which are all the responsibility of the Attorney-General, be properly resourced through increased funding and the appointment of advisory and education officers to fulfil their additional roles and duties.

If changes are made it is critical that there is funding to support them, especially for public awareness and professional education

Personal Communication

Investment in a comprehensive implementation process and strong support mechanisms for ADs will encourage their uptake and result in greater compliance with individuals' wishes about treatment interventions, especially at the end-of-life, and fewer applications to the Guardianship Board for appointment of guardians and administrators.

The Review Committee heard many stories from families, the SA Ambulance Service, medical specialists and GPs about inappropriate transfers of elderly people from nursing homes to hospital emergency departments and then to intensive care units, which did not comply with their life goals and care preferences. If ADs are better understood and more widely used and recognised, then it should follow that people's wishes would be respected. Inappropriate and unwanted hospital transfers would be reduced and people would be

cared for in a familiar environment when they are dying. International studies have shown that when ADs are in place in nursing homes and aged care facilities, care is provided in more appropriate (and less expensive) settings, and resources are directed more appropriately. Under this welcome scenario, the community would benefit from savings in health dollars that could be better invested in preventative and curative health – and in supporting an effective and respectful system of advance directives.

Recommendation 2

THAT the Legal Services Commission, the Office of the Public Advocate and the Guardianship Board be properly resourced through increased funding and staff appointments to effectively fulfil their additional roles and duties

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CONFIDENTIAL

Guidelines and Forms

Development of guidelines and forms

Audiences

The changes to South Australia's ADs and advice on how they will operate will need to be communicated to different audiences with different needs. These will include:

- the South Australian community, where awareness of advance directives is low
- lawyers, financial advisers and GPs advising clients and patients about advance directives
- adults seeking to complete an advance directive
- agents being appointed under an advance directive
- witnesses signing advance directives
- health and aged care professionals required to abide by advance directives
- financial and bank staff required to abide by advance directives.

ADs, and health ADs in particular, have traditionally been aimed at elderly and frail people, and those who have been diagnosed with a life-limiting condition; however the Review Committee's consultations indicate that South Australians want their ADs to apply to a wider range of circumstances. ADs are relevant to people with episodic mental illness, and to people with risky occupations who want to ensure that if they are injured their chosen agent will be making decisions on their behalf. International studies have demonstrated that ADs offer benefits to legally competent people with physical disabilities or communication difficulties who want to ensure that their expressed views are respected and assumptions are not made about what constitutes quality of life for them.

In the first instance, a communication strategy will ensure the public and professionals:

- understand what ADs are and how they can be useful for future planning
- are aware that these have recently changed
- and know where they can access the forms and further information.

Professionals in the health, aged care, legal and financial sectors will also require guidelines tailored to their needs to assist them to advise patients, residents and clients and to abide appropriately by ADs. The communication strategy is discussed further in Section D.

However, once a person has decided to complete an AD, it is intended that comprehensive but easy-to-read guidelines will be available to explain the options and choices, and to help South Australians record their wishes in a straightforward manner that can be understood and actioned by others in the future. These guidelines will include advice to agents about their role and criteria that witnesses must apply.

The forms were so complicated we made up our own 121

The documents should be in plain English but also detailed to reduce to a minimum any discretion of the agent 701

The recommendations made here are intended to provide a framework for the development of forms, guidelines and support material, recognising that this may be undertaken by Government departments or subcontracted.

Development and validation

It is important that the forms and accompanying guidelines are developed and used together, as they are intrinsically linked. It is intended that the form would be separate, but linked logically to the relevant part of the guidelines, similar to the 'taxpack' model. In this format, the guidelines would follow the form and provide advice on completing each section in order.

Preparing guidelines and forms that are relevant to a diverse community is a particular skill. They need to be easily understood by people with different language and cultural backgrounds and different levels of education, and not be subject to misinterpretation. They also need to be a reference that can be retained and referred to later when decisions are being made and where questions might arise.

Given the diversity of audiences, the guidelines should be drafted in consultation with a range of people from different communities and professional sectors to ensure they meet the needs of those who complete them and those who will be required to abide by them.

Forms require particular expert advice – many a form has appeared simple enough when drafted but found to be confusing when used in practice. It is important that both forms and guidelines are tested with their intended audiences so they can be adapted to ensure they work effectively before they are finalised. This will require focus groups to be established for each audience for both guidelines and forms. The Review Committee has received offers from community groups, particularly in the aged care sector, such as the Aged Rights Advocacy Service, Health Consumers Alliance, the Alliance for the Prevention of Elderly Abuse and the Seniors SA Culturally and Linguistically Diverse Forum who are keen to participate in such focus groups to ensure the materials meet the needs of their members. In addition, the Legal Services Commission has a reference group, and the Palliative Care Council and other active community organisations in the health and aged care sector have expressed a strong interest in ADs and their application.

Recommendation 3

THAT the forms and guidelines be drafted in consultation with a range of people from different communities and professional sectors to ensure they meet the needs of those who complete them and those who will be required to abide by them

Utilising one form for medical, health, lifestyle and financial ADs would seem the way to go as the 3 situations would be brought to one's attention when say...considering finance and could be in a book form provided it is not so complication that costly legal advice will be necessary to have the forms understood [by the public] 74I

Evaluation and revision

The take-up rate of the new ADs should be monitored through mechanisms such as assessing the number of hard copy versions taken, the number of hits and downloads on the web site, a feedback form from trained witnesses, and the number of completed forms sighted in a selection of aged care, health and financial agencies. An evaluation of the guidelines and forms should be undertaken when they have been in use for between one and two years, depending on the rate of take-up, to assess whether changes are needed to the format or text to make them more accessible or relevant.

Recommendation 4

THAT the take-up rate of the new advance directives be monitored

THAT an evaluation of the guidelines and forms be undertaken when they have been in use for between one and two years, depending on the rate of take-up

Guidelines for completing the form

The Review Committee recognises that well-prepared guidelines are critical for the effective implementation of the new ADs, and will form the backbone for their effective use and operation. The guidelines will perform an educational and informative function covering both the completion and application of ADs, so will remain a useful reference after the form has been completed and signed – for the person, their agents and professionals from whom they seek advice and services.

It is envisaged that the guidelines will be made available in several forms and formats to accommodate different audiences and needs, including hard copy and web-based versions. The Review Committee regards an 'advance directives web site' as integral to a modern system of advance directives with the capacity to meet the needs of a wide range of communities and locations.

It is important that the guidelines and forms are intrinsically linked to ensure all those involved understand the responsibilities undertaken and the authority conferred on agents. The Review Committee proposes that the forms require the person, any appointed agents and the witness to sign a statement on the form that they have read and understood the guidelines.

Guidelines: Design and structure

Feedback to the Review Committee indicated the guidelines need to be easy to read and navigate, and in large font as a high proportion of readers are likely to be elderly. Large blocks of text should be avoided. Instead the design should lend itself to scenarios and examples, leading statements and prompts that generate thought and discussion. Several submissions explained they found the 'stories' in the Advance Directives Review Issues Paper helpful in illustrating how ADs might be usefully applied in practice. Short anecdotes in boxes separated from the text which present familiar or anticipated problems that advance directives might help to solve could be effectively applied in the same way to the guidelines.

Hard copy version

Many people prefer to use a printed copy of such documents. The Review Committee suggests that together, the guidelines and forms comprise a kit which could include wallet cards and other useful adjuncts. It is envisaged the kit would include information about the benefits of completing a personal and an agent AD, with both forms attached.

Web-based downloadable version

The application of improved information and communication technologies has been shown to increase the completion and use of ADs. An advance directives web site containing the guidelines and forms in pdf format would allow them to be downloaded and printed. Following the guidelines in the same way as the hard copy version, the form could then be completed, signed and witnessed. This would allow key concepts and phrases to be linked by hypertext to definitions and explanations. The downloadable form would also be suitable for use by lawyers, financial planners, GP surgeries and aged care facilities, and could also be completed online and printed.

Web-based online version

The Review Committee suggests the advance directives web site also allow the guidelines to be followed and the form to be completed online, with an online tutorial for those people unfamiliar with such web features. This model would allow integration of the guidelines with the form, so that questions and advice prompts pop up as sections are completed, and inclusions could be either selected from choices listed or entered in freeform. The Commonwealth's online passport application form provides a model.

Recommendation 5

THAT an advance directives web site be established and maintained

THAT the guidelines and forms be made available in a range of formats including hard copy, downloadable and online versions

THAT the guidelines use scenarios and stories to illustrate and clarify how advance directives can be used and applied

Guidelines: Language and terminology

Language is an important communication tool. Complex legal language makes the current advance directives inaccessible to many South Australians, including those for whom English is their second language and people who have an aversion to involvement with 'anything legal'. That is why the Review Committee strongly advocates that ADs be portrayed as a means of personal empowerment, rather than as 'handing over power' to others. The Guardianship Board's role is one of protection of vulnerable adults, whereas ADs are focussed on autonomy and ensuring personal choices are respected in the future. The Review Committee recommends that the forms and guidelines be couched in terms that reflect respect for the autonomous choices of competent adults, such as *directions* and *agency* rather than *guardianship* and *attorneys*. This would promote public confidence in South Australia's ADs and increase their acceptance and uptake.

Submissions and consultations indicate the public wants information and forms in simple, easily-understood, non-legal language. Examples given of unfriendly legalistic terms included donee, enduring, jointly, severally, attorney and powers. The Review Committee found the terms *advance directive* and *agent* were more easily understood than *powers* and *attorney*. It is important that the language used in guidelines and forms is meaningful, consistent and simple to translate, with terms explained at the outset in a glossary in the kit and by hyperlink in the web version.

Currently they [the forms] all have too much legal wording...use simple English and not too complex in structure...use the KISS theory 23IH

It would be particularly useful to make *advance directives* a recognised term used consistently throughout South Australia (and nationally) by including a clear definition of the term in the law and guidelines. It needs to be made clear that advance directives are statutory instruments, to avoid confusion with non-statutory advance care plans. It should also be made clear what weight should be given to non-statutory advance care plans.

There is value in ensuring that language and terminology remains congruent between the legislation and the guidelines, with both being cast in non-legalistic terms that are readily applied by non-lawyers. This would prevent individual interpretations of the law by financial institutions and health and aged care professionals, and facilitate lawyers providing clear legal advice consistent with the guidelines.

The Review Committee considered several alternatives for describing the person's circumstances which trigger the use and application of advance directives. Legislation nationally and internationally uses a range of terms:

Mental incapacity	<i>SA Guardianship and Administration Act 1993</i>
Impaired decision-making capacity	<i>Qld Powers of Attorney Act 1998</i>
Inability to make decisions	<i>UK Mental Capacity Act 2006</i>
People who lack capacity	<i>UK Mental Capacity Act 2006</i>
Impaired decision-making ability	<i>ACT Powers of Attorney Act 2006</i>

Of these, the Review Committee preferred that the guidelines use the Australian Capital Territory term *impaired decision-making ability*. This avoids the pejorative tone of incapacity, refers to ability rather than inability, and applies to both partial or complete loss of decision-making functions.

Recommendation 6

THAT legislation, information and forms be written in simple, easily-understood, non-legal language

THAT the guidelines and forms refer to impaired decision-making ability rather than incapacity

Guidelines: Content and inclusions

The guidelines for the general public should be broadly targeted to the population, and complement other detailed guidelines developed specifically for the health, aged care, legal and financial sectors. They should offer practical advice about the roles and responsibilities of agents being appointed, and the duties of professionals required to abide by ADs once decision-making capacity is diminished or lost. There is value in those completing ADs being able to understand the role and duties of the witness and how their instructions might be carried out at a future time. Likewise, it would increase professional confidence in ADs if members of the health, aged care, legal and financial sectors were aware of the stringency of witnessing criteria and the decision-making advice provided to agents. Separate guidelines for each group would diminish these benefits.

The public guidelines should at least cover the following points.

1. For adults seeking to complete an advance directive, guidelines should include

- Who would make decisions for them in the absence of an AD and how those decisions would be made
- What they need to consider in determining which AD to use depending on their needs and situation
- How to write a personal AD with advice about
 - discussing their expectations and desires with family and others close to them
 - recording values and life goals, and what to them would be intolerable or burdensome
 - examples of phrases to choose from and what they would mean in practice
 - what will happen when they lose decision-making ability, and how decisions will be made on their behalf under a personal AD

- How to write an agent AD with advice about
 - choosing agents, appointing multiple agents, and requiring agents to act together or separately
 - deciding whether to write instructions, or to simply discuss with their agents or families their values and life goals and what would be intolerable or burdensome for them
 - setting conditions and triggers
 - appointing monitors¹, particularly for financial decision-making
 - what will happen when they lose decision-making ability, and how decisions will be made by their agent
- When they should seek advice about complex arrangements from a GP, accountant or lawyer
- Where to keep their form and who to tell
- How to revoke their AD

2. For agents (and monitors) being appointed under an advance directive, the guidelines should include

- What responsibilities agents are undertaking
- How to assess the person's decision-making ability, explaining that this may fluctuate, and the need to assist the person to make their own decisions for as long as they can
- How agents are required to make decisions, including abiding by instructions, applying contemporaneous substituted judgement, ensuring proper care and protection, and considering least restrictive alternatives
- How multiple agents should make decisions, and the need to advise each other of decisions made
- What to do when the person fails to accept his or her inability to make decisions
- What monitors should do, and the obligations on agents required to report to a monitor

3. For witnesses signing advance directives, the guidelines should include

- Applying the criteria for competence, and what to do when competence is questionable
- Completing the witness statement and check list for assessing competence

4. For those seeking advice, the guidelines should include

- The different roles of the Legal Services Commission, the Office of the Public Advocate, the Guardianship Board and the Public Trustee
- Problem-solving and dispute-resolution pathways

The guidelines should be inclusive of culturally diverse communities and recognise the needs of Aboriginal people and people with disabilities.

Recommendation 7

THAT the guidelines for the general public be broadly targeted to the population, and complement other detailed guidelines developed specifically for the health, aged care and financial sectors

THAT the guidelines offer practical advice about the roles and responsibilities of the person completing the advance directive, any agents being appointed, the witness, and professionals required to abide by advance directives once the person's decision-making capacity is diminished or lost

¹ See page 41 for an explanation of the monitor's role

Focussing on outcomes

The Review Committee recommended in the Stage 1 Report that people writing instructions for future health care be encouraged to write them in outcome terms in ordinary language, rather than attempting to write medical orders in advance of any disease or injury. South Australian studies and surveys indicate that most people find writing medical instructions quite daunting. A recent international study reports that few individuals want to stipulate specific medical treatment preferences, but prefer instead to record their values and their goals for care. Participants in the study valued cognitive functioning, independence and dying with dignity.

The guidelines should explain what is meant by values and life goals, intolerable and unacceptable circumstances, and burdensome and intrusive interventions. Submissions suggested scenarios and example statements will be most useful in this regard, and will also provide a means to generate thought and discussion, but tick-boxes were not generally supported. There are good advance care planning guides that provide well-tested models that can be drawn upon when the guidelines are being drafted.

Nevertheless some people may find it challenging to think through and write down their values, life-goals and preferred outcomes. The experience of the Respecting Patient Choices Program at The Queen Elizabeth Hospital suggests that a set of sample outcome statements would make it easier for people to either select a personally appropriate statement or formulate their own from suggestions provided. It would be important to include sample outcome statements relevant to healthy active people and others suitable for people who have a diagnosed life-limiting condition or a physical disability, and for frail elderly people who are already dependent on care services at home or in an aged care facility. The guidelines should help the person to consider and balance preferred health outcomes with treatment burdens, and suggest that for existing health conditions expert medical advice should be sought about the likelihood of treatment burdens and outcomes.

In devising sample statements, the Review Committee recognises the importance of both

- testing them with lay people to ensure they are simply stated and their import is commonly understood, and also
- consulting experts who may need to abide by them to make sure they can be interpreted consistently and implemented in practice.

This will be particularly important for personal ADs because no agent is appointed. In this case, health professionals and family members are required to make decisions that respect the person's views about what constitutes quality of life. The guidelines should include general advice to families and others about abiding by personal ADs, with detailed instructions to health professionals about making decisions when a personal AD is in place provided in separate professional guidelines.

It is glowingly obvious that the current design of the forms [EPA/PA] is seriously ambiguous

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Medical experts have advised the Review Committee that some people will still want to record refusals of specific interventions in certain circumstances, in either a personal or an agent AD. For example, competent adults who already have a diagnosis and a prognosis for their condition will often develop a sound understanding of the course of their disease and the likely outcomes of various treatment options. The guidelines should advise such people to confer with their medical practitioner to ensure that their instructions will be properly understood and can be actioned, but assure them that the decision to refuse treatment is theirs to make and will be legally binding in the circumstances they specify.

Recommendation 8

THAT the guidelines include example outcome statements that have been tested through focus groups of lay people and experts to ensure a wide and common understanding of their meaning and intent

THAT the guidelines also provide advice to those who want to specify refusals of certain treatments in advance

Expressing wishes about a range of future circumstances

Although ADs in health care are usually associated with end-of-life decisions when a person is dying, they can be very useful to record wishes or delegate decision-making to others during periods of impaired decision-making ability earlier in the life course.

However it is important that when a person writes instructions or conditions in an AD, and particularly in a personal AD, they are clearly designated as intended to apply either only in end-of-life situations or at other times. Decision-making ability may be lost temporarily, such as in episodic mental illness, gradually as in dementia, or suddenly as in head injury. Different diseases can have different trajectories, some resulting in mental capacity being lost while mobility is maintained and others limiting physical capacity but not affecting decision-making ability. The guidelines should provide advice on how to write an AD to cover a range of situations in which ADs may be useful and explain the importance of designating under what circumstances any instructions or conditions are intended to apply.

Similarly, the guidelines should explain that instructions may be designated as binding or advisory and recommend that binding instructions be limited to described circumstances. Scenarios may be helpful to illustrate the pitfalls of blanket refusals of specific medical treatments or specific residential requirements. However guidelines should provide assurance that a refusal of a particular treatment, for instance on religious or ideological grounds, will be binding if the reasons are plainly stated and it is made clear that the refusal was intended to apply in all circumstances.

Web-based versions of forms and guidelines would allow for pop-up choices reminding people to designate when their instructions are intended to apply and whether or not they are intended to be binding. The hard copy versions should offer similar flexibility and specificity without complicating the form.

Recommendation 9

THAT guidelines advise that where instructions or conditions are recorded in advance directives, the person clearly designates when or under what circumstances they are intended to apply and whether they are intended to be binding or advisory

Instructions for after death

Submissions and consultations indicated that the public expects to be able to use ADs to indicate a willingness to donate organs or preferred burial plans. Rather than preventing such inclusions, the guidelines should advise that generally ADs and agent appointments cease on the person's death and encourage more appropriate means of communicating such information. For example, organ and tissue donation intentions are best registered on the Australian Organ Donor Register, and burial preferences in a will.

However the Review Committee recognises the usefulness in some circumstances of a record in an AD of what arrangements have been put in place and by what means. Sample statements in the guidelines may provide useful prompts, and forms could be designed to accommodate such information as an optional adjunct.

Recommendation 10

THAT guidelines advise that instructions intended to be followed after death may be written in an advance directive, but also point out more appropriate mechanisms for communicating such wishes to families eg organ donor register

Being able to write down things [in an AD] about where I want to be buried (my country)...would stop a lot of family squabbles

Personal communication, Aboriginal consultations

Guidelines for agents making decisions

Agents may need advice to assist them to make decisions based on outcome statements. The Stage 1 Report includes a pathway for agent decision-making which should be replicated in simple terms in the guidelines (see appendix).

The guidelines should emphasise that, each time a decision is required, in the first instance the person should be assisted to make their own decision if they are able, until it is determined that the person's decision-making ability is impaired to the extent that they are unable to make any decisions. Once it is determined that the agent should be making the decision, the guidelines should advise the agent to endeavour to make the decision the person would have made had they been competent.

Agents should be advised to consider the person's values and life-goals, comply with any relevant instructions on the form, and in the absence of instructions, seek their current views if possible, reflect on previous conversations and views expressed by the person, seek expert advice, consult with others, balance social and cultural factors as the person would, then, in the light of the advice and evidence available to the agent, make the decision. In the case of health decisions, the agent should seek to avoid intolerable or unacceptable outcomes and burdensome interventions as specified by the person in their AD or in previous discussions. The agent should balance the likelihood of treatment outcomes, in terms of their impact on valued life activities, with the burdensome nature of interventions. This is a lot for an agent to consider but a checklist presented in logical order would be helpful to guide and support agents when making decisions.

...it must be clear that the agent makes the decision based on their knowledge and belief of what the person would want and the medical advice at the time

30PI

Examples and scenarios would assist to illustrate what kinds of previous discussions count as evidence of a person's wishes, how to assess whether the person intended their stated instructions to apply in the current circumstances, and other potentially grey areas. The guidelines should provide general advice for agents when making financial decisions, including the need to keep records and protect the person's financial interests, and list sources of advice.

However, the guidelines should assure agents that there will often be more than one right decision in any given situation, so they are not required to determine the 'one right answer' but rather to think about what the person would have wanted and make a sound and considered decision that respects the person's autonomy.

Recommendation 11

THAT the guidelines provide a checklist for agent decision-making based upon the pathway outlined in the Advance Directives Review Stage 1 Report

Forms

Accessing the forms

The majority of submissions preferred that AD forms be readily available and free. At present, forms under the Consent Act can be downloaded for free from the Department of Health web site or collected in hard copy from Services SA. EPA forms can be downloaded free from the Land Titles Office web site, and both the EPA and EPG forms can be purchased from the Legal Services Commission and Services SA for about \$1, or as kits which retail for over \$20 and include guidance for completing the forms. Although cost may be a limiting factor in uptake of ADs, the uptake of MPAs and Anticipatory Directions (which are free) is considerably lower than that of EPAs and EPGs suggesting that cost is not the only determinant.

I balked at the cost of the EPA DIY Kit...I think it is wrong that the Government wants to make a profit on a kit which I believe should be a public service...

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It may be likely that forms and guidelines will increasingly be downloaded from the web site, considerably reducing the cost to government of printing and distribution. Web-based materials can be easily accessed from a home computer or through libraries and other community facilities. Regular users such as GP surgeries, aged care facilities and lawyers' offices will be encouraged to download forms for their patients, residents and clients from the web site or use the online facility.

Printed copies of the forms and guidelines for those who require hard copies should be printed and distributed from a central location to ensure effective stock management and data collection and, if reprints are ever required, the latest version is made available. The Review Committee suggests that the Legal Services Commission host the web site and that they and Service SA maintain stocks of printed copies, because they currently have the required infrastructure.

Members of the Expert Advisory Panel recommended that distribution be facilitated through multiple community sources such as council offices, divisions of GPs, Legal Services Commission regional offices, post offices, libraries and the Office of the Public Advocate. It should also be possible to order printed copies via phone or email from a central location such as the Legal Services Commission, and have them posted out.

Recommendation 12

THAT advance directive forms and guidelines be readily available and free

THAT the Legal Services Commission be resourced to manage the web site

THAT the Legal Services Commission and Service SA be resourced to manage the printing and distribution of printed copies of forms and guidelines

Form design

Current AD forms vary in colour, design and format, which adds to public confusion and doubts about the authenticity of unfamiliar documents. The Review Committee is aware that at present law firms print their own versions of the EPA and EPG for their clients, but agreed that this should no longer be permitted. The value of a consistent recognisable form outweighs the convenience of individual versions. The Review Committee recommends

that AD forms, guidelines and promotional materials follow an easily recognisable design and colour scheme to promote acceptance, recognition and awareness. This would be reinforced by a consistent web site design.

There should be information and forms available at all customer service centres and a web site with the same information 611

The Respecting Patient Choices Program uses a green sleeve in patients' medical record to identify advance care plans and ADs, and Flinders Medical Centre has advised that they are persisting with the green signature colour to facilitate easier recognition in their advance care planning program. This evolving consistency should be harnessed in the design of the forms and other materials. The Review Committee has been advised that forms prescribed in Regulations must be printed in black and white, so consideration should be given to prescribing only the contents of the form in Regulations. However the legislation could permit a professionally designed form to be approved by the Attorney-General as the legally recognised form. This would enable the exclusive use of a readily recognised form that will be easily authenticated. However, a black and white printed version would need to be acceptable because many people may be unable to print or photocopy forms in colour.

Recommendation 13

THAT a single recognisable design be applied to advance directive forms, guidelines and promotional materials

THAT only forms in a design and format approved by the Attorney-General be recognised as South Australia's statutory advance directives

Format and content of form

The personal and agent forms should be separate, but included in the one kit. Both should allow sufficient room for personal instructions to be written. Forms should be designed to allow for binding and advisory instructions to be designated, and for end-of-life instructions to be differentiated from instructions applying at other times.

There should be a simplified form with room for naming different agents and instructions 25PIL

The agent AD form should be designed to be suitable for someone intending to appoint an agent for only financial decisions or for the full range of decisions. The forms should be simple and straightforward for a person who just wants to appoint one agent to make all decisions, but be structured to allow flexibility to appoint different agents for different types of decisions. It should be possible, for example, to appoint one agent to make health and personal decisions on the 'health and life management advance directive' form and two other agents to make financial decisions on the 'financial advance directive' form. The witnessing section will need to be carefully designed to permit such flexibility.

Expert Advisory Panel members suggested that forms should be able to be completed in parts at different times. However, the layout of the form should encourage and enable

those seeking to address their financial needs to simultaneously appoint the same or different agents to make health and other personal decisions. By this means, the Review Committee hopes the uptake of health and personal ADs would increase to match at least the current uptake of financial ADs.

The Review Committee recommends the following be included in the form:

- The person's name, address and date of birth to enable confirmation of identity
- Contact details for all appointed agents
- A signed declaration that the person, their agent/s and monitor/s have read and understood the guidelines, and understand and accept their roles and responsibilities
- A witness statement and contact details for the witness in case it is necessary to seek further advice about evidence of the person's competence in the future (the Guardianship Board advises they would find this useful on occasions)
- The capacity to appoint both agents and monitors, and for separate witnessing for each appointment when they sign on separate occasions (particularly for interstate agents)
- A choice of triggers whereby they become operational, including frailty and immobility as well as loss of mental capacity
- Sufficient space to record values and life-goals, and a health-related section where preferred or intolerable outcomes, unwanted burdensome interventions and specific end-of-life instructions can be recorded
- The option of stating wishes about transfer from nursing home to hospital in the event of a life-threatening situation; this was requested by GPs specifically for elderly nursing home patients
- A built-in regular review process, with capacity to record the date of review if no changes are made, and a revocation section on the form to record when a new AD is completed

Consideration should be given to offering a choice of long and short versions of the form that allow for complex instructions to be recorded, but also for appointment of agents with no written instructions for those who would prefer to simply discuss their wishes with their agent. However use of the long version should be encouraged both to ensure that the person's wishes are recorded and known and to limit the potential of abuse by a single agent unfettered by either instructions or oversight.

Printed and electronic versions will require slightly different formats:

Printed forms

It is preferable the forms are able to be removed from the kit and completed as the person works through the guidelines, ideally with their agent or agents, much like the taxpack with which most people would be familiar. The kit for the agent AD would ideally include copies of forms for appointed agents that incorporate advice about making decisions on behalf of the person. The personal AD form should include a copy of the form for the person's GP or other health professional, including an explanation about abiding by the terms of an AD. The hard copy form would include sections for financial, health and other personal instructions, so any sections not used would be required to be crossed out and signed.

Web-based downloadable forms

The web-based version would enable multiple copies of blank forms to be printed and completed. It would be useful if information for agents or GPs could be printed on the back of the respective forms.

Web-based online forms

Online completion would provide the capacity to write longer statements and instructions on the form without the need for crossing out unused sections, and only sections completed would print. Although the form could be completed online, it would need to be printed then signed and witnessed. Multiple copies could be printed, and the completed form could be saved and emailed for advice or comment from others.

An online form with a prescribed computer design that I think would better serve the purpose than with the written word only...Scenarios can be used to highlight the different situations people could find themselves in....which will be easy to do with a computer software programme

25PIL

As technology advances, making available a secure means of recognising and validating electronic signatures, AD forms may be able to be completed and witnessed online.

Privacy considerations

Advance directives are personal, rather than private, documents.

The value of an AD is diminished if its existence and contents are kept secret. Research indicates that many people confuse ADs and wills, believing that the instructions they write in an AD for their agents mean that they are private and should not be shared. However, in order to ensure that agents are acting legitimately and abiding by written wishes, others need to be aware of who has been appointed and what the AD permits them to decide.

Ambulance officers are sometimes made aware that an AD exists and told of the contents, but it either cannot be found (because it has been securely hidden from view) or the spouse refuses to share it 'because it is private'. The guidelines and forms should make it clear that copies should be shared and originals should be filed where they will be able to be accessed when they are needed in order for the person's wishes to be followed.

Tasmanian legislation makes advance directives public documents and requires their registration on a public register. Tasmanian forms require a statement to be signed to the effect that the person understands that the completed and registered form will be a public document.

Nevertheless, the Review Committee recognises that it would be inappropriate for the bank to hold a record of a person's health instructions, or a hospital to include instructions of a financial nature in the medical notes. It is suggested that the agent advance directive form be divided into two sections: the health and life management advance directive and the financial advance directive. This would permit it to be printed or copied in sections, so that copies of relevant pages can be provided to appropriate people. It may be possible to have the name and contact details of agents with the witnessed signatures on the first page, and the person's values and life-goals recorded on another page, with either financial instructions or health and other personal instructions recorded on subsequent pages. This is a matter of expert form design.

Recommendation 14

THAT it be made clear in guidelines that advance directives are personal rather than private documents, which must be readily available when needed

THAT form design allow for financial sections to be separate from health and other personal sections so that copies can be distributed appropriately

Witnessing

Protective function

The Stage 1 Report explained that witnesses provide a protective function for those completing ADs by ascertaining that the person

- is an adult
- is signing the document voluntarily without coercion, pressure, or undue influence by others
- appears to understand the choices, context, and consequences of completing an AD.

If the witness is not satisfied that these criteria are met by both the person and their agent/s, they must refuse to witness the document. The person and the agent may complete the forms at different times and in separate locations. Separate witnesses would be permissible, but the witness must assess whether the individual understands what they are doing and is signing the form voluntarily.

The guidelines should explain the role of the witness and the requirements and limitations placed on them. Guidelines should provide a list of questions that the witness should ask so that the person, their agents, and the witness have a common understanding of the witness' role. It is important that the witness interviews the person alone, without agents present. If the person has limited proficiency in English and the witness is not proficient in the person's native language, an interpreter who is neither a family member nor an agent should be used.

Witnesses should be required to complete a checklist on the form of criteria that must be met, confirming that the questions asked were answered to their satisfaction. They should sign a witness statement on the form and record their credentials and contact details.

Witnesses should be encouraged to keep a diary record of ADs they witness, including names and dates.

Witnesses should be independent

21PIH

Recommendation 15

THAT witnesses be required to sign a witness statement attesting that they are satisfied the person and their agent/s meet the criteria for validity

Who should be a witness

The Review Committee considered several alternatives when determining who should witness ADs including whether:

- there should be one or more witnesses
- the witness should be independent and objective
- the witness should know the person
- there should be two witnesses, one independent and one who knows the person.

Queensland forms require a single witness whereas Tasmanian forms require two. Victorian forms require two witnesses, one a statutory witness from a list and another who can be a friend but not a relative. There is value in the witness being an independent and objective person previously unknown to the parties. The benefit of a second witness who

knows the person is that they may be in a better position to ascertain whether there is coercion, undue pressure, or lack of understanding.

The Review Committee agreed that one independent witness was sufficient, as there is evidence that bringing together a number of agents and witnesses can be difficult and can present a barrier to completing ADs. Feedback suggests that making witnessing requirements more onerous would reduce uptake of ADs.

I have been a JP for over 30 years and have...attended the library on a weekly basis [to witness documents]...this is utilized and people who attend are very grateful
19IL

In the Stage 1 Report the Review Committee recommended that family members, agents, paid carers, and treating health professionals not be witnesses because of the potential for them to have a conflict of duty when decisions are required. In Stage 2, the Review Committee explored alternatives for who should be a witness including whether:

- the law should prescribe a list of witness categories
- only trained witnesses should be permitted to witness ADs
- JPs should be allowed to be witnesses
- witnesses should only be JPs
- there should be a list of professionals approved as witnesses
- witnesses should simply be registered professionals

The Review Committee did not seek to limit the number and range of people who could be witnesses but received expert advice about the importance of witnesses understanding their role and being competent to carry it out.

Currently the three Acts list several categories of people who can be witnesses, which are not consistent. They all include certain lawyers and JPs, but the MPA and Anticipatory Direction include certain qualified professionals such as pharmacists and members of the clergy, and also police officers who have been 'proclaimed' for the purpose. Issues raised in this review illustrate the current confusion and inconsistency with classes of persons acting as witnesses to various documents. The Review Committee preferred a wider range of witnesses than is currently available to ensure ease of access, but that witnesses be trained professionals.

Expert witnesses raised concerns about JPs witnessing ADs without recent training, and particularly about elderly JPs continuing to witness documents when they may no longer have the ability to discern whether coercion or undue influence is occurring. JPs are able to witness a signature, but assessing that strict criteria are met requires special training.

After considerable deliberation, it was decided that witnesses should not be limited to a list of categories. The Review Committee agreed that witnesses should be required to be 'registered professionals' who had completed an accredited training course. This would mean that any professional active in a profession that was required to be registered in order to practice (such as lawyers, police officers, registered nurses, pharmacists and teachers) could complete a training course and witness ADs. JPs would also be able to witness ADs provided they completed the required training and undertook regular refresher training. This would increase the availability of witnesses in the community. Professionals who have been deregistered for an offence and JPs who failed to complete refresher courses would cease to be accredited witnesses, which would help to maintain high standards and increase protections for the public.

Retired registered professionals who continue to take refresher courses at regular intervals could continue to be recognised as accredited witnesses. In the interests of retaining their involvement (but only so far as they remain competent themselves to carry out the function)

the Review Committee suggests that the extension to post-retirement may be beneficial for both witnesses and communities, especially in rural South Australia.

I believe they [witnesses] do need special training - such training has been given by various groups and training is also available through TAFE...

19IL

An exception would be required to recognise the role of notaries, who witness advance directives for South Australian citizens who reside outside of South Australia, including overseas. However, notaries would also benefit from regular training which could be undertaken through online tutorials.

It is appropriate that a registered training organisation develop and provide the training course for witnesses. A list of accredited witnesses needs to be maintained that is publicly available and linked to the AD web site. The training need not be onerous, but must set an acceptable standard that ensures witnesses are competent and knowledgeable. Registered training organisations could access legal training expertise at other organisations such as the Legal Services Commission, and could train and accredit other trainers to deliver the course. The course should also be available in tutorial format online. Funding will need to be provided to enable the course to be provided for free or at minimal cost, but should be free for retirees who are continuing their witness role.

The Review Committee recognised the need for an incentive for people to undertake training to become a witness, such as a business benefit or professional development. The course should be of a level that may be recognised as professional development. Accredited witnesses should be permitted to promote their accredited status at their place of business and to place advertisements in the local press.

The Review Committee recognised that lawyers are likely to continue to charge for completing and witnessing ADs, but other registered professionals such as pharmacists and police officers have not generally levied a fee for witnessing such documents. Most current witnesses regard confirming competence and signing a legal document as a public service. It would be unreasonable to prevent lawyers charging their clients if they provide legal advice as well as witness ADs, and GPs must be able to bill their patients if they provide medical advice in the course of a consultation where they witness an AD. However charging for only witnessing ADs should not be permitted and an advance directive witnessed as part of a medical or legal consultation should not attract a supplementary fee for the witnessing. The extended range of witnesses should make it easier for people to find a witness who does not charge if cost presents a barrier to them completing an AD.

Recommendation 16

THAT witnesses be registered professionals and JPs who have completed an accredited training course, and notaries practicing interstate and overseas

THAT consideration be given to allowing retired registered professionals who undertake ongoing or refresher training to continue to be witnesses

THAT witnesses not be permitted to charge a fee for simply witnessing an advance directive

Retrieving and using advance directives

Retrieving completed forms

Ensuring availability when needed

Unless completed AD forms are readily available when decisions need to be made, their usefulness is seriously diminished. The Review Committee heard stories of ADs being filed away in lawyers' offices, hidden under the bed with the person's will, or secured in a bank vault with the house deeds. Sometimes the AD was not found until the will was read or the house was to be sold.

The Review Committee considered several options to ensure availability of ADs that fall into three categories:

1. rely upon personal alerts
2. rely upon existing information management systems
3. establish a new system of registration.

The Review Committee agreed that reliance on personal and existing system alerts provided reasonable coverage, by enlisting both individuals and professionals in assuring ADs are known about so they can be actioned. The value of establishing a South Australian advance directive register was questioned. The Review Committee reached the view that a register would not add sufficient assurance that a completed AD would be found when needed or offer protection from abuse to justify the significant establishment and running costs it would entail.

Personal alert mechanisms

There are many strategies that individuals can apply personally to ensure their AD is available when they are unable to make decisions.

Providing copies to others

The most reliable mechanism is providing copies to others at the time the AD is completed. This should be emphasised in the guidelines as a fundamental first step. Currently EPA and EPG kits include two copies of the forms which can be simultaneously witnessed and signed, so that the agent is immediately provided with their own copy. Online mechanisms would allow for multiple copies of the completed form to be printed. The Review Committee suggests there may be value in providing separate information sheets in the kit for

- agents and monitors that explains the decision-making framework
- the person's GP, hospital or aged care facility to be incorporated into their file, which provides advice on how to abide by an AD
- the person's bank, accountant or financial advisor for their files which provides advice on the legal status of ADs in South Australia.

Consultations revealed certifying copies can be onerous but may need to be continued. Advice can be given that banks, GPs and others need only sight the original and then take a copy for their file. They should not need an original in their file, but could mark the copy to indicate the original was sighted. Currently financial institutions frequently require ADs to be produced, with a certified copy preferred rather than compromising the integrity of the original document. The original document is usually left with the solicitor or retained by the person completing the AD or their agent. The reasons for certifying copies where they are legally required should be explained in the guidelines.

...there is merit for a tear-off or punch out card for the wallet/purse containing vital information about wishes and agents 1PIL

Personal alerts

Currently, Rotary clubs distribute 'fridge magnets', a clear plastic pocket labelled 'Emergency Medical Information Book' in green which can contain an AD or important medical information and be affixed to the fridge. These were designed by the SA Ambulance Service to make it easier for ambulance officers to retrieve such information, and promoted through seniors groups. They have proved popular amongst elderly South Australians, and the program should be supported and extended. Having a free fridge magnet may stimulate interest in completing an AD to put into it.

GPs expressed concern that their nursing home patients' ADs were often not available outside of routine hours because they were filed securely in the office of the director of nursing and rendered inaccessible to the locum doctor and the agency nurse on duty. A similar mechanism to the fridge magnet – perhaps a green pocket and card that could be affixed to the back of a resident's door – is required for such situations.

In addition, the Review Committee recommends that a wallet card be included in the kit, and be downloadable from the web site, to enable recording of agents' contact details and where the AD is stored. This mechanism has been used interstate and overseas and found to be useful, particularly in an emergency eg car accident.

Family discussions

Research into organ donation rates indicates that discussion of future wishes with family and friends is critical to ensuring that information is available about a person's wishes when others are making decisions on their behalf. The message to 'tell your family and others close to you your wishes' is just as valid for advance instructions intended to be actioned during periods of lost or diminished capacity during the person's lifetime.

Reports indicate most people complete agent advance directives but do not record any instructions, which makes prior discussions critical for agent decision-making. A national campaign would be the optimum means of addressing this, as all states and territories face similar challenges with implementing their ADs.

[I have a large family with many different relationships]. If everyone knew what the wishes were then it would reduce stress, arguments etc. It would still be difficult but it would make it simpler knowing that these were the wishes and that someone is there to see that they are respected
30PI

Recommendation 17

THAT those completing advance directives be encouraged to provide copies to relevant people

THAT wallet cards be provided and fridge magnets be promoted to help ensure that the existence of advance directives is better known, and contact details of agents can be readily retrieved

THAT an ongoing program encouraging the public to discuss their future wishes be implemented, and that Ministers work towards a national program in the longer term

Existing alerts

Electronic alerts are likely to be the favoured means of communicating important personal information in the future. The Review Committee considered several existing opportunities.

Personal cards

Medicare cards are distributed nationally by the Commonwealth government, but do not currently include state-specific information. They are unlikely to provide a suitable means of recording ADs because families often have multiple people listed on one Medicare card, so it will not be apparent to whom the AD alert pertains.

Consideration is being given to whether the proposed 'Australia card' to be issued to each individual adult could record a person's organ donor status. Whether it may also be able to accommodate AD status at a state level would need to be explored nationally.

Driver's licences are issued to individuals and are state-based, but not every adult has a driver's licence. Non-drivers are able to apply for an identity card. The South Australian driver's licence card currently records organ donor status. These cards may be able to accommodate an AD alert.

None of these systems is likely to be able to record information about the contents of an AD or the contact details of an agent, but would alert to the existence of an AD. This may be useful for health ADs, but does not offer many benefits for financial ADs.

Existing information management systems

There is no common computing system across the health, aged care and financial sectors. The aged care sector and the private health sector are regulated by the federal government while the public health sector is state regulated. The financial sector is mainly private, but regulated by federal legislation.

The hospital admission form used across South Australia's public health sector provides a place to record which AD the patient has completed, but emergency admission forms do not record ADs. The USA Patient Self-Determination Act requires all hospitals to ask on admission whether the patient has completed an AD, which has driven an increase in uptake of health ADs. It is recommended that national accreditation standards for Australian health, medical and aged care facilities require that advance directives be checked on admission with copies filed in the person's record, and any treatment plan written is congruent with the person's AD. The use of a green sleeve in the front of hospital medical records should be encouraged to ensure that ADs and advance care plans are readily accessible. This could be usefully extended to residents' records in aged care facilities and patients' records in GP clinics.

There is a trend internationally towards incorporating ADs and advance care plans into health and hospital information systems, and ensuring that clinical staff are alerted to their presence and contents at appropriate stages of admission and treatment. International studies show that this can increase the uptake of health ADs and better ensure that treatment complies with the patient's expressed wishes. There are existing computing systems within the South Australian health sector with the capacity to record the existence of an AD. A computer network called OACIS records patient information across the South Australian public hospital system and is being rolled out to some GP surgeries and community health providers. OACIS allows sharing of diagnostic and prescribing information when a patient is being treated at a facility distant from their medical or hospital file. It is intended that over time OACIS will be extended to most GPs, country hospitals and the SA Ambulance Service and will permit 'alerts' to be highlighted. OACIS complements and links with other hospital-based computer networks, but does not extend into private hospitals.

A system of alerts has been developed to enable OACIS to record the existence and type of AD on admission, but is yet to be implemented throughout the health system. The facility to scan ADs and call them up on screen is being investigated. It is important that completed

ADs are scanned rather than summarised because of the risk that a typed summary might be incomplete and misleading.

Unlike OACIS, the national HealthConnect computer network is voluntary and patients choose whether to enlist on it. It does not currently seek information about completed ADs. In the future, there may be potential for all personal health information, including a person's ADs, to be included in a national portable electronic health record.

Lodgement of an EPA with the Lands Titles Office is currently required before a financial agent can sell real property, such as a person's home or land. Lodgement is usually delayed until it is required for the sale of real estate, whereby the Land Titles Office stamps and numbers the original and retains a copy. It is considered prudent for EPAs to be lodged before the person loses capacity if it is anticipated that a person's home will need to be sold to secure their ongoing accommodation in care so that any problems with the AD can be resolved early. The fee for lodgement is in excess of \$100, and applies also to any revocations and changes that require re-lodgement. It is intended that the requirement for LTO lodgement of ADs would continue where an agent is appointed to make financial decisions involving the sale of real estate.

Recommendation 18

THAT the Minister for Health propose to the Australian Health Ministers' Conference that accreditation standards for health, medical and aged care facilities require that advance directives be checked on admission, are filed with the person's record and can be easily located

THAT resources be available to ensure that hospital information systems can record the existence and contents of the health-related sections of advance directives, and these be made accessible across the broader South Australian health system

THAT the use of a green sleeve in the front of a hospital medical record to hold ADs be promoted and encouraged

THAT lodgement of financial advance directives with the Lands Titles Office continue under current arrangements for people who own real property

Values and limits of a register

Submissions presented mixed views about the benefits of a register to record completed advance directives. Most submissions that supported a register agreed registration should be free but were divided about whether it should be compulsory.

*[registration] is too cumbersome...there could be optional registration
..if it were compulsory there would be a question as to whether
directives not registered are valid... 701*

A register should ensure that the existence of an AD is known when it is required to be used for decision-making, and that its contents can be retrieved in a timely manner so decisions will be informed and made by the relevant agent/s where appointed. Registers of financial and health ADs have been implemented overseas, however there is little evidence internationally or locally that registers of health ADs achieve these outcomes. Unless registration is both free and compulsory and a program is in place to generate a high level of ongoing awareness about registration, registers tend to be incomplete and thereby lose some of their efficacy. The Review Committee recommends against requiring an AD to be

registered in order to be valid, as this risks reducing the number of ADs completed and complicating the process.

Tasmania is the only Australian jurisdiction to require completed advance directives to be registered. Tasmanian EPAs must be checked by and lodged with the Land Titles Office and EPGs must be registered with the Guardianship Board in order to be considered valid. Guardianship Board registration is free but, as in South Australia, LTO lodgement attracts a substantial fee.

The Review Committee considered schemes such as the Tasmanian register and examined the benefits of registering an AD at 'activation'. However, for most people 'activation' is not an event, it is a process that happens over time. The person sets the trigger for its use, and may or may not set conditions on the agent. Decision-making ability is usually lost by degrees, and the agent takes on progressively more decisions over time. Fluctuating capacity can mean that the agent makes some decisions for a period of time, but when the person recovers decision-making reverts to the person. Consultations indicate public support for advance directives to be used during episodic mental illness to respect the person's autonomy.

The Advance Directives Review Committee's decision-making pathway recognises and accommodates fluctuating capacity and episodic mental illness by requiring that the agent:

1. initially checks whether the person can make the particular decision, and ensures optimum circumstances for decision-making
2. then supports the person to make their own decisions
3. then takes over complex decision-making that the person finds beyond them and
4. only when decision-making ability is lost completely and irreversibly does the agent take over.

The Review Committee concluded that there is often no defined point when an AD is 'activated' and 'activation' needs to be reversible, making a registration scheme based upon 'activation' unworkable for the public.

South Australia has had a voluntary register of MPAs and Anticipatory Directions with MedicAlert since 1999. ADs registered with MedicAlert were reviewed in 2004 when the Chief Executive Officer advised that MedicAlert had never received a request for information about registered ADs from a medical or ambulance officer. At that time, there were less than 200 ADs registered, predominantly in its first two years of operation and mostly by very elderly people, so it is likely that many of the registrants are now deceased. There were EPGs registered as well as MPAs and Anticipatory Directions, and also some interstate ADs. Registrants are issued with a bracelet or pendant inscribed 'palliative care act' (in reference to the Consent to Medical Treatment and Palliative Care Act). There is a one-off cost of \$55 for registering, but no follow-up unless the registrant has registered other medical information, in which case they are contacted annually to update their file, including their ADs, at an annual cost of \$16.50.

The Review Committee investigated the Tasmanian register and found that the Tasmanian EPG register was similarly unsuccessful in the beginning, with only 200 EPGs registered in the first six years. More recently an active publicity and education campaign by the Tasmanian Guardianship Board and Public Advocate increased awareness of ADs and there are now approximately 8,000 registered documents. About 2,500 of these have been completed by Jehovah's Witnesses, who have adapted the statutory form for the specific purpose of refusing blood transfusions.

Overseas registers in Scandinavia, Canada and the USA were examined, but many of these are privately run, voluntary and expensive for registrants. No international model covers both financial and personal ADs.

Clearly the usefulness of a register relies not on the person registering their AD, but on the professional who is required to abide by it seeking to affirm its existence. Establishing a register without mandating it be accessed would inappropriately raise registrants' expectations that their wishes will be known and acted upon in the future should they lose the ability to make their own decisions. It is not clear why no health professional had ever contacted MedicAlert seeking information about an AD. MedicAlert is contacted regularly

about drug allergies or other medical information, but it may be that the words ‘palliative care act’ on a bracelet is not a meaningful prompt.

However, international evidence suggests that medical practitioners are prepared to consult agents who identify themselves as such and relatives, but are reluctant to access registers of patients’ preferences. It is therefore more important that relatives are made aware of the existence and contents of an AD. This is also borne out by the Australian experience with the national register OF organ donation intentions. Medical practitioners are expected to check the Australian Organ Donor Register routinely when a person is diagnosed as brain dead to determine if they recorded their wishes about donation, however a high proportion of intensivists surveyed stated they did not (and in many cases would not) check the register, despite the high registration rate of potential organ donors.

In determining the likely benefit of an AD register, the Review Committee considered a number of questions:

- Who should manage the register? Should it be government run, or devolved to the private sector?
- Should the register be free or charge a fee? Should it be government funded or contracted to a private provider on a fee for service or grant arrangement?
- Should the register be voluntary or compulsory? Would only a select few register their AD if it was voluntary, like MedicAlert? Would a low registration rate discourage professionals from checking the register?
- Could a single register accommodate both financial and health/personal ADs?
- Who should register an AD? Should ADs be registered when they are completed or when decision-making ability is lost? How would this point be determined since loss of decision-making ability may be gradual, reversible, or fluctuate?
- Should ADs be considered invalid until they are registered? How would it be clear on reading an AD (without checking the register) that it was validly registered?
- Would a revocation be invalid until it was registered? If an AD is revoked, would the last registered AD be considered valid?
- Should register staff check that the AD was properly completed and witnessed before accepting it for registration?
- How would existing ADs be accommodated if only registered ADs were valid? What if the person had already lost capacity?
- Should the register only hold information about the registrant, contact details of agents, and where the AD can be found? Or should it retain and provide a full copy of the AD?
- Who should be permitted to access the register? What identity checks would be needed to authenticate enquiries?
- How should the registered AD be provided? By fax? By email? Read over the phone?
- How would a register monitor the actions of agents? Could a register prevent abuse by agents? Would the fact that the AD is registered deter fraudulent decision-making?
- Can professionals be compelled to check a register when circumstances arise whereby a decision is needed for a person with impaired decision-making ability?
- Could a register be accessed in a health emergency? Registers of financial ADs may only be required to keep business hours, but access to health ADs may be needed at any time of the day or night.

The Review Committee discussed these complexities at length, recognising that establishing a register of ADs in South Australia would be a serious undertaking with a high level of establishment and resource costs. If the benefits of a register are not commensurate with such public investment, then a register of ADs could not be justified. The critical outcomes sought are that

- the existence of an AD is known
- the AD can be retrieved
- the contents can be accessed or the agent contacted
- abuse and fraud are prevented.

Overall, the Review Committee recommends that the benefits of a register do not outweigh the impositions. The Review Committee believes there are better means of assuring these outcomes are achieved that do not bear the cost and resource implications of a register. There is no evidence that requiring registration prevents abuse or raises the uptake of advance directives. However, adding unnecessary administrative steps risks ADs being seen as overbearing government bureaucracy rather than a means of personal empowerment, and is likely to confuse the public and limit uptake; complicate decision-making by agents; complicate care by GPs, ambulance officers, hospitals and aged care services; and overload the Guardianship Board and its staff.

Evidence indicates the unreliability of requiring professionals to routinely check a register. It is better to rely on means such as wallet cards whereby the person or their agent, both of whom have a direct stake in the terms of an AD being applied, brings their AD to the attention of professionals. Fraudulent decision-making would be better addressed by encouraging people to appoint their own monitor and require regular reports. All in all, the closer the recording and retrieval system is to the person and their agent, the more likely it will be used, and used effectively.

Financial ADs could be considered separately. Although banks and financial advisers often keep a copy of their clients' ADs with their files, there is no register of financial ADs. Most banks are national and apply national policies to their local branches, which may not properly account for variations across state and territory laws. An assessment of bank and credit union policies demonstrated divergent practices from close scrutiny of ADs by senior staff to ensure they were validly completed to simply taking a copy for the file. It would be difficult to establish a state register of financial ADs and legally require national banks to check it, and a register of ADs would not of itself limit fraud or abuse.

The Federal Parliamentary Inquiry into the Law and Older People recommended in 2007 that the Standing Committee of Attorneys-General develop and implement a national register of enduring powers of attorney. The Review Committee considered the benefits of a national register of financial, health and life-management ADs, recognising the benefits that might accrue to authorities in such an arrangement, but preferred a model premised on making ADs more accessible.

The Review Committee suggests instead a national voluntary *repository* for ADs, to enable people or their agents to retrieve their AD or know where it is stored when it is needed, which may be of benefit for the many Australians who travel interstate or relocate. A national repository would introduce economies of scale, accommodate the variations in ADs around the nation, and make 24 hour access more economically feasible. Submissions suggest that to be most effective a national advance directives repository would need to be free to registrants and enquirers, and preferably be web-based to enable ADs to be scanned in without alteration or transcription and to ensure broad geographical accessibility.

Recommendation 19

THAT South Australia not establish a State register of advance directives

Encouraging regular review

Consultations with local experts confirmed concerns reported in the international literature about ADs 'becoming out of date'. Local evidence suggests that sometimes an appointed agent has died or lost decision-making capacity when they are needed to make decisions. In addition, current medical ADs require medical instructions, so they sometimes stipulate refusals of treatments that are no longer used. However, this problem is better addressed by discouraging the writing of medical orders in ADs and instead recording life-goals and preferred outcomes. Nevertheless, the Review Committee recommends that strategies for keeping ADs up-to-date should be examined.

The Review Committee considered the value of setting an expiry date on ADs, perhaps of 5 or 10 years. However, it was decided automatic expiry was unlikely to ensure ADs remain current and would compromise the autonomy of people whose capacity diminished at or around the expiry date who were legally unable to complete a new AD or rewrite an expired one.

An annual living will day would be a good idea...a reminder to check and update paperwork...a video or DVD should be made for distribution to education centres and for the general public
52IH

International literature emphasises the need for public education programs and regular reminders to increase the uptake of ADs. The guidelines should encourage people to review and if necessary update their AD as personal and family circumstances change, in much the same way as they should regularly update their will. The onset of a chronic disease, the death or disability of an appointed agent or a change of living arrangements or circumstances may precipitate a change to an AD. Sometimes there may be external changes that prompt a review. The discovery of new treatments for a diagnosed condition may alter a person's perception of burdensome interventions, or increasing age and acceptance of constrained mobility may make circumstances previously deemed unacceptable seem more tolerable. If the terms of an AD require amendment, the guidelines should advise that a new AD be prepared and the original revoked.

To support this advice, an annual 'life in order' day is suggested as part of the public awareness program. South Australians should be encouraged once a year to review their advance directives, their wills and their organ donor status. Lawyers, financial advisers and GPs should be prompted to remind their clients and patients to review their ADs at regular intervals or whenever circumstances change.

Recommendation 20

THAT the guidelines recommend advance directives be regularly reviewed and updated

THAT there be a public reminder program, such as a 'life in order' day, to encourage annual review of completed advance directives and to prompt professionals to remind their clients about the need to review their advance directives

Making decisions under advance directives

Capacity assessment

An assessment of the person's decision-making ability may be needed to determine

- whether a personal AD should be followed
- whether an agent needs to make decisions
- whether a relative or carer needs to make decisions in the absence of an AD.

The Stage 1 Report explored capacity and decision-making at some length, acknowledging that decision-making ability may fluctuate or slowly fade, and that people sometimes lose insight into their own capacity so resist delegating decision-making to others. The Review Committee recognises that in ordinary circumstances agents routinely assess whether the person is able to make their own decision on a day-to-day basis, and problems seldom arise. The Stage 1 Report recommended that such informal assessment of decision-making ability by agents continue, and that a formal assessment of capacity only be required if there is disagreement or the person's capacity is questionable.

The guidelines therefore should include general advice for agents about assessing the decision-making ability of the person to make the decision in question including:

- supporting the person to make their own decision to the extent possible
- assessing the person's process of decision-making, not the decision they make
- not making assumptions about the person or their values
- respecting the person's values, and not applying their own
- taking sufficient time and explaining the context, consequences and choices in a way the person can understand
- considering the nature of the decision to be made, its complexity and the risk of adverse outcomes
- choosing the optimum time of day and circumstances to enable the person to make their own decision, or deferring the decision if possible to a time when decision-making ability is optimised, and
- seeking advice to confirm their assessment if they are unsure or if agents disagree.

Similar advice will be relevant to relatives making decisions for a person in the absence of an agent AD or a guardian, who may not have read the advance directive guidelines. Such advice may be best communicated to the broader community through educating health, aged care, legal and financial professionals.

More specific advice will be required by health and aged care professionals who may need to make decisions, or assist relatives to make decisions, when a personal AD has been completed but no agent is appointed. This should be included in the guidelines for professionals (see Section D).

Medical professionals have too much power to decide incapacity...should outline a test for capacity and provide for partial or fluctuating capacity

701

The Review Committee lamented the absence of comprehensive national guidelines on assessment of decision-making capacity, but recognised these are needed to address broad issues across all jurisdictions, not just in South Australia. Capacity is assessed for many decision-making circumstances besides determining whether an AD should apply. The Review Committee considered what happens at the moment, whether practice should be standardised, and the level of advice that South Australian guidelines should provide. It was concluded that, rather than prescribing specific guidelines applying to South Australian ADs, nationally agreed guidelines for assessing decision-making capacity should be developed by experts.

A similar conclusion was drawn by the Federal Parliamentary Inquiry into the Law and Older People in 2007, which recommended that a nationally consistent approach to the assessment of capacity be developed and implemented through the auspices of Australian Attorneys-General and Health Ministers.

The New South Wales Government has very recently produced a Capacity Toolkit² to guide professionals and carers who need to assess a person's capacity or make decisions for them. This document relates to the application of NSW legislation and advance directives which limits its relevance for South Australians. However the principles it espouses are sound, the advice it provides is consistent with the Review Committee's recommendations, and the language and format used makes it very accessible. A more generalised national

² http://www.lawlink.nsw.gov.au/lawlink/diversityservices/LL_DiversitySrvces.nsf/pages/diversity_services_capacity_toolkit

version of this document that is not specific to the legislation in any single jurisdiction would be a useful guide to assess capacity. In the interim, with the cooperation and permission of the NSW Attorney-General's Department, there may be value in adapting the NSW version to the South Australian legislation and making it available locally.

Recommendation 21

THAT the guidelines include general advice for agents about assessing the capacity of the person to make the decision in question

THAT the Attorney-General proposes to the Standing Committee of Attorneys-General that the NSW Capacity Toolkit be adapted so it applies generally across Australian states and territories

Making decisions with a personal advance directive

At present there are four South Australian ADs and evidence indicates people may complete one or more of them in various combinations. It is not unusual for a person to complete only an Anticipatory Direction to provide medical instructions for their end-of-life medical treatment. The proposed personal AD will provide a broader scope than the Anticipatory Direction, and will permit people to write instructions to apply to a wider range of circumstances, record values and life-goals, and advise about residential and other personal preferences.

Some people will complete a personal AD and set their wishes and preferred outcomes for health and care in place, and back that up by appointing an agent to make decisions. In those circumstances, the terms of the personal AD will bind the agent where they are relevant and intended by the person to apply. Others may choose only to complete a personal AD without appointing an agent, so relatives (broadly defined as described in the Stage 1 Report) and health and aged care professionals will be legally required to adhere to the terms of the personal AD where they are relevant and intended by the person to apply. A personal AD will not cover financial decision-making.

Guidelines will be necessary to assist relatives and professionals to make decisions in this new environment. The decision-making pathway for agents described in the Review Committee's Stage 1 Report (see appendix to this report) is intended to also apply to relatives when making decisions. In addition to the guidelines that accompany the forms, to help relatives follow the pathway, a concise stand-alone pamphlet describing and explaining the decision-making pathway in simple terms should be developed and be made available in hospital and aged care facilities. Since agents are required to follow the same decision-making pathway, there may be value in these being made relevant to both relatives and agents. The Office of the Public Advocate booklet 'Now you are a Guardian' provides a model, and the NSW Capacity Toolbox includes advice that would be relevant.

I never thought about separate sections for the different [decision-making areas] events but I think it is a good idea as the medical interventions will be different in different circumstances. It also gives the AD a clearer path to designate when they are prepared to die and not accept traditional treatments
21PIH

Separate specific guidelines for health and aged care professionals should include decision-making pathways under a personal AD and emphasise the requirement to consult with and advise relatives and those close to the person. It will be important that decisions are made

by those who know the person and understand their life-goals and values, but that their decisions are informed by the advice of knowledgeable professionals.

Both the professional and public guidelines will need to make it clear that

- health professionals make an assessment about what treatment interventions might be futile and therefore not warranted and what treatment options should be offered
- it is the relatives' role to determine, following the decision-making pathway, what treatment the person would have consented to or refused in the current circumstances.

In the absence of any relatives or carers able or willing to make a decision, or in an emergency where a personal AD is available to guide decision-making, the health professional will be required to make a decision about treatment that is consistent with the terms of the personal AD. In assessing the relevance of those terms, the health professional will need to make an assessment, in good faith, of whether the terms are relevant to the current situation and whether the person intended their instructions to be applied in the prevailing circumstances. This is no different to what health professionals are required to do currently when presented with an Anticipatory Direction.

The guidelines and forms will encourage those completing personal ADs to record outcomes they would find intolerable or unacceptable and interventions they would find burdensome or intrusive to guide the health professional's decision-making. It will be important that the law offers adequate protection to health professionals who make a decision in good faith that

- a given intervention had not been refused and
- would not be expected to result in an outcome the person described as intolerable.

Such decisions should not attract criminal or civil liability (provided there is no evidence of negligence) even if the outcome subsequently adversely affected the person's quality of life to an extent they would find unacceptable. A team approach to such decision-making is currently the norm, especially for treatment withdrawal, and should be encouraged. It must be acknowledged that medicine is not an exact science and outcomes are not entirely predictable.

Recommendation 22

THAT the guidelines for the public include advice for relatives to assist them to follow the decision-making pathway when the person has completed a personal advance directive but not appointed an agent

THAT guidelines for both the public and professionals explain that health and aged care professionals must consult with relatives if circumstances permit, and that if no relatives are available, such professionals are bound to follow the same decision-making pathway as relatives

THAT a concise stand-alone pamphlet explaining the decision-making pathway for relatives and agents be developed and made available in health and aged care settings

Making decisions with an agent advance directive

Given the experience with current ADs, it is anticipated that many people completing an agent AD will simply appoint an agent but not write instructions. Some will choose not to complete the section on values and life-goals, but rather to have that discussion with their agent. The guidelines included with the form should assist agents to make decisions in a range of such circumstances, and should advise the agent how to follow the pathway in making their decision. The guidelines should make it clear that health and aged care professionals are required to consult with agents and advise them about available treatment interventions that are likely to be beneficial, but it is the agent who ultimately makes the decision.

The guidelines that accompany the form should help the person conduct a discussion with the agent so they can better understand the person's values, the types of decisions they want their agent to make, with whom they want their agent to consult, and the level of flexibility they accord their agent in following their wishes.

Fluctuating capacity could be assessed by agents by always seeking the person's views and using substituted judgement based on the knowledge of the person

601

The guidelines should advise agents

- how decisions will be made if they are uncontactable, unable or unwilling to decide
- about agents' obligations to make collaborative decisions if more than one agent has been appointed and the AD requires them to make decisions together, emphasising that it is the duty of the first agent contacted to consult with the other agents
- about the requirement to inform other agents of decisions made separately if the AD permits individual agent decision-making
- how to work with and report to a monitor, if the person has appointed one
- to seek advice if there is disagreement between agents or the person is uncooperative, and to whom they can turn to help resolve disputes
- how to apply to the Guardianship Board to be removed from their role of agent if they are unable or unwilling to continue.

Recommendation 23

THAT guidelines for agents include advice about

- *discussing intentions when an agent advance directive is being completed*
- *following the decision-making pathway when making decisions using an advance directive*
- *any obligations to report to or consult with others and*
- *how to seek help with dispute resolution*

Financial advance directives

Protections against abuse

Some submissions raised concerns about banks not recognising statutory ADs but insisting their own forms were completed to delegate financial management of a person's account and to protect the bank from risk. The Guardianship Board expressed concern about cases of suspected coercion where financial ADs were revoked and reassigned to a different agent by elderly people who were not legally competent to do so. It appears that some staff working in financial institutions are not always conversant with the requirements of, and protections offered by, local legislation regulating ADs.

Concerns were raised in consultations that, like other business sectors, some policies and practices of the financial sector are increasingly driven by risk management as much as by customer service. Given the national scope of many banks and financial institutions that provide services to South Australians, changing this culture to one of respecting autonomy, while safeguarding the interests of vulnerable people, will be a challenge. To counteract

risk management behaviours, the Review Committee decided, rather than set a penalty in legislation for banks and financial advisers who fail to recognise South Australian ADs, it is better to protect financial institutions from liability when they abide by ADs in good faith. The Review Committee therefore recommends reliance on professional education through bank risk managers and protections for staff who comply with ADs, and similar programs for other parts of the financial sector.

Recommendation 24

THAT a professional education program be developed for managers and staff of banks and other financial institutions to be delivered through risk managers or their equivalents that explains

- *the statutory nature of advance directives in South Australia*
- *the requirements for completing and revoking an advance directive and*
- *the protections offered for compliance with an advance directive that appears to be validly completed and witnessed*

Appointing monitors

Submissions to the Advance Directives Review expressed concerns about financial agents making decisions which put the person's financial viability at risk, or seeking to preserve an anticipated inheritance rather than spending the person's money on caring for them appropriately. The validity of these concerns was reinforced by Review Committee members who have experience with the Guardianship Board or the Public Trustee. However, the Review Committee is conscious that most financial agents carry out their role effectively and fairly, and that the extent of problems should not be overstated because cases where disagreements arise are brought to the attention of complaints bodies.

One form properly designed could cover enough to remove much of the confusion and disputation that is created now by the lack of or misunderstanding of the current forms

221

The Review Committee examined a range of options to limit the risk of abuse by financial agents, but remained cognisant of the need to ensure that a solution to address one problem does not cause others. A heavy-handed approach to eliminating abuse and fraud risks penalising ignorance or inexperience, discouraging those willing to take on the role of agents, thereby reducing the uptake of ADs and overloading government agencies with oversight responsibilities. The Review Committee was keen to find solutions that would not unduly add to the workload of the Office of the Public Advocate, the Public Trustee and the Guardianship Board, but that supported financial agents to perform their role well rather than imposing overbearing scrutiny. It is only when fraud occurs or disputes arise that protection is required, at which stage Guardianship Board involvement is appropriate.

Some interstate laws allow or encourage the person to appoint the Public Guardian or the Public Trustee as their agent, or as one of their agents, to ensure good decision-making. However such arrangements place an inordinately large load on government agencies and cannot adequately replace the insight of an agent who knows the person well. Oversight of an agent's decision-making may be desirable in many personal or family situations, but that should not translate to a requirement for government or official oversight.

British Columbia's Representation Agreement allows a person to appoint their own personal monitor to oversee the activities and financial decisions of their agent. The monitor is either

a trusted person of the person's own choosing or a dependable company, provided the person had sufficient funds to pay for their services if this was a requirement. The agent is required to report to the monitor, or in the case of a law firm or a financial institution to their designated representative, on a regular basis, and to produce regular accounts. In fact it is currently possible for a person to appoint such a monitor under South Australia's current EPA and to require reports, but this is not well known.

The Review Committee agreed that encouraging monitors to be appointed would add another level of protection and help prevent cases of abuse. Administrators appointed by the Guardianship Board and financial Attorneys appointed under an EPA are required to keep records. Whilst keeping the burden manageable so as not to discourage people from becoming agents, agents making financial decisions should be required to retain receipts and account printouts as evidence of financial transactions, and where a monitor is appointed, to provide the monitor with a summary report on a regular basis. For transparency and to avoid misunderstanding in the future, the form should require reporting arrangements and expectations between agents and monitors to be stipulated. When a monitor is appointed the AD must specify in writing the reporting requirements between the agent and the monitor including

- the frequency of reports
- whether reports should be verbal or in writing
- what the reports should cover and
- whether and what payments are to be made to the monitor from the agent's funds.

Monitors should be able to bring concerns about agents' decision-making to the attention of the Public Advocate and the Guardianship Board in the same manner as other concerned individuals. However, the optimum balance of autonomy and protection would be achieved if the monitor's role was supportive of the agent rather than merely investigative and disciplinary. The Review Committee recommends that appointment of monitors should be actively encouraged for financial agents and extended to include agents making non-financial decisions. A monitor for health decisions should not be a company, but rather a trusted knowledgeable individual of the person's choosing.

Recommendation 25

THAT a person be able to appoint a trusted individual as a monitor for financial and other decisions

THAT a person be able to appoint a company such as a law firm or a financial institution as a monitor to oversee their agent's financial management

THAT guidelines recommend specific reporting arrangements for the agent are documented in the advance directive when a person appoints a monitor

THAT the appointment of monitors for both financial and other decision-making be actively encouraged

Public and professional education

Public education and support

Studies have shown that simple, single-component community information programs have been less than successful in increasing the public's knowledge about or completion of ADs. A comprehensive strategy is required if a greater uptake of ADs is to be achieved. It takes a substantial effort to learn about and then complete an AD, and benefits commensurate with that activity must be effectively communicated. Different audiences and age groups will respond to different messages, so a targeted communication strategy is likely to prove more effective and more affordable. People who are sick or elderly are more likely to be motivated to find out about ADs and see them as relevant; the challenge will be to engage healthy competent adults.

Communication strategies need to be tailored to a range of target audiences to encourage voluntary behavioural change:

- members of the public who do not know what an AD is and what it is for
- those who have heard about ADs and are actively seeking further information
- individuals who are contemplating completing their own AD
- people who have completed an AD or have been appointed as an agent but who have questions about their operation in their particular circumstances.

Increasing public understanding of ADs requires several different approaches:

1. Public awareness which is an active and broadly targeted strategy for informing the general public about what ADs are and how they can be useful
2. Public information about ADs whereby information is made available in a range of settings so that people who are already aware of ADs can seek and find answers to their questions about how to complete one
3. Public advice about completing ADs as a one-on-one service to help people and their agents to complete their AD
4. Problem solving and support mechanisms which assist agents when making decisions, mediate differences in views, and help resolve disputes.

Awareness programs for the public should recognise the cultural and linguistic diversity of South Australia's population, and recognise that ADs are not appropriate for everyone. They must be complemented by education programs for the professional sectors so that when individuals approach their lawyer, doctor, accountant or aged care provider they share a common understanding about ADs.

Raising public awareness

Public awareness about ADs is low, and misunderstandings are generated by confusing legal terminology. Once new legislation is in place, the Review Committee recognises the need for an active program of community engagement and information dissemination that makes effective use of the media to communicate changes to ADs in simple terms that are meaningful to the community. A social marketing approach that builds upon likely media interest in new laws and policies has proved effective overseas. The key messages for the general public should be focussed on the usefulness and relevance of ADs for ensuring a person's wishes are known so they can be acted upon, and where forms and supporting information can be accessed.

The Review Committee received positive feedback on the Advance Directives Review Issues Paper that indicated the community welcomed the clarity with which ADs were explained. The subsequent consultation process presented opportunities to further clarify the terminology and purpose of ADs with a range of community groups and public forums. Although radio programs and the press provide a useful vehicle to alert the public to changes to law and policy, experience in this area suggests public meetings and community groups also play a critical role in raising awareness, especially with older people.

The public awareness campaign should make use of existing communication strategies that already target information to relevant community audiences. The Public Advocate and staff of the Legal Services Commission are often asked to speak about ADs and guardianship at public meetings. The Respecting Patient Choices Program is often asked to deliver presentations on their advance care planning program to health-related audiences and wider public forums, and the Palliative Care Council and Alzheimer's Australia have presented information sessions about the Consent Act and health ADs to community groups for many years. Seniors SA provides a regular series of public forums, and is keen to add presentations on ADs to their annual agenda. Many such community organisations provide links to ADs on their web sites, but for many people personally hearing a presentation delivered and having questions answered is more meaningful and more likely to motivate them to complete an AD. Studies locally and internationally indicate that people are reluctant to discuss future incapacity and death, especially their own, so a broader focus on autonomy rather than the end-of-life is warranted to combat such reluctance.

The Office for the Ageing report: *Our actions to prevent the abuse of older South Australians*, identifies roles for the Aged Rights Advocacy Service, the Office of the Public Advocate, the Legal Services Commission and the Office for the Ageing which focus on AD information and awareness which will serve to supplement these efforts.

The Aboriginal Legal Rights Movement advises that the best means of communicating the value of ADs to Aboriginal families in the north of the state is through supplementing resources to enable extra field officers to conduct visits to and sessions with remote Aboriginal communities. These and other existing community-based communication systems should be harnessed to raise the profile and uptake of ADs.

Lack of follow up informative advertising of the legislation prolonged the misconceptions and concerns. Greater public awareness is essential if [this new] legislation is to be of any use and may eliminate many concerns and increase their [AD] use
52IH

It is critical that all presenters at community forums convey a consistent message in consistent terms. Seniors SA and other peak bodies requested that a training kit including materials for distribution be provided to support public awareness sessions. To this end the Review Committee recommends that the Legal Services Commission be resourced to produce a downloadable PowerPoint presentation, a DVD and materials for distribution, and to conduct 'train the trainer' sessions for willing volunteers. Such materials could be provided via the web site, supported by an on-line tutorial.

Recommendation 26

THAT a program of community engagement and information dissemination be implemented through effective use of the media and of existing community-based forums

THAT the Legal Services Commission be resourced to produce a training kit including electronic and printed materials for use by community agencies providing presentations to the public

THAT the Aboriginal Legal Rights Movement be funded and resourced to communicate and promote the value of advance directives to remote Aboriginal communities

Providing public information

Information about ADs needs to be readily available and easy to find. Printed information, in plain English, should be widely available in a range of metropolitan and country locations such as CentreLink, CareLink and local council offices; Service SA; libraries and post offices; and city and regional offices of the Legal Services Commission. Pamphlets explaining what ADs are and how they can be used should be developed and distributed widely, including to GP surgeries, lawyers' offices, marriage celebrants, funeral directors, financial planners and organisations such as the Aged Rights Advocacy Service, Council of the Ageing, Seniors SA, Alzheimer's Australia, Carers SA and the Palliative Care Council.

In addition, the Review Committee recommends that the advance directive web site provide simple advice up front about the benefits of completing an AD. The web site should be searchable, include frequently-asked questions and fact sheets, a list of accredited witnesses, and provide links to other useful web sites. Aged care organisations should be encouraged to link their web sites to the advance directives web site hosted by the Legal Services Commission rather than develop their own information. By this means, information is readily updated at one access point. Printed materials should provide the web address and a list of local offices and agencies where forms and guidelines can be found. The forms and guidelines should be available via the web site, and in hard copy through multiple community sources including council offices, divisions of GPs, Services SA, Legal Services Commission regional offices, post offices, libraries and the Office of the Public Advocate.

It is recommended that advice on completing, using, and abiding by Ulysses Agreements be prepared with expert input and distributed through the mental health sector.

Older people also find the different forms confusing, one large booklet to complete all the necessary items in one foul swoop would be good

23IH

Recommendation 27

THAT printed information explaining the value and role of advance directives be developed and distributed to a range of country and metropolitan access points

THAT the advance directive web site provide materials and simple advice for people considering whether to complete an advance directive

THAT advice on completing, using and abiding by Ulysses Agreements be prepared with expert input and distributed through the mental health sector

Public advice and support

Community-based support has proved essential both nationally and internationally if ADs are to realise their aims of respecting autonomy and ensuring individuals' wishes are honoured.

The Review Committee considered how advice, support and advocacy could be best provided both to those completing ADs, and to agents and families when they need to make substitute decisions. Based on expert advice, it was determined that the Legal Services Commission is best placed to provide the former, and the Office of the Public Advocate the latter.

When completing advance directives

Once a person has decided to complete an AD and has accessed the forms and guidelines, they may find that they require advice tailored to their specific circumstances in order to complete the form. Many currently seek advice from their lawyer, accountant or GP, or from the Legal Services Commission.

Studies demonstrate that people find completing ADs challenging. Many struggle to decide who would best manage their financial affairs for them, and what conditions they should set on their agent's decision-making. Most Australians have never written their life goals or recorded their personal values, nor thought through what outcomes they might want from health treatment. Although the guidelines will be sufficient for some, others will benefit from the assistance of a trained adviser.

...should be hotline where people can seek advice for the wording in their AD

25PIL

The Review Committee recommends that a free public advice service be implemented for people completing advance directives, for the provision of one-on-one advice either in person, via email, or over the phone. It is suggested a telephone helpline be initiated and coordinated by the Legal Services Commission as an extension of services they already provide. A web site feature that allows questions to be emailed to the Legal Services Commission would be particularly beneficial.

The Review Committee recommends that advisers located in community centres and local council offices be trained to assist people who need extra assistance when they are completing their AD or being appointed as agents. In addition, the Review Committee suggests that trained GP practice nurses could assist and advise patients about wording the terms of their AD so that their wishes will be understood and can be actioned.

Recommendation 28

THAT a free public advice service be implemented for people completing advance directives that provides one-on-one advice either in person, via email or over the phone

THAT advisers located in community centres and local council offices, and GP practice nurses, be trained to assist people who need extra assistance to complete their advance directives

THAT the Legal Services Commission be resourced to coordinate training for these roles to ensure consistency

When making decisions using advance directives

Once an AD is in place, the Office of the Public Advocate is best placed to provide advice to agents about the operation of ADs, to answer questions about assessing capacity and making decisions under ADs, and to guide agents to follow the decision-making pathway. The Office of the Public Advocate should also be the source of advice and support for relatives and medical practitioners making decisions under a personal AD.

The resources of the Office of the Public Advocate should be focussed on offering case-specific advice to individuals and families, rather than general advice to the public.

Recommendation 29*THAT the Office of the Public Advocate be resourced to advise*

- *agents about their decision-making role*
- *families and health professionals about making decisions when there is a personal advance directive in place but no agent appointed*

Dispute resolution

The Advance Directives Review Committee's Stage 1 Report recommended a stepped dispute resolution process:

1. firstly, seeking advice from the Public Advocate (or designate) with a view to negotiating a decision more congruent with the guidelines
2. if this is unsuccessful or unhelpful, appealing to a tribunal (the Guardianship Board) with the power to review the decision
3. the option to ultimately appeal to the Supreme Court.

This was based on the understanding that, under the Guardianship Act, the Guardianship Board's role is to solve problems for vulnerable adults, but not to interfere in functioning families and the good management of care. The Guardianship Board should only be involved with ADs when problems arise, with the Public Advocate in the role of gatekeeper. Consultations with the aged care sector highlight concerns that those whose experience regularly brings them into contact with 'problem cases' do not recognise problems with ADs are relatively rare, and in fact they solve many potential problems for the aged care sector.

Submissions generally agreed that mediation is a simpler (and cheaper) means of resolving disputes which should be encouraged, rather than litigation and appeals. There is a variety of circumstances when mediation would be beneficial such as when decisions are being made but where

- the agent disagrees with health professionals
 - agents disagree with each other
 - relatives disagree with the agent
- about whether
- instructions are relevant to the case
 - instructions were intended by the person to apply to the circumstances
 - instructions were intended to be advisory
 - circumstances have changed since AD was written
 - interventions would be considered burdensome
 - outcomes would be considered intolerable
 - a financial decision protects the person's financial interests
 - and what the person would have decided.

The Public Trustee has only a limited role in providing advice and mediation because their principal role is as a substitute decision-maker. However, they should continue to provide information and advice to the public on financial ADs through their office, web site and materials.

It is proposed that the Office of the Public Advocate be the primary provider of mediation services when disputes arise about the application of non-financial ADs, and the Legal Services Commission for financial ADs. However, the Review Committee also suggests that community mediation centres may provide a useful avenue for resolving family disputes, as they play a role in resolving other intra-familial problems. This would allow the Legal Services Commission to direct inquiries to appropriate mediation services if the dispute could not be resolved by simply providing information. The Review Committee recommends that extra mediation officers would be needed at the Office of the Public Advocate to fill this role, and extra advisers at the Legal Services Commission.

[the appeals system] has to be a system that is immediate as in hours not weeks. An official would need to come to the hospital, home etc where the person was and meet with the different people
 30PI

The Stage 1 Report recommended that the Office of the Public Advocate play a gatekeeper role for the Guardianship Board. Sometimes a person who has appointed an agent disputes that their capacity is diminishing and they require care and support with their decisions. In such circumstances, it is proposed that the Guardianship Board be able to confirm impaired capacity to enable the agent to act rather than appointing a guardian or administrator. This introduces an additional role for the Guardianship Board when an agent has already been appointed:

Currently the Guardianship Board functions as a protector of people who have diminished capacity and are deemed unable to manage their own affairs. The Board can appoint a guardian as a substitute decision-maker. This role would continue if a person has not appointed an agent. The Review Committee recommends that when the person has already appointed an agent, the Guardianship Board's role should be to assess the person's capacity to make the particular decision in question and authorise the agent to make that decision (such as the need for residential care) if appropriate.

The Guardianship Board may require different kinds of evidence to make the latter decision. It will be important that the Board has access to expert interview reports as well as assessment reports. Given that OPA staff would have already assessed the situation and referred the case to the Guardianship Board because mediation did not achieve a practical solution, their reports will comprise much of the evidence on which the Board relies to make their decision.

The Review Committee discussed whether the guidelines should explain the mediation and appeals process in detail. However it was decided that the guidelines should simply encourage discussion and advise agents and families to seek expert advice through 'family team meetings' with members of the clinical team (for health decisions) or community mediation officers (for financial decisions), and if disagreement continues, then seek the advice of the Office of the Public Advocate or the Legal Services Commission who can then provide appropriate advice on other resolution options from that point forward.

Recommendation 30

THAT when disagreements arise about the application and interpretation of advance directives, the advance directive guidelines encourage discussion and advise agents and families when to seek advice from the treating clinical team, the Office of the Public Advocate, the Legal Services Commission or community mediation officers

THAT where the person has already appointed an agent, the Guardianship Board's role should be to assess the person's capacity to make the particular decision in question and authorise the agent to make that decision if appropriate.

Professional education

Once the new legislation is in place, a professional education program should be implemented for the financial, legal, health, aged care and community sectors. This will need to be tailored to address the particular situations and complexities that arise in each sector when substitute decisions are required.

The education programs should emphasise the statutory nature of ADs, the role of agents to make decisions, the requirement to endeavour to make the decision the person would likely have made in the circumstances, and the protections for professionals who act in good faith when abiding by an AD that appears valid.

Guidelines for health professionals

Consideration should be given to separate guidelines specific to

1. health and aged care professionals required to abide by ADs covering
 - the legal status of ADs, when they apply, how to interpret instructions in a personal AD, the requirement to follow the decision-making pathway in the absence of agents or relatives, respecting agents under an agent AD, protections for those abiding by ADs, and applying problem-solving and dispute-resolution processes
2. financial and bank staff required to abide by ADs covering
 - the legal status of ADs, when they apply, respecting agents, protections for those abiding by ADs, and applying problem-solving and dispute-resolution processes

The professional guidelines should be comprehensive, and offer guidance and protocols to be followed in a range of commonly-encountered circumstances including

- assessing whether the person has the capacity to make the decision, or needs assistance to make it
- confirming that an AD is valid
- contacting agents, in particular when there are multiple agents
- seeking advice from the Public Advocate to help resolve differences of view
- requesting a review of an agent's decision from the Guardianship Board
- abiding by ADs during temporary loss of capacity or episodic mental illness
- abiding by a Ulysses Agreement.

The health and aged care guidelines should also include guidance about

- determining whether the AD applies in the current circumstance
- deciding what treatment options should be offered from a medical perspective, and assessing and explaining likely outcomes of treatments to the extent that these can be predicted
- consulting with and informing agents and assisting them to make decisions
- advising and informing relatives making decisions when no agent is appointed but a personal AD becomes operative
- making decisions consistent with a personal AD where there are no appointed agents, guardians or relatives
- making decisions in emergencies, in suspected suicide attempts, and when iatrogenic events occur.

It is envisaged that simple stand-alone guidelines for following the decision-making pathway will be made available in health, medical and aged care settings to support health professionals in dealing with relatives and agents who are making decisions.

Training for health professionals

Feedback suggests a need for both formal and informal training for professionals to ensure a full understanding of law and policy. Formal training should be available to all staff who may come across ADs, but informal training may be sufficient to provide regular updates.

The Review Committee has been assured that most relevant professions have access to professional development programs that offer formal training through colleges, societies and professional organisations. Formal training sessions would be most effective if linked to existing continuing education programs and risk management training, and accredited to attract professional developments points where such arrangements exist. To ensure consistency and quality, professional organisations and risk managers should be encouraged to use and adapt a standard training module. This could usefully be provided as a kit including a DVD, prepared handouts, and the public and professional guidelines. Online training for rural and remote professionals should be considered. Training service providers could adopt a 'train the trainer' model once programs are well established. A mechanism to ensure consistency and accuracy across training modules would be required. The Review Committee suggests this be coordinated by the Legal Services Commission.

Medical colleges, the Law Society and Divisions of GPs run regular training sessions, and country GPs receive online training in some areas. It will be important that palliative care, ambulance, mental health, emergency department and ICU staff receive training in applying and abiding by ADs, and that training be made available to all levels of health professionals including nurses, allied health, and community-based staff and GPs.

Training for health professionals should include an explanation of advance care planning and the role of ADs in that process, pointing out that ADs are not limited to end-of-life decision-making but can operate during other periods of lost capacity. Trained health professionals should be encouraged to initiate discussions about advance care planning and advance directives with their patients, and to direct them to appropriate community-based resources and support services if they need broader information and advice.

There should be more education of medical and nursing staff...should be a part of undergraduate and post graduate courses

52IH

The Respecting Patient Choices Program currently led through The Queen Elizabeth Hospital has been training South Australian health professionals in advance care planning, including the use of health and medical advance directives, since 2004. Research around the world indicates clearly that in the health sector ADs work most effectively when embedded in an advance care planning framework. The Respecting Patient Choices Program achieves this by driving a cultural change in health care organisations and putting in place systems such as organisational support frameworks, policies, procedures, documentation and data-bases to make advance care planning function effectively in clinical settings. The Program has been shown to be cost-effective when rolled out to aged care facilities in Victoria. The Respecting Patient Choices Program, along with other evidence-based advance care planning programs, should continue to be supported financially and logistically in the future to complement the implementation of the new ADs. This will help ensure that health professionals understand their responsibility to make clinically-informed judgements about treatment options and appreciate the role of ADs and advance care planning in respecting people's wishes across health, hospital and aged care settings.

My experience of the RPCP has given me the opinion that it should be available in all hospitals. For older people especially it is an easier method than the sterile AntD form

28IH

Training on the use and application of Ulysses Agreements should be offered to mental health, emergency department and ambulance staff, and others as appropriate. Information should be made available to police officers explaining Ulysses Agreements and their role in ensuring their effective application.

To ensure that all relevant staff receive initial and ongoing training in applying and abiding by ADs, the Review Committee recommends that completion of training programs be required by accreditation standards and service agreements in the health and aged care sectors. It is recognised that this will not be as easily achieved in the financial sector. Nevertheless, courses for bank staff should be organised in cooperation with the major banks, to be delivered through banks' risk management sections.

If my parents' GP told them to [complete their AD] they would. They believe in their GP's advice and use him as their counsellor, so maybe the GPs can have kits to provide to their clients that are elderly or have been diagnosed with an illness
23IH

Recommendation 31

THAT guidelines for professionals be comprehensive, tailored to different sectors, and offer protocols to follow in a range of commonly-encountered situations

THAT a standard training module be developed that can be adapted to different professions and circumstances and that is accredited and qualifies for professional development points

THAT participation in formal training programs be required for health and aged care professionals, and this requirement be incorporated into accreditation standards and service agreements

THAT the Respecting Patient Choices Program, along with other evidence-based advance care planning programs, should continue to be supported in the future to complement the implementation of the new ADs across health, hospital and aged care settings

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Appendices

- **Bibliography**
 - **The decision-making pathway**
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The decision-making pathway

The decision-making pathway for agents, relatives and health professionals making decisions for others.

1. Consistent with the ethical principle of respecting autonomy, when called upon to make decisions on behalf of a person, an agent should be required to first assess, considering the nature of the decision to be made, whether the person requires assistance and support to make their own decision or whether the situation requires a decision by the agent

2. Should it be determined that

- the person is incapable of making, or unwilling to make, the decision in question
- and, in the case of temporary or fluctuating capacity, the decision cannot reasonably be postponed, without serious consequences, to a time when the person's capacity or willingness might be regained

it is appropriate for the agent to decide

3. The agent (always acting in good faith) must

- comply with any directions written on the form that are relevant to the current decision and which were intended by the person to cover the current circumstances
- adhere to any conditions and accommodate any relevant wishes to the extent possible

In the absence of any relevant written instructions or directions, an agent must

- seek the person's current views and preferences to the extent they can communicate these
- be guided by values and life goals that the person has described, and what for them constitutes quality of life
- give full consideration to any wishes or decisions in the matter previously expressed by the person, whether written or verbal, and give particular weight to any advance care plan the person has completed
- consider decisions and actions taken in the past that indicate the person's personal beliefs
- consider their cultural, linguistic and religious preferences
- balance the person's rights and personal autonomy with their proper care and protection, endeavouring to minimise restrictions on their basic rights and freedoms
- consider the adequacy of existing informal arrangements for the person's care and the management of their affairs and the desirability of not disturbing those arrangements and
- make the decision they believe the person would have made contemporaneously if they had not lost capacity or were willing to decide personally

and specifically

- for a health-related decision, avoid interventions the person has described as burdensome or intrusive, seek and consider the advice of health professionals about the likelihood of treatment options resulting in circumstances the person has described as an unacceptable or intolerable level of functioning, and make decisions that seek to avoid such circumstances to the extent this can be predicted
- for a financial decision, exercise reasonable diligence to protect the financial interests of the person, taking into account the person's needs and circumstances

4. If there is no means to ascertain what the person would have decided in the specific instance, the agent must make the decision that best protects the personal best interests and well-being of the person.