South Australian Government

Response to the Review of the *Advance Care Directives Act 2013*

June 2020

Government of South Australia

SA Health

Introduction

The *Advance Care Directives Act 2013* (SA) (the Act) was passed by the South Australian Parliament in 2013 and entered into force on 1 July 2014.

The Long Title of the Act declares that it is:

> *"An Act to enable a person to make decisions and give directions in relation to their future health care, residential and accommodation arrangements and personal affairs; to provide for the appointment of substitute decision-makers to make such decisions on behalf of the person; to ensure that health care is delivered to the person in a manner consistent with their wishes and instructions; to facilitate the resolution of disputes relating to advance care directives; to provide protections for health practitioners and other persons giving effect to an advance care directive; and for other purposes."*

The 7 objects of the Act are set out in section 9 and include as follows:

(a) To enable competent adults to give directions about their future health care, residential and accommodation arrangements and personal affairs;
(b) To enable competent adults to express their wishes and values in respect of health care, residential and accommodation arrangements and personal affairs, including by specifying outcomes or interventions that they wish to avoid;
(c) To enable competent adults to allow decisions about their future health care, residential and accommodation arrangements and personal affairs to be made by another person on their behalf;
(d) To ensure, as far as is reasonably practicable and appropriate, that health care that is provided to a person who has given an advance care directive accords with the person's directions, wishes and values;
(e) To ensure that the directions, wishes and values of a person who has given an advance care directive are considered in dealing with the person's residential and accommodation arrangements and personal affairs;
(f) To protect health practitioners and others giving effect to the directions, wishes and values of a person who has given an advance care directive;
(g) To provide mechanisms for the resolution of disputes relating to decisions made on behalf of those who have given an advance care directive.

The Act also provided for a review of its operations. Section 62 of the Act reads as follows:

(1) The Minister must cause a review of the operation of this Act to be conducted and a report on the results of the review to be submitted to him or her.
(2) The review and the report must be completed before the fifth anniversary of the commencement of this Act.
(3) The Minister must cause a copy of the report submitted under subsection (1) to be laid before both Houses of Parliament within 6 sitting days after receiving the report.

The statutory review of the Act was conducted by Professor Wendy Lacey over a 10 week period from 10 April 2019 until the end of June 2019. The Review made 29 recommendations for reform of the operation of the legislation. The Minister for Health and Wellbeing tabled the Review in the South Australian Parliament on 1 August 2019.

SA Government Response

Of the 29 recommendations contained in the report the South Australian Government supports (in full or in principle) 22 of the recommendations and will undertake further consultation in relation to one recommendation.

While the Review did not note any fundamental issues with the operation of the Act, it did raise questions as to the uptake of Advance Care Directives in the community, in particular raising questions around the level of support and public education provided by the South Australian Government following the Act's commencement in 2014.

The South Australian Government is committed to increasing the uptake of Advance Care Directives (ACDs) in South Australia and has either supported or supported in principle those recommendations which will aid in this endeavour.

The Review also noted the involvement of the Attorney-General's Department in some aspects of the Act, and the Attorney-General's Department has been consulted in the preparation of this response.

The recommendations of the Review can be addressed broadly in terms of a set of themes.

Oversight and Advice

The Review's recommendation for the establishment of a statutory multidisciplinary Advance Care Directives Advisory Board to advise the Minister on all aspects of ACDs (Recommendation 24) is not supported.

The Government will establish a non-statutory oversight group to provide advice to the Minister on implementation of the recommendations. Such a group will provide more flexibility than a statutory advisory board.

Education and training for professionals

A training program for Justices of the Peace (JPs) and social workers is recommended to ensure that they are well equipped to meet the legal requirements for witnessing ACDs Recommendation 12). While the Government agrees with the provision of training, it is not considered that a mandatory program will deliver better outcomes than a voluntary program.

Educating the community

The Report notes the relatively low take up of ACDs in South Australia while acknowledging that it is still higher than the other Australian States and Territories with a statutory ACD regime. The report recommends replicating the two highly successful volunteer groups on the Fleurieu and in the Barossa which provide people with advice and assistance to complete an ACD and provide referrals to JPs for witnessing. People wanting to complete an ACD often would like to discuss it with a third party and these groups provide a means for this to occur in a community context.

The Report recommends that these groups are established in each council area. Following the establishment of these groups an ongoing comprehensive education and awareness campaign is recommended to inform and educate the community about ACDs. The Government supports these recommendations. While these recommendations will require additional resourcing, this will be met through existing Department for Health and Wellbeing resources.

The greater use of ACDs in residential aged care facilities would be of benefit to residents, facilities and the health networks. Many residents would prefer to be cared for in place.

SA Health is currently funding pilot projects with Clayton Church Homes, HammondCare, Palliative Care SA and GP Partners Australia to trial different ways of working with residents, their families and facility staff to encourage conversations around end of life care and complete ACDs or other advance care planning documents. Initial results from the Clayton Church Homes project show the trial has more than doubled the completion of ACDs or other advance care planning documents amongst residents from 34% to 69% (data as 15 May 2020). The pilot projects will inform the rollout of further projects under the Comprehensive Palliative Care in Aged Care Project Agreement over the next four years.

Changes to the Act, forms and kit

The changes the Review proposes to the Act respond to a number of widely shared concerns and are generally supported.

A key area of contention in the operation of the Act has been the provisions that require a substitute decision maker to sign an ACD before the grantor. The intent is that a grantee is prompted to have a conversation about their duties with the grantor and the grantor's wishes. The Review and non-legal stakeholders strongly support this approach, including the Australian Medical Association.

The Law Society argues that this approach is cumbersome and detrimental, in particular to regional South Australians. Some of the Law Society's issues could be addressed by allowing electronic signatures to be used.

The redesign and streamlining of the current form and DIY kit is recommended to simplify the process of completing an ACD. Many respondents to the review found both the form and kit confusing and overwhelming. The Government supports this position and will initiate this redesign in collaboration with stakeholders.

Recommendation 13, which proposes an offence for witnesses who have failed to comply with the legal requirements for witnessing, is not supported. Having witnesses, who are mainly volunteers, liable for an offence for what may be an inadvertent administrative error, would discourage involvement.

The recommendation to use a voluntary register for ACDs (Recommendation 6) is not supported as it may undermine both unregistered ACDs and other valid documents.

Office of the Public Advocate and SACAT

It is recommended that there is no change to the powers or functions of the Office of the Public Advocate apart from the repealing of declaratory powers which have never been used (Recommendation 18).

Recommendations 19 to 21, which seek statistics from the South Australian Civil and Administrative Tribunal on ACDs, and decisions that it may make in regard to ACDs is not supported. The Attorney-General has advised that ACD applications account for less than one per cent of all matters heard in SACAT. The collection of statistics would require an upgrade to SACAT's case management system, and the cost of this upgrade cannot be justified for the volume of matters. General publication of reasons for SACAT determinations in ACD matters is largely prohibited by section 58 of the Advance Care Directives Act 2013, unless the person who gave the relevant ACD consents, or on application by a person who has a proper interest in the matter. Given the small number of ACD matters heard by SACAT any research project on the decisions SACAT may make is not likely to be representative of how the Act is implemented more broadly in the community.

Suicide

The Report recommends that the Act is amended to make it explicit that an ACD cannot be used to deny life-saving treatment following a suicide attempt or an act of self-harm (Recommendation 29).

This matter has been dealt with separately by the promulgation of a regulation under the Act to enable treatment to be provided in these circumstances. This regulation was gazetted on 11 July 2019. However, the Government indicated that this was an interim response, and legislation would be introduced. There is a risk that legislation to prevent suicide could undermine the legitimate wishes of an individual to refuse treatment, thereby undermining the intention of the Act.

At the heart of the philosophy of consent to medical treatment law is the principle that a person can refuse medical treatment even if to do so would precipitate their death (e.g. Jehovah's Witnesses and blood transfusions).

Recent cases in South Australia have raised concerns that ACDs could be used to “assist” in a suicide by requiring that lifesaving care is withheld.

An ACD cannot initiate treatment that would facilitate death – that would be murder or euthanasia.

However, health professionals are concerned that a person may seek to reduce the risk of an unwanted intervention.

Proponents of ACDs warn against the regulation on the grounds that it could undermine the legitimate wishes of people with ACDs, as health professionals could read suicide and self-harm broadly and, in many cases, the intent of the person is not clear.

The Government will undertake further consultation prior to the introduction of the aforementioned legislation.

Other Matters

Some matters not directly related to ACDs were investigated by the consultant including the interaction between the need to recruit organ donors and ACDs. Allocating a specific part of the ACD form to the issue of organ donation is recommended (Recommendation 26).

Support is given to undertaking public consultation or commissioning research in regard to how people with limited or impaired decision-making capacity can be facilitated to record and convey their wishes for future medical and other care (Recommendation 25).

The South Australian Government supports these recommendations as they ensure the ACDs are more fully integrated into the broader health system.

Response to Recommendations

RECOMMENDATION	GOVERNMENT RESPONSE
1. The government should reinstate 1, but preferably 2, positions within the Department for Health and Wellbeing, with the dedicated role of promoting understanding and awareness of ACDs. This/these role(s) should work in collaboration with community and advocacy groups to promote the understanding and uptake of ACDs, as well as taking leadership of an ongoing education and training program for clinicians and health practitioners in each of the Local Health Networks (LHNs).	Supported in principle. These positions could be located in the Local Health Networks.
2. Both the ACD Form and the DIY Kit need to be reviewed and the latter significantly updated. Each needs to be tailored for a lay-person and contain sufficient information for a person to complete an ACD without the necessity to consult either a lawyer or a doctor. However, both documents should make it clear that speaking with both (or either) a lawyer and a doctor may result in the completion of an ACD which more closely reflects the wishes and preferences of the person.	Supported. Both the ACD Form and the DIY Kit should highlight supports available including supported workshops, lawyers and health professionals.
3. The Act should be amended to make it expressly clear that it is not intended to operate to the exclusion of the common law. Directives which meet the common law requirements must be treated as legally valid. In addition, non-statutory directives, irrespective of form or whether they appear in a statutory ACD, should be treated as relevant and highly persuasive, particularly when decisions are being made with regard to medical care and treatment, or personal preferences, at the end of life.	Supported. The Government also intends, through these amendments, to support the development of non-statutory directives completed by people who lack capacity.
4. Each Local Health Network and hospital should be required to report annually to the Minister on their practices and protocols for identifying, managing and implementing ACDs (in any form). Hospitals must adopt a 'whole of hospital' approach to identifying, flagging and managing ACDs. Each institution must also develop a system for recording conversations and treatment plans (including the 7 step pathway) which incorporate non-statutory directives in files related to ACDs. These files must be digitally retained by each hospital.	Supported.

RECOMMENDATION	GOVERNMENT RESPONSE
5. The use of digital copies of ACDs should be both permissible and promoted within South Australia's hospitals. The Act should be amended to facilitate this process and provision should be made in the Act to ensure that medical practitioners and hospital staff are entitled to rely on the purported validity of an ACD contained on a patient's My Health Record.	Supported.
6. The South Australian Government should consider conducting a trial in relation to the development and use of a voluntary register for ACDs. Any register should be devised following consultation with relevant stakeholders and involve an independent evaluation following a sufficient length of time. One of the components for evaluation must be the improved level of compliance with ACDs in clinical settings.	Not supported. A register may undermine both unregistered ACDs and other documents.
7. A clear protocol should be developed for use in South Australian hospitals which ensures that questions are not limited to the existence of ACDs, but extend to questions regarding a previous, valid instrument, including Enduring Powers of Guardianship, Medical Powers of Attorney and Anticipatory Directions.	Supported. This protocol should include any other evidence of a patient's wishes such as 'My Life Decisions' document and relevant information from aged care facilities.
8. The Act and the ACD form should be amended to make it absolutely clear that there is no limit on the number of SDMs that can be appointed.	Supported.
9. The wording in section 22 of the Act should be changed from 'jointly and severally' to 'separately and together'.	Supported.
10. The Act and the ACD form should be amended to enable people to have a hierarchy of SDMs, with one or more preferred SDMs, as well as alternate SDMs (ie, appointing a spouse as the preferred SDM and children as alternate SDMs). All SDM appointments should be able to be exercised together and separately.	Supported.
11. Schedule 1 of the Regulations needs to be amended and the list of suitable witnesses limited to health practitioners, legal practitioners, judges and magistrates, social workers and Justices of the Peace.	Supported in principle subject to the consultation envisaged in Rec. 28.

RECOMMENDATION	GOVERNMENT RESPONSE
12. Justices of the Peace and social workers should be required to complete a professional training course, approved by the Department for Health and Wellbeing, every 2 years. Such courses must address legal requirements under both the *Advance Care Directives Act 2013* (SA) and the legal effects of the *Office for the Ageing (Adult Safeguarding) Amendment Act 2018* (SA).	Partly supported. The provision of training courses is supported but these courses should not be mandatory. The need for refresher courses is to be assessed.
13. The government should give consideration to the inclusion of an additional offence where witnesses have failed to comply with the legal requirements for witnessing.	Not supported. Having witnesses, who are mainly volunteers, liable for an offence for what may be an inadvertent administrative error would discourage involvement.
14. The Department for Health and Wellbeing should assume responsibility for the establishment of new volunteer ACD groups in each council area, drawing on the experiences of similar groups in Victor Harbor and the Barossa. The Department should also facilitate the establishment of networks between volunteers, local hospitals, the local council and Justices of the Peace.	Supported in principle.
15. The government should resource an ongoing and targeted education campaign for aged care providers around ACDs, delivered by the Department for Health and Wellbeing.	Supported in principle.
16. There is no clear legal or other reason to reduce the powers or functions of OPA, other than those recommended under Recommendation 18.	Supported.
17. Section 45 of the Act should be amended to require OPA to discontinue a matter where a reasonable suspicion of elder abuse exists and refer the matter to SACAT for determination. OPA should be entitled to disclose the general basis of that suspicion in a written referral to SACAT. Consideration should also be given to an amendment which requires OPA to publish on its website, as well as notify all parties accessing the DRS from the outset, that evidence of elder abuse will trigger a discontinuation of mediation and that a referral to SACAT will follow.	Supported.
18. The declaratory powers of OPA under s 45(5)-(9) have never been used and should be repealed.	Supported.

RECOMMENDATION	GOVERNMENT RESPONSE
19. In order to inform future policy and resourcing decisions of government, either SACAT or the Attorney General's Department should collate, on an annual basis, statistics and analysis on SACAT's jurisdiction, including its jurisdiction in ACD matters. The information should be made available to both the Attorney-General and the Minister for Health and Wellbeing.	Not supported. ACD applications are less than 1% of all matters heard in SACAT. The collection of statistics would require an upgrade to SACAT's case management system. The cost of this upgrade cannot be justified for the volume of matters. Reporting is also likely to be understated with ACD-related matters occasionally arising incidentally in the hearing of guardianship matters. SACAT does not record such ad hoc matters. General publication of reasons for SACAT determinations in ACD matters is largely prohibited by s58 of the ACD Act unless the person who gave the relevant ACD consents, or on application by a person who has a proper interest in the matter.
20. The Minister should commission and fund a research project focussed on the decisions of SACAT related to ACDs to build understanding of how the *Advance Care Directives Act 2013* (SA) is being implemented. The research should investigate all aspects of the Act's effect and operation but should examine the extent to which ACDs are invalidated or revoked and the reasons for invalidity or revocation, the extent to which ACD appointments are revoked and the reasons for revocation, applications by hospitals or hospital staff for decisions regarding binding refusals of health care, the nature of those applications and the outcomes of such cases, the frequency or rate of internal reviews of SACAT decisions, and any other relevant matter.	Not supported. Such a project is unlikely to result in reliable empirical data on matters given the comparatively small number of ACD matters heard by SACAT, and therefore is not likely to be representative of how the Act is implemented more broadly in the community.
21. Assuming that recommendations 19 and 20 are implemented, the government should review the adequacy of SACAT's resourcing and staffing levels.	Not supported.
22. A new section of the Act is required which imposes clear requirements on interpreters. In particular, interpreters must be duly qualified as interpreters of the relevant language, they should be adult with capacity and they should be subject to similar requirements as apply to witnesses under section 15.	Supported.
23. The government needs to fund a comprehensive education and awareness raising campaign throughout the state, but only following the establishment of local, community owned programs which support the completion and adoption of ACDs.	Supported in principle.

RECOMMENDATION	GOVERNMENT RESPONSE
24. The government should establish a new Advance Care Directives Advisory Board to advise the Minister on all matters dealing with ACDs. The Act should be amended to ensure that the Board reports directly to the Minister on an annual basis, and that LHNs are required to report annually to the Board with regard to their compliance with the Act. Membership of the Board needs to be diverse and should be limited to 2 year terms, with the exception of inaugural appointments in key disciplines.	Not supported. The Government does not consider there is the need for a statutory advisory board. The Department of Health and Wellbeing will convene a non-statutory oversight group to provide advice to on implementation of the recommendations. Such a group provides more flexibility than a statutory advisory board.
25. The government should conduct a public consultation process and/or commission research for determining how persons with limited or impaired decision-making capacity can be facilitated to record and convey (including through supported decision making) their preferences for future medical care, accommodation and personal matters. The consultation must engage with the disability sector and be framed by a human rights based approach.	Supported.
26. The government should ensure that organ and tissue donation is the subject of a separate section in the ACD Form (Recommendation 2), and that any education or training programs delivered through Recommendations 1, 2 and 11 include relevant information on such donations.	Supported.
27. The Department should investigate how the use of digital signatures could be implemented under the Act, and make appropriate amendments to the Act if required.	Supported. Amendments to the Act should also consider the order of signing.
28. Before any changes are made to the certification requirements surrounding ACDs, the Department should engage in a broader consultation with key stakeholders, taking into account the recommended changes to the list of authorised witnesses in this Report. Any consultation for this purpose should include the relevant bodies representing particular classes of witnesses, the Local Health Networks and the Law Society.	Supported. Access for South Australians in regional areas will also be a focus.

RECOMMENDATION	GOVERNMENT RESPONSE
29. The Act must be amended to ensure that it is explicit, in the operative provisions of the Act, that an ACD cannot be used as the basis for refusing life-saving treatment following an attempt to suicide or cause self-harm. The remainder of an otherwise valid ACD must be preserved.	Subject to further consultation. While ACDs should not be used as a tool to facilitate clear attempts of suicide, the legitimate wishes of patients to refuse treatment should not be over-ridden. This is not the intention of the Act. Further consultation will be undertaken with key stakeholders on this recommendation, prior to the introduction of a legislative amendment.

For more information

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