



Ms Brooke Craven
Director
Office of the Secretary
Department of Justice
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HaveYourSay@justice.tas.gov.au

Dear Ms Craven,

Thank you for the opportunity to provide comment regarding the ***Guardianship and Administration Amendment (Advance Care Directives) Bill 2020***. I also appreciate meeting with representatives from the Ministers for Justice and Health, and Department Justice, on 7 October 2020, to discuss Palliative Care Tasmania Limited's (PCT) specific issues regarding the Amendment Bill. This submission will revisit those issues.

As you are aware, PCT is the peak body for palliative care in this State and has been advocating for the legislation of advance care directives (ACD) for some time. Our experience providing advance care planning and ACD education to thousands of Tasmanian community members and service providers, continues to reinforce the confusion many Tasmanians have regarding the legal validity of ACDs.

PCT welcomes the Government's commitment to strengthening Tasmania's end of life strategic policy environment through this Amendment Bill. Overall, we support the Amendment Bill and are happy to work with the Government in the future to ensure its effective integration across service providers and communities.

As discussed, PCT does have some issues regarding the current draft. These are detailed below.

Young People

PCT supports young people having the option to complete a legally binding ACD. The Amendment Bill requires young people under 18 to be deemed competent by a person before they can achieve this.



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The United Nations Convention on the Rights of the Child requires that the evolving capacities of children are respected. In terms of the Amendment Bill, PCT believes that young people under the age of 16 should be assessed to determine their maturity and level of understanding. However, we believe that young people aged 16 and 17 should be deemed as “adults” for the purposes of determining legal competency regarding the development of their ACD.

Appropriate safeguards are already in place if medical practitioners do not believe adults have legal capacity and this would also apply to those ages. This is in line with the Gillick Competency Framework which has its origins in British case law and is widely used in the UK and Australia.

In addition, PCT believes that competency for young people under 16 should, primarily, be determined by medical practitioners, not “a person”.

Mental Health

There is some confusion over whether usual mental health issues impacting people with life limiting conditions (depression, anxiety) could be included in an ACD, given the Amendment Bill states health care does not include the assessment and treatment of a patient’s mental health under the *Mental Health Act 2013*.

Following discussions with your department, PCT understands that the intention of the Amendment Bill in this regard is only to apply to those people under mental health orders. In those cases, it is likely a person would not be deemed to have legal capacity. However, PCT would urge the Government to ensure information and education is provided to service providers and the Tasmanian community regarding this. Tasmanians should be able to state in their ACD they do not want any treatments for those usual mental health issues associated with dying.

Reducing risks for potential misrepresentation and elder abuse

PCT believes there may be an increased risk in these areas without some changes to the Amendment Bill. For example:

- S35B(i)(i) – PCT agrees that consideration must be given to any past wishes expressed by the person. However, this section is ambiguous in that “any past wishes” could mean verbal or written. PCT is concerned that there is a risk this could be misused to shorten a person’s life eg “mum said she didn’t want life prolonging

treatment”, or provide treatment a person did not want. It is important that there is some rigour placed around how past wishes are determined.

- S35E(iv) – PCT believes that the communication method of the person should be understood by an autonomous person, not potentially one close family member who may benefit from the death of the person.
- S35I(2) – PCT agrees that a paid carer should not be able to witness an ACD. However, PCT believes this should be extended to include unpaid carers and volunteers.
- S35J(a) – While it is entirely appropriate for interpreters to be used by people for whom English is not their first language, PCT is of the strong belief that accredited interpreters should only be used. PCT has had discussions with some of our clinician members who have all stated that the chances for information not being relayed appropriately when using family or friends as interpreters is high.

PCT acknowledges that there may be a shortage of accredited interpreters in Tasmania. However, COVID-19 has taught us that we are able to address these shortages through virtual mechanisms. We would also encourage the Department to review the work of Dr Phillip Good, an Australian palliative care clinician, who has studied the experiences of interpreters in supporting palliative care patients. Dr Good had examples of family members not relaying appropriate information because they did not want to let their loved one know they were dying. This would obviously have potential impacts on the information that may be recorded in an ACD.

- S25Q(3)(b) – PCT believes this should also include determining the validity of the ACD, particularly when people are admitted into residential aged care. PCT understands there may have been cases in Tasmania where a person enters a residential aged care facility (RACF) with an ACD that may be dated a week or two before admission. However, it is clearly obviously that the person suffers from severe dementia and lacks legal capacity. In these cases, a family member may have filled out the form and had the person sign it, not understanding what they are signing. If a facility manager has questions on validity, these should be referred directly to the Board.

Health Practitioners not compelled to provide particular health care

PCT has some concerns regarding S35S which talks about health practitioners being able to refuse to comply with provisions in an ACD. PCT agrees that health practitioners should not provide futile treatments; treatments that are not going to positively impact quality and/or length of life. PCT also agrees that there may be emergency circumstances where a medical practitioner cannot ascertain whether a person has an ACD and provides life sustaining treatment until that can be ascertained. However, where a directive in an ACD is reasonable, medical practitioners must follow that directive.

S35Z appears to provide broad ranging protections for medical practitioners and persons responsible who do not act in accordance with an ACD. Unless “good faith” is defined by exemptions for not providing futile treatments and emergency situations where the existence of an ACD is unknown, these protections should be removed.

PCT also believes penalties should be introduced for medical practitioners and enduring guardians/persons responsible who knowingly go against a person’s directives in their ACD.

General Comments

1. After discussions with the Department of Justice and the Ministers for Justice and Health representatives, PCT understands and supports, that should voluntary assisted dying (VAD) become legal in Tasmania, a person will not be able to opt for VAD within their ACD. This is in line with VAD and ACD legislation nationally and internationally.
2. In those cases where capacity returns, PCT believes a medical practitioner should be required to let a person know that their ACD was implemented when they lacked capacity, and at the moment they regained capacity, the ACD is now no longer in use (see S35W).
3. PCT commends the Government for recognising (under S35E(7)(c)) that decision making may fluctuate. This will provide an opportunity for people with dementia, in particular, to complete and register an ACD.
4. PCT strongly supports S35ZG(4) where a person who gave an ACD is to be party to any hearing before the Board. PCT encourages the Government to appropriately resource the Board, and Legal Aid, to ensure that bedside hearings can be conducted effectively.

5. In terms of the ACD form, as you are aware, the Department of Health, formed an Advance Care Directive Working Group with representatives from the Partners in Palliative Care Reference Group. A new ACD form, and information sheet, has been developed and endorsed by the Department with support from key stakeholders. PCT believes that responsibility for the form and relevant supporting information should remain with the Department of Health.
6. PCT understands that ACDs will need to be registered with the Board and a repository of ACDs will need to be developed. PCT believes that the Department of Health should have responsibility for managing any ACD repository. In practice it will primarily be Tasmanian Health Service employees and primary health providers that would be utilising this system. Health practitioners will need 24 hour access to this repository. This is critical when supporting a dying person.
7. The Amendment Bill talks about medical practitioners using reasonable action to determine whether a person has an ACD. This should include checking with the regulatory body/repository and being able to obtain a copy quickly. An Enduring Guardian or Person Responsible should also be able to obtain a copy of a person's ACD if they need to.
8. PCT does not support the introduction of any fee for the registering of ACDs. This would prohibit many Tasmanians from completing an ACD.
9. PCT understands that the Amendment Bill is separated into medical directives (what care I do not want) and wishes. We believe that a person should be able to state their preferred place of care as part of their wishes, and these should be met if reasonably practicable. This is important as we know that many Tasmanians wish to be supported to die at home, however they define home.



PCT is looking forward to continuing our work with the Tasmanian Government to ensure Tasmanians have control over the medical care they receive when they are dying.

I am happy to discuss any of these matters in more detail with you.

Yours sincerely

A handwritten signature in black ink, appearing to read "Colleen Johnstone", written over a light blue horizontal line.

Colleen Johnstone
CEO

