

**Submission concerning the Guardianship and Administration Amendment (Advance Care Directives) Bill 2020**

Live and Die Well was recently set up to provide an alternative voice on the issue of end-of-life choices by a group of likeminded individuals whose common interest was the protection of the vulnerable. The group developed [ten key principles](https://livendiewell.org/#!/StandFor) to guide its work2, with two of them concerning advance care directives:

* We urge the Government to codify in legislation the common law position on end-of-life decision making and provide a basis for advance care planning.
* We believe that expanding the awareness and use of Advance Care Directives (ACDs) will provide people and their families with improved peace of mind as they need to approach their end of their life.

Consequently, Live and Die Well is supportive of the goal of the draft legislation to enshrine in legislation a number of common law protections for ACDs. This development will help give ACDs a more solid legal basis and ensure that they are taken seriously by health care and aged care institutions. As the legal status of ACDs improves, their acceptance in the community is likely to improve.

The main reason that Live and Die Well support the use of ACDs is that they help to give people more certainty that their end of life care will be carried out in harmony with their beliefs and preferences. This gives people and their families better peace of mind. Furthermore, the process involved in developing an ACD necessitates a number of conversations with family members so that they can become aware of a person’s beliefs and preferences well in advance of a medical crisis. This forward planning can help avoid the tendency that relatives of a patient nearing the end of their life from putting pressure on medical staff to overtreat the patient. A clear ACD should enable relatives and medical staff to understand the goals of a person’s care plan as their health condition changes.

The other significant health advantage in respect to ACD is their likely impact on the provision of quality palliative care. One of the challenges for palliative care providers is that they are often referred patients later than they should have been. This delay in referral can be a function of the care plan being too focused on treatment. As a result, the patient’s pain has not been well controlled and this can cause stress for both the patient and their family. A well-articulated ACD could provide clear instructions for family members and health professionals on when the patient wants palliative care to be the priority of their care plan. Early referral to palliative care services can help achieve optimal pain management and improve the end-of-life experience for both the patient and their family.

The improved legal status of ACDs will help build awareness of the importance of end-of-life planning and this will help to encourage people to talk about death with their families and medical professionals. A number of recent reports have highlighted the growing stigma related to talking about death. A number of groups and initiatives have been established to address this stigma including *Dying to Know Day* and *Death over Dinner*. Anything that helps in getting people to talk about one of the inevitable parts of life, death, the less fear and anxiety will surround the journey towards death.

Despite the positive impact of ACDs, Live and Die Well have the following concerns about their use:

* We don’t want ACDs to be used for access to assisted suicide/euthanasia. While the current End-of-Life Choices bill being considered by Parliament requires decision making capacity to be established as part of the eligibility criteria, other jurisdictions such as Canada and The Netherlands have eventually expanded their laws in this area to use ACDs as a way of opening access to assisted suicide/euthanasia for those who have lost capacity. While the current scope of the draft ACD bill concerns the refusal and withdrawal of treatment, we do not want this scope to be expanded to include the choosing of assisted suicide or euthanasia (defined in the End-of-Life Choices bill as *Voluntary Assisted Dying*).
* We are concerned that a culture may develop in respect to ACDs in which life sustaining measures (especially nutrition and hydration) are routinely withdrawn from patients due to the instructions in their ACD. We do not want this practice to be the default for patients that do not have an ACD. In the event of what is likely to be a temporary loss of independent operation, we believe that it is important for life sustaining measures to be continued. Life needs to be given priority over death when people haven’t developed an ACD. It is important for medical staff to refrain from making any valued judgements about the quality of life of patients in the absence of an ACD.
* We would prefer that ACDs to be high level instruments that are not too prescriptive. If they become too prescriptive then it might make medical treatment quite tedious as the doctor might have to be constantly liaising with the guardianship board.

We thank the Department of Justice for this opportunity to make some comments in relation to a legislative initiative to strengthen the status of ACDs.

Kind Regards

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Live and Die Well