Advance care planning: lessons from a study of Tasmanian enduring guardianship forms

Uptake of available instruments is low, and death is the “elephant in the room”

There is an ongoing global conversation about death and the process of dying. Despite half a century of clinical, academic and public policy activity by specialist palliative care workers — and by many others, including health administrators, academics, artists and writers — it is common to hear the same issues recycled with the oft-repeated comment that we “do not do this well”. Clinicians struggle with treatment abatement decisions and issues relating to causes of and responsibility for death. Pathways to death (“death ways”) are changing, with increasing numbers of people dying in old age, slowly over 1–2 years, with multiple comorbidities (which often include dementia) and greater numbers of significant medical decision points.

The public often has expectations of curative capacity that exceed reality (fed by a technically optimistic health industry) on the one hand, and exhibits widespread concern about bad dying on the other. Although improvement of clinical care is essential, it needs to be supported by public health promotion activities aimed at improving preparation for the end of life.

Lack of capacity has been identified as a major barrier to timely and appropriate limitation of life-prolonging medical treatment, and deployment of palliative and terminal care. Despite considerable global enthusiasm for the potential role of advance care planning to solve the challenge of decision making at the end of life, uptake is low and utility in clinical situations is contested.1 However, there has been recent common law endorsement of the status of advance care directives in Australia,2 and an Australian randomised controlled trial has shown that advance care planning improves adherence to patient wishes and family satisfaction.3

Enduring guardianship is a specific legal instrument that can be part of the broader context of advance care planning,4 a process that enables individuals to consider and make decisions about their future health care in consultation with their doctor and other health care professionals, family members and other important people in their lives. Consultations with lawyers for will drafting and with superannuation or financial planners may also bring up these issues.

Under the provisions of the Guardianship and Administration Act 1995 in Tasmania, people aged 18 years or older can appoint a substitute decisionmaker known as an enduring guardian, and the document of appointment is registrable with the Guardianship and Administration Board. Tasmania is the only Australian jurisdiction, and one of few in the world, to operate a state-funded registry to require registration of completed enduring guardianship forms with a guardianship board.

From 1995 to 2010, 10 040 enduring guardianship forms were lodged with the Guardianship and Administration Board. This represents uptake by about 2.7% of the state’s eligible adult population, despite information being widely disseminated across the state.4 It sets a benchmark for comparing uptake of substitute decisionmaker instruments in Australia, and possibly overseas.

To assess uptake and use of the Tasmanian legislative provisions, and to obtain data to inform future developments in advance care planning in Tasmania and elsewhere, a study of enduring guardianship forms was commissioned by the Office of the Public Guardian for Tasmania.5,6

A one-in-20 sequential sample of forms was analysed (n = 502) in this study.5,6 Forms tended to be completed by retired people aged over 60 years (63% by women and 37% by men, for forms on which sex was specified). Despite legal assistance to complete an enduring guardianship form not being mandated, 39% of the forms showed evidence of legal input. Textual analysis showed substantial evidence that people tend to copy examples used in advisory material provided.

Nearly half the forms (47%) contained a statement about end-of-life care and indicated a preference for the deployment of timely and appropriate palliative care. These directions were usually made in general terms, and copied verbatim from examples. Quality-of-life considerations appear to be underpinning these
statements, as seen from these extracts from the forms that were analysed:5

When I am unable to walk outside by myself I would like to be taken out to the sun for a few hours every day whenever possible.

As a lover of fine music I would like to be able to listen to classical music in the evenings.

I wish to hear Christian music even if I seem to show no response. Care should be taken to ensure that others are not annoyed.

I do not want to be force fed.

If I am bed ridden and only able to verbally communicate by sounds, not speech, and if the sounds which I make annoy others around me I do not wish to be given medication to silence me unless the noise is extreme and all other measures have been tried.

Despite the fact that enduring guardianship powers lapse at the time of death, 14% of the forms analysed provided direction to appointed guardians on wishes regarding organ donation.2 So it does not seem to be understood that the powers of substitute decisionmakers lapse at the time of death.

These data show what a generic legal instrument such as a guardianship tool can achieve in terms of advance care planning without a dedicated public health campaign focused on medical care or death and dying.

While the enduring guardianship instrument is clearly a statutory provision, advance care directives do not have statutory force in Tasmania, but have been supported in common law in Australia and other common law jurisdictions. It seems that the strongest position in medicine, ethics and law is to appoint a substitute decisionmaker under the relevant jurisdictional provisions, and preferably provide that person with oral or written instructions about values and wishes. Regardless of the legal status of advance care directives, doctors surely have an ethical obligation to respect what they know of patient wishes.

In addition, it is widely recognised that it is the process of advance care planning that matters: that people reflect on their values, beliefs and wishes about end-of-life health outcomes, and then advise those around them and their health care attendants. This process is seen as having pre-eminence over the completion of formal legal forms.7

All adults should be encouraged to appoint an enduring guardian (or equivalent) and write an advance care directive, using a format that addresses end-of-life issues, preferences, beliefs, values and unacceptable treatment outcomes. Directions on enduring guardianship forms, including those that specify aspects of personal care, should be actively sought and incorporated into a care plan if the person is admitted to a hospital or an aged care facility.

While capacity is important, broader action is required. For example, a Healthy Dying Initiative has been developed in Tasmania to improve care and decision making at the end of life.8 This consists of three components: a goals-of-care framework, an advance care directive for the end of life, and a number of health-promoting interventions aimed at raising awareness about

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