

In search of a good ending



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Despite much development and increasing complexity in health care, humankind's mortality rate remains at 100%. Given the ubiquity of this experience, it could be argued that an important, universal health outcome measure is a "good death". In the late 1990s, a qualitative study identified five things that people want when they approach the end of life: avoiding suffering; avoiding the prolongation of dying; achieving a sense of control; and relieving burdens on, and strengthening relationships with, loved ones (*JAMA* 1999; 281: 163-168). More recently, Australian researchers involved with the Respecting Patient Choices Program in Victoria conducted a randomised controlled trial that objectively demonstrated that advance care planning — "whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care ... should the patient become incapable of participating in treatment decisions" (*CMAJ* 1996; 155: 1689-1692) — improved end-of-life care and patient and family satisfaction and reduced stress, anxiety and depression in surviving relatives (*BMJ* 2010; 340: c1345). In this issue of the *MJA*, several contributions examine end-of-life care from different perspectives.

Since 1995, adults in Tasmania have been able to appoint and legally register a substitute decisionmaker (known as an enduring guardian) to make health care decisions when they lack capacity to do so themselves. Ashby and colleagues (*page 188*) report that uptake of this option from 1995 to 2010 in the eligible population was only 2.7%: a missed opportunity, considering the authors' belief that the process of advance care planning is just as beneficial as the legal documents arising from it. Another Tasmanian project, the Healthy Dying Initiative, seeks to improve care and decision making in and out of hospitals at the end of life. It includes a "goals-of-care" framework for clinicians to state whether goals are curative, palliative or terminal, and advance care directives.

We are getting better at planning care at the end of life for cancer patients, but what about the many Australians who will die from chronic disease? Burgess and colleagues (*page 186*) say this scenario holds particular challenges. As patients with multiple morbidities slowly deteriorate, they require active disease management, but they also need help to control distressing symptoms, and emotional, spiritual and psychological support for themselves and their families. The authors call for a system that allows and supports both these needs simultaneously.

Some doctors believe we should go a step further in assisting patients at the end of life. Willoughby and colleagues (*page 190*) put forward the position of Doctors for Voluntary Euthanasia Choice (www.drs4vechoice.org). Under current health care provisions and professional ethics guidelines, they are concerned that some patients still have unrelievable forms of pain and others may be forced to endure a wretched but ongoing existence. They call for voluntary euthanasia to be legalised, following the precedent set in several other countries.

As Wilkinson points out in the introduction to our new occasional Ethics series (*page 220*), we have some way to go before our conflicts about the big issues in medicine — such as how far we should go to assist in a good death — are resolved. He offers three principles that might help guide the way: universalisability (could we apply to ourselves what we are proposing to do to others?), consistency, and a willingness to be guided by the wishes and values of the individual most affected by a decision.

When it comes to the third principle, some of the advance care directives analysed by Ashby and colleagues indicate that, for many, the wishes for end-of-life care are simple, practical and clearly articulated: "I do not want to be force fed" or "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".

These wishes, at least, we should be able to grant.

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Pioneers and pride

Professor Ian Maddocks was recognised for his pioneering work in palliative care when he was named the 2013 Senior Australian of the Year by Prime Minister Julia Gillard. He knew early on that he wanted to make a difference and went on to a distinguished 14-year career in Papua New Guinea before returning to Australia to help shape the palliative care discipline in this country. Karen Burge spoke with him about his journey (*page C1*). Narrow-focus clinics are the subject of our Money and Practice

feature, as Annabel McGilvray speaks with general practitioners who opt to practise in subspecialties (*page C7*). Our Medical Mentor is Eva Segelov, medical oncologist at St Vincent's Hospital in Sydney, associate professor of medicine at the University of New South Wales and principal investigator on a number of oncology clinical trials (*page C6*). Dr Nicholas Hayden is the registrar we talk to about how he combined his medical studies with his professional rugby career (*page C6*).