

Planning for death must happen long before the last few days of life

October 18 2018, by Imogen Mitchell



People need time to learn about their options and think about their preferences.
Credit: [Val Vesa/Unsplash](#)

Our experience of death obviously shapes the final moments of our own life. It also shapes the experience and [remains in the memories](#) of those

around us.

Around 160,000 Australians [die each year](#), but few achieve the type of death they would like. Some 60 percent of us [would like to die at home](#), but less than 10 percent [are able to](#). Up to 30 percent are admitted to intensive care before they die in hospital.

As an intensive care specialist for more than two decades, my colleagues and I do the best we can to provide high-quality [end-of-life care](#).

But too often end-of-life planning begins in the last few days. By then it may be too late for patients to choose where they want to die, who they want to be cared by, how they want their symptoms managed, and how to access the right sort of care to make all this happen.

Lack of planning affects us all

To make meaningful decisions about end-of-life care, people need to have an idea of what will be important to them as they reach their final months and days. This is difficult and confronting in our death-denying culture.

What [becomes important](#) toward the end of life is a sense of spiritual peace, minimising burden to others, maximising control over one's life and strengthening relationships with loved ones.

Advanced care directives are one way of helping people think of what would be important to them in their dying months and days. These directives allow trusted decision-makers to convey one's preferences concerning end of life when decision-making capacity is impaired. Such preferences can include whether one would want life support in the event of a life-threatening situation.

They aren't always perfect, though, as we find they are unable to provide clear guidance for each specific patient context in the [intensive care unit](#). However, they can provide a useful trigger for families to have conversations about end-of-life planning.

Nationally, our [uptake of advanced care directives](#) is as low as 14 percent. With no advanced care plans or early end-of-life care conversations, families are left to make decisions when patients are too confused or physically unable to communicate meaningfully. Sadly, I often talk to families who are unaware of their loved one's wishes and, even worse, of just how unwell their loved one is.

Patients often in the dark

Families aren't the only ones left in the dark when it comes to understanding the disease trajectory of their loved one. Too often, the patients are unaware of their disease trajectory. They may either be unable to comprehend it or are in denial.

However, in addition, doctors often avoid these discussions – wishing to cure the disease – or don't [have the time or skills](#) to describe what the disease trajectory looks like as a patient enters the final year or months of life.

As a chronic condition deteriorates and with no clear direction for care, patients are frequently admitted and readmitted to acute hospitals with the intent of a cure. Patients with chronic heart failure, for instance, could come to hospital due to a worsening of their condition, which could be made even worse by a chest infection.

Without a clear direction of goals of care, intensive care intervenes. Snap decisions are made on the run and suddenly patients and families find themselves in the [intensive care](#) unit surrounded by machines and a

bevy of doctors and nurses.

Up to 60 percent of acute patients are [admitted to hospital out-of-hours](#) when frequently only junior doctors can care for them. A junior doctor can provide short-term management plans but is often poorly equipped for longer-term goals and to deliver empathetic and clear end-of-life care conversations.

During business hours, senior and more experienced doctors will review patients and provide better, longer-term management plans, which can include referral to specialist palliative care teams. These teams relieve the suffering of patients and their families by comprehensively assessing and treating physical, psychological and spiritual symptoms.

Improving the system

From 2019, the [national health care safety and quality regulator](#) will implement minimum standards for end-of-life care. These will provide guidance to hospitals, nurses and doctors on how to meaningfully engage patients and families in decisions around end of life.

This will help ensure patients are encouraged and supported to express their preferences about end-of-life care and that this care is delivered in accordance with those preferences.

Yet, there are challenges across all health-care sectors. Two recent reports from the [Grattan Institute](#) and the [Productivity Commission](#) describe how many people approach the end of their lives in hospitals where care may not align with their preferences.

The reports show demand for end-of-life care in the community, such as community-based palliative care, far exceeds its availability. Nursing homes are ill equipped to manage end-of-life care, which often results in

traumatic (and costly) trips to hospital.

Improving the end-of-life care experience means planning, funding and delivering an integrated service across different settings and jurisdictions. Importantly, there needs to be a national conversation about end-of-life care to prompt both health professionals and patients to talk about dying so we all receive a safe and high-quality end-of-life experience.

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