

# Why it pays to plan your end-of-life care

## Adapted from:

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Planning your end-of-life treatment isn't a priority for most people. The reality is that only 15 per cent of Australians have actually documented their health preferences. Yet, it could be one of the most important decisions we ever make.

Research by Advance Care Planning Australia, funded by the Australian Government, shows that only 30% of the 65+ population is prepared with instructions for their final medical care.

General practitioner Dr. Chris Moy has often come across situations when patients lose control of their end-of-life medical treatment.

He says it's due to a lack of planning and conversation on the sensitive subject while they are still able to express themselves.

"Because things have been unsaid, it becomes very difficult for other people who'll have to make decisions for the individual. At the end of life, there's a very high chance you're actually either going to be unconscious or delirious or in a situation where you can't make decisions for yourself. The whole end of life situation becomes this big conflict - a very traumatic time. You may get care that you don't want but then even when you do die, those left behind may be left with the legacy of incredibly deep psychological trauma."

Dr. Moy recommends thinking ahead and communicating your wishes to those whom you trust.

"Most people should think about having some sort of documentation to actually indicate who would make decisions for them when they can no longer make decisions. Because one never knows when that may happen but probably worth considering that anyway - talking to your loved ones about things but obviously becomes far more an issue as you get older or if you have some serious illnesses. Probably a very good time while you're still able to make those decisions to start doing this advance care planning."

Linda Nolte is the Program Director of Advance Care Planning Australia.

She says a chat with your loved ones often isn't enough for your final wishes to be granted.

She shares the example of a healthy 75-year-old-man who had instructed his family not to resuscitate him if he ever becomes critically ill.

Unfortunately, he was left in the very situation he tried to avoid when he became unconscious in a life-threatening emergency.

"So there had been a very valuable conversation but no documentation available and decisions had to be made in a hurry because of the nature of the event that occurred to him. He was fully treated and he is still alive but he is unable to talk, he can't eat, he can't walk, and he can't

toilet himself and he will need to go into permanent care."

Nolte says the instructions of whether or not to receive life-prolonging treatment must be clear for the clinicians to follow.

"For Advance Care Directives to be legally binding, we recommend that the form that is recommended by the state or territory is used. So the form will need to have the person's full name on it. It should have their date of birth, their address, the contents about what their preferences or values are but it also should be signed, dated, and witnessed."

There is a process where people can appoint the person they want to make decisions for them when they are no longer able to express themselves rather than leaving things to chance and the default system under the law.

The 'substitute decision-maker', is to make decisions that the person would've wanted. Not what they think is best, but what they think their friends or loved one would've wanted."

The reality is that only 15% of the Australian population has actually documented their health preferences at the end of life.

It is even less likely for those whose first language isn't English to have an advance care plan.

Having worked in oncology and aged care for many years, Linda Nolte has often seen family conflicts that could be prevented if directives were communicated in the first place.

"Particularly, like if a mother or a father have spoken to their daughter and often had more in-depth conversation but they've not told their other son or other children the same information - that's what can lead to some conflict."

In the Chinese culture that Dr. Chris Moy was raised in, the word "death" is a taboo not to be uttered.

While it's a sensitive topic in some cultures, Dr. Moy says it's necessary for people nearing the end of life to discuss it with their loved ones.

"It's often less about the issue of talking about death but it's the word 'death' which is the problem. But then they end up with no advance care planning even when they might want it if they actually understood what it was about and then they end paying a terrible price and their families as well."

Dr. Moy says sometimes it's about discussing your values and beliefs to work out what sort of medical care is in your best interest.

He highlights a fairly common scenario of people with diabetes being confronted with the potential of amputation.

"Certain individuals themselves would actually have keeping their leg, for example, more important than actually keeping on living."

It's also about considering the quality of life you want and the legacy you wish to leave behind.

“What people want, I think, is actually the ability to determine their fate and I think whether it is to have the opportunity to have treatment that would keep them alive as long as possible because they want to keep going or to be allowed to let go because their existence is so painful or it's so distressing to them that it goes against their values.”

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