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Tough conversation worth having

Adele Horin
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It was my mother's 84th birthday last week, and we gave her an unusual gift: the opportunity to talk to us about her end-of-life medical treatment. A gift more removed from a fluffy pair of slippers is hard to conceive. She was reluctant at first to embark on the conversation. But it was important.

She pulled out some documents she had half-heartedly stashed away for this visit to Perth from her two Sydney-based children (the third child arrives from London soon). The documents were an advance health directive booklet and one on enduring power of guardianship.

My mother, a widow, is managing quite nicely in her own house. She is not a fluffy slipper kind of woman. For her birthday we also gave her a pair of boots (of her choosing) and she had looked a million dollars at the jazz club the night before. At the gym, which she attends three times a week, her fellow fitness enthusiasts, in their 50s, 60s and 70s, had brought cakes for her birthday and rightly made a fuss of her.

But the day may come when my mother will face choices about how much medical treatment to undergo and may be too incapacitated to make her wishes known.

It might never happen, or it could happen next week or in 10 years. But if it does happen - dementia, a massive stroke, a serious accident - and she needs medical treatment to prolong her life, I want to be able to lay my hands on the document that specifies my mother's wishes.

The advance care directive, still a work in progress, specifies that my mother is happy to have antibiotics, blood transfusions and pain relief medication but she doesn't want cardiopulmonary resuscitation if her ribs are likely to be broken in the process and cause long-term pain; and if she is in a coma with no chance of recovery to a normal life, she doesn't want her life prolonged with various treatments.

Having seen my father die from cancer, she has strong views about experimental chemotherapy of the kind that worsened the quality of his last months; or of any chemotherapy if she has dementia.

Trying to be specific and graphic was difficult and discomforting, and I'm sure we have left bases uncovered. But to have made no attempt to get my mother's wishes down in writing might one day make things much, much worse.

It is astounding how few Australians appear to have completed an advance care plan or an enduring guardianship which designates a proxy to make personal and medical decisions (financial matters are covered by an enduring power of attorney).

The nation's foremost expert on end-of-life planning, Professor Colleen Cartwright, of Southern Cross University, says fewer than 25 per cent of Australians have taken care of this difficult business even though these documents are backed by force of law.

The lack of such documents can lead to emotional scenes in hospital intensive care or emergency units, with siblings fighting, screaming, and threatening each other around a parent's bedside. If a terminally ill parent is whisked to hospital, doctors are put in an awful bind when a daughter says "no feeding tube" and a son accuses his sister of wanting to kill off their dad.

"The classic case," Professor Cartwright says, "is the daughter who flies in from Melbourne or California and has not seen mum for 10 years. The rest of the family and the doctors have agreed to switch off the ventilator because there's no point in prolonging the dying. But out of guilt, out of her own needs, the daughter from Melbourne or California says no."

That's when it's good to point to an advance care directive.

Bedside battles can also be waged with doctors who string people up to so many tubes that loved ones can't get close to say goodbye. What mum may have always said - "no resuscitation if my heart stops" - may carry little weight in the absence of a written document. Professor Cartwright is often told by distraught relatives: "The doctors just wouldn't listen."

Given clear written instructions make such a difference, why don't more of us take the time to commit our wishes to paper?

If people have thought of it at all, they may believe the process is expensive or requires a lawyer (neither applies). Advice is widely available on the internet (aslarc.scu.edu.au is a useful site). In NSW there is no mandated form, though many organisations have produced suitable forms; even the back of an envelope is acceptable. A person can give a general statement of their wishes and values or be very specific about what they do and don't consent to. Our own experience might have benefited from access to descriptions of likely medical scenarios and the benefits and burdens of different treatments. I can't recall where I picked up that CPR in the frail often entails breaking ribs.

The possibility of family arguments cannot be entirely eliminated if language in a care directive is vague and open to interpretation: "Don't use extraordinary means" is a case in point. What is "extraordinary" to one person may be commonplace to another. That is why Professor Cartwright also advises the appointment of an enduring guardian.

I hope my mother kicks up her heels for years to come. It was a tough conversation to have on her birthday. But now I realise it was she who gave us a gift.

This story was found at: ***http://www.smh.com.au/opinion/society-and-culture/tough-conversation-worth-having-20120629-217so.html***

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