

# Vital choices

## Making advance care directives

End-of-life decision-making often treads the fine line between arguments for individual autonomy and against euthanasia. A new computer program by a US physician has re-ignited debates about the utility of advance care directives in Australia. Michelle Lam reports.

The advance care directive (ACD) is slowly becoming part of the suite of documents in estate planning, which includes a will, power of attorney, binding death nomination and an enduring guardian. But the camp is split on how important ACDs are, especially if there is an enduring guardian in place already.

Some, such as Darryl Browne, principal of Browne Linkenbath in Leura, think that ACDs should be “part of the arsenal” of every lawyer in order to comprehensively discuss estate planning issues. He says it is important for people to document their wishes in an ACD.

“I think it is really hard for others to make those sorts of decisions for us,” Browne told *LSJ*. “Ideally, it would be something that everyone should consider. As lawyers, we should raise it in the con-

sciousness of our clients no matter what age they are.”

Others, like Pam Suttor, a partner with L Rundle & Co, think end-of-life decisions should be left to the “clinical good sense of the treating doctor” or

*“The [enduring guardian] is where a person appoints a substitute to make a decision, the [advance care directive] is the person’s decision.”*

**Darryl Browne, principal of Browne Linkenbath in Leura, says advance care directives should be part of the arsenal of all lawyers when talking to clients about estate planning issues.**



PHOTO: KEITH FRIENDSHIP/MONTE LUKE

the enduring guardian who can “exercise their independent mind to make an informed decision in the best interest” of the person. “The ACD would only fetter that decision,” Suttor told *LSJ*, “preventing the guardian from making a good and proper decision.”

“I think ACDs have a lot of pitfalls because, especially if they have been put in place very many years before death, there would have been many technological advances, so that what people say they want in their 40s may not be what they want in their 80s or 90s.

If they are done when people are quite aged, old people, even those in high-care nursing facilities, have fluctuating views on whether they want to cease life or seek treatment.”

People also have to remember to update their ACD or it may no longer reflect their

wishes, she says.

An enduring guardian should be sufficient in most instances because it gives the power to consent to medical procedures – it is a substitute decision-maker, Suttor explains. “The enduring guardian only comes into play once a

had an incredible intellectual life in the face of severe disability, and, on a more everyday scale, a client of hers who survived a three-month coma.

“Objectively, even with a degree of brain damage, she has a better life than if she were dead. She could see her children grow up, has her own home and lives independently,” Suttor said.

### Making your wishes known

NSW Health describes an ACD as “a document that describes one’s future preferences for medical treatment in anticipation of a time when one is unable to express those preferences because of illness or injury” (*Using advance care directives – NSW*, see [tinyurl.com/cwv173u](http://tinyurl.com/cwv173u)). The ACD is distinguishable – and should be separate – from an enduring guardian, according to Darryl Browne. “The latter is where a person appoints a substitute to make a decision, the former is the person’s decision,” he explains.

There are no uniform laws in Australia dealing with ACDs. Last year, the Clinical, Technical and Ethical Principle Committee, set up by the Australian Health Ministers’ Advisory Council, produced “A National Framework for Advance Care Directives” and a “Code for Ethical Practice for Advance Care Directives”. They are aspirational documents with a goal towards national laws in this area. The documents are currently being considered by the states and territories.

In NSW, we rely on the common law case of *Hunter and New England Area Health Service v A* [2009] NSWSC 761 (see “Refusing medical treatment in advance”, *LSJ*, February 2010) where Justice McDougall found that “an individual’s right to self-determination prevails over the state’s interest in the preservation of life even though the individual’s exercise of that right may result in his or her death”.

US physician and bioethi-

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person lacks capacity. They can make the decision, in the particular circumstances, as long as there is informed consent about the procedure or informed consent about refusing the procedure.”

Suttor argues that the ACD, while it expresses the person’s autonomy, is still substituting their decision-making for that of an expert. “To usurp the position of the treating medical team, you are playing god, you’re saying, ‘I know the outcome’, without any training or skill.”

Importantly, she says, people can’t predict if they can live with the particular medical circumstances they may find themselves in, and the contributions of many would have been lost if they had ACDs to refuse treatment. She cites, for example, Stephen Hawking, who has

**People should rely on the expertise of the medical team and the informed decision of their enduring guardian if they lack capacity to make end-of-life decisions, says Pam Suttor, partner with L Rundle & Co.**



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## ADVANCE CARE DIRECTIVES

cist Benjamin Levi, who was in Australia speaking on advance care planning recently, said ACDs only come into play if and when the person loses capacity.

“It’s crucial to understand that the document does not override the patient and their wishes,” he told *LSJ*. “If they have decision-making capacity, the ACD has no standing, but it still has value in terms of the thought that they put into creating it. It will make them better informed in the decision that they make.”

Levi says putting a document together often helps people take a systematic approach to thinking through the issues.

While it’s well and good to trust the expertise of the treating medical team, the reality is that they often don’t have a prior relationship with the patient, and so can’t know the patient’s actual wishes, which is important for medical decision-making, he says.

“The question is, ‘can the patient engage with the health care team to help them make the decision that the patient would want?’”

And leaving the decision to an enduring guardian is not as simple as it might seem. “Often, the hurdle is for people to recognise that when they make decisions for a loved one who lacks capacity, their job is not so much to make the right decision, as to be the voice of that person, to represent what they would have wanted,” Levi said.

To that end, Levi, who works at Penn State College of Medicine in the US, has developed a computer-aided ACD program with fellow physician Michael Green called “Making your wishes known” ([www.makingyourwishesknown.com](http://www.makingyourwishesknown.com)), which walks people through the process of advance care planning, and helps elicit their wishes for future life-or-death medical decisions.

“Our goal is not for people to decide for more or less medical treatment, or for things to end sooner – rather that everyone involved is better prepared so that medical decisions

## MAKING YOUR WISHES KNOWN

### Program developed by physicians, useful for lawyers

Benjamin Levi, US physician and bioethicist at Penn State College of Medicine, says the “Making your wishes known” program is meant to be educational, helping people “better understand the implications of various medical conditions and treatments”.

For example, “on TV, when people get CPR [cardiopulmonary resuscitation], they survive 95 per cent of the time and seldom have any deficits”. But in point of fact, he says, fewer than 10 per cent of people survive to be discharged home, and of those who survive, 75 per cent are left with neurological damage. “If people went off what they saw on TV, they would think they would survive CPR and just get on with their lives.”

So, the program goes through various medical scenarios, such as a stroke, being in a coma, living with dementia and suffering a terminal illness; as well as what common life-sustaining treatments, like dialysis, mechanical ventilation, CPR and using feeding tubes involve, all the while asking users to think about what

they think they would or would not want to endure.

Based on users’ responses to those questions, the program then generates both a general wishes statement and specific wishes for particular medical circumstances, which users can edit so the final document accurately represents their values, goals and wishes.

“So far, our research shows that the program does a good job of articulating people’s wishes,” Levi says.

In fact, a 2011 study in the *Journal of Clinical Ethics* showed the advance care directives (ACDs) generated by the program helped physicians accurately translate patients’ wishes into treatment decisions 84 per cent of the time. On a scale of 1 (extremely poor) to 10 (extremely well), patients rated the accuracy of physicians’ medical decisions based on their ACDs at 8.4. Physicians rated their confidence in accurately translating patients’ wishes into clinical decisions as 7.8 (where 1 is not confident and 10 is extremely confident).

Levi said the results were promising, but stressed

made on the individual’s behalf are more in keeping with what they would have wanted.”

The freely available online program is very detailed, running through various scenarios and medical treatments (see box).

Levi acknowledges that ACDs are made with “various levels of uncertainty” and “even the best program can’t replace an engaged conversation with a well-informed physician or other healthcare provider”. But it does help people understand more fully the kinds of decisions that may have to be made and engages them to think about the issues before a crisis arises,

he maintains.

From start to finish, the program can take one to two hours to complete, and Levi admits “not everybody is prepared to spend the time”. Still, he says “it is a problem to rush through the issues”.

“Taking shortcuts on something that may mean the difference between life or death only short-changes yourself,” he points out. “It’s important people think about not only what they want to live with, but the effect it will have on people around them, their family.”

Browne, though, believes a shorter document that covers the main points can do the job. “A client has to be highly

that the document should be viewed as a draft – “not something that tells people what they believe, but that helps them get started”.

He recommends people share it with others and get feedback. Ideally, it would be used to have more informed conversations with the enduring guardian, healthcare providers, and others whose input can help individuals finalise their ACDs.

“Only by having these kinds of conversations are people likely to really understand what their loved ones want and what the ACD is intended to mean,” Levi says.

The program is useful for Australian lawyers in that it “will help them and their clients understand more fully the range of medical conditions and treatments that commonly arise and will give them the background that helps their clients think systematically through the medical decisions”, he says.

In future, Levi plans to use the program to train lawyers on how to have conversations with clients on ACDs, and use it as a tool in those conversations. □

motivated to go through the detailed document. There’s a turn-off factor.

“As a lawyer, I would be reluctant to go through them with clients. There is a level of knowledge that I don’t possess because it involves discussion of fine medical treatment. Clients will need to talk to a doctor because it’s asking them, ‘I do not agree/agree’ to each question.

“I’ve only had three clients who’ve gone down that route. In each case, it was something that was recommended by their doctor. I think there has to be care in doing it that way.

“Over the years, I find a



**Benjamin Levi, a US physician and bioethicist at Penn State College of Medicine, has developed a new computer-assisted program to help people create advance care directives.**

PHOTO: STUART MULLIGAN

*“Often, the hurdle is ... to recognise that when they make decisions for a loved one who lacks capacity, their job is not so much to make the right decision, as to ... represent what [the person] would have wanted.”*

shorter document is one that motivates most people.”

The ACD he uses, which was created with the help of a registered nurse, includes various conditions that have to exist before the directive applies, then requires that a doctor must certify that the person is terminal or incurable, finally it goes on to say that the person doesn’t, or does, want certain types of treatment.

As to the efficacy of his pro forma ACD, Browne says clients, including medical practitioners, have regularly relied on them and he hasn’t heard of any issues.

#### **Creating an ACD**

In making an ACD, Browne says a practitioner needs to ensure that their client has capacity to do so – similar to making a will.

“It’s also absolutely critical that it be clear, precise and unequivocal,” he emphasises. That means no aspirational

statements such as, “Physicians should forego heroic measures”, or “I don’t wish to be a vegetable”. “If clients are not clear in their ACD, it becomes a matter for interpretation and gives rise to the potential for legal dispute.”

Further, acting contrary to an ACD is not only tortuous but can amount to criminal conduct, he stresses.

An ACD should be separate from an enduring guardian. “The enduring guardian may end in circumstances where a person may not want their ACD to end,” Browne says.

“It’s still possible to have them operate together by having wording in the enduring guardian document that says that the enduring guardian needs to act in accordance with the ACD. That will link the two documents but won’t mean that when the enduring guardian falls over, that the ACD collapses as well.”

Browne’s pro forma requires

the signatures of two witnesses, though he says it’s not necessary – just as having a written ACD is not necessary, but preferable.

“There’s something to be said

about the fact that wills require two independent witnesses, and that it is also a requirement in binding death nominations under the superannuation legislation,” Browne said.

“It makes it important for the client that they are doing it in a really formal way, as it’s the most important document they will ever sign.”

Legally, he says, the witnesses can attest to the client’s capacity, as well as their voluntariness in making the ACD. “It’ll eliminate, as much as one can, any issues that give rise to a contest.”

Practitioners should encourage clients who have ACDs to review them regularly, Browne says. Though hesitant to put a time span on it, he suggests a review at least every two or three years, and revocation where appropriate.

Once created, an ACD should be distributed and shared with the enduring guardian, family and loved ones, and be readily available to all those who provide care, Levi says. His advice is: “People will want to share their ACD with others, but shouldn’t expect it to do all the work. It’s best thought of as a vehicle ... to have more informed conversations about their end-of-life wishes.” □