

# A matter of life and death

Celia Kitzinger and Sue Wilkinson argue there's a role for psychologists in helping people with their Advance Decisions

**Many of us will lose the capacity to make our own decisions at some point in our life, and we may then receive medical treatment we would not have chosen for ourselves. Through the 'Advance Decision' (AD), the law provides the opportunity to refuse such treatments *in advance*. We argue that psychologists have a key role to play in raising awareness of ADs and helping people to write them.**

All of us are at risk of a sudden loss of capacity to make our own medical decisions – for example through a car accident or sporting injury that causes severe brain injuries. Older people are at additional risk of losing capacity due to brain injuries caused by falls (the leading cause of traumatic brain injury among people over 65: Tromp et al., 2001), or by age-related medical conditions that can strike suddenly (like a stroke) or cause gradual loss of capacity (such as dementia). Many of us will lose the capacity to make our own decisions towards the end of life.

When someone is unable to give consent, the default position is that clinicians provide medical treatments that they believe to be in the person's best interests. These treatments may well be what we would have wanted if we could have chosen for ourselves. But sometimes they are not. Some people have religious reasons for wanting to refuse particular treatments – like a Jehovah's Witness who refuses blood transfusion. Other treatments may be unwanted because they are experienced not as saving life but as prolonging the dying process, or as maintaining a quality of life that the person would not consider worthwhile.

Person-centred care, at any age, is important to the profession of psychology. Advance Decisions (ADs) are a vital tool for protecting people's rights not to receive medical treatments that they do not want – a right that may be under threat simply because they have become unable to make or communicate their decision. Yet very few people have written

their own. Could it be time for psychologists to fill a gap in an area that is literally 'life and death'?

## Refusing treatment

People's views about quality of life differ widely, and may change over time. Psychological adaptation to chronic illness and disability has been extensively studied from a wide range of perspectives (e.g. Livneh & Parker, 2005; Smith & Sparkes, 2005). Many people adapt, finding meaning and value in a life they would previously have considered unbearable (Kampman et al., 2015). Others do not – especially when maintaining their lives requires ongoing treatments they experience as burdensome. Patients with decision-making capacity may refuse further cancer treatments, prioritising 'quality' over 'quantity' of life, or request the withdrawal of ventilation with the consequence that they die (Phelps et al., 2015).

In an important court case in 2002 that set the precedent for later judgments, a 43-year-old former senior social worker who was paralysed from the neck down after a bleed in her spinal cord decided that life as a quadriplegic on a ventilator was intolerable to her. She asked the doctors to remove the ventilator and took them to court when they refused. Granting her request, the judge made it clear that 'a mentally competent patient has an absolute right to refuse to consent to treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death' (*Ms B v. An NHS Hospital Trust* [2002] EWHC 429 (Fam)).

When people have the mental capacity to refuse treatments their refusals are binding. Through the mechanism of the AD, the law provides the opportunity for us to refuse *in advance* treatments that might otherwise be provided for us once we lose capacity. We can use an AD to say, for example, 'I refuse a feeding tube if I have dementia' or 'I refuse a feeding

### questions

How can psychologists help people plan ahead for their future medical treatment?

How do Advance Decisions address people's concerns with quality vs. quantity of life?

### resources

ADA (Advance Decisions Assistance) is a small charity, set up in June 2015, to: raise awareness of ADs and help people to write them (including simple examples and one-to-one support); provide training for GPs, psychologists and other healthcare professionals; conduct and support research into ADs:  
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## 'I do not consent to be kept alive... I should like to die in my own bed'

We have personal experience in our family of the way in which an AD can work to support an older person's wishes at the end of life. Sheila Kitzinger (Celia's mother, pictured) campaigned for autonomy and choice in childbirth, challenging its medicalisation. She expressed the same values around dying, making her own choices to refuse treatment when she had capacity, and writing an AD to refuse treatments for when she might lack capacity. At 86 she had cancer and many other diseases of old age and reached a point where she declined further investigations or interventions. Her AD (signed and witnessed in accordance with the requirements) stated:

*If the time comes when I can no longer take part in decisions for my own future, I want to receive whatever quantity of drugs can keep me free from pain or distress, even if death is hastened. If there is no reasonable prospect of recovery I do not consent to be kept alive by artificial means. I do not wish to be transferred to hospital and should like to die in my own bed.*

When her GP surgery tried to insist, a few weeks before she died, that Sheila should be transferred to hospital after a 'mini-stroke', she said no. The GP questioned her mental capacity to refuse hospitalisation. We read out her AD and she stayed home. Later the AD empowered both us, as family members, and also her healthcare providers, to provide 'person-centred care' with confidence that we knew what Sheila's wishes were. (For more details see Kitzinger & Kitzinger, 2015.)



tube, ventilator, CPR and life-prolonging antibiotics if I am in a continuing vegetative state'. One man with motor neurone disease dictated an AD (using eye movement on his alphabet board) refusing all life-prolonging treatment (including ventilator and tube feeding) 'in the event that my disease progresses to a stage where I am unable to communicate my needs and lose the ability to have any control over my decisions of my care and management' (*X Primary Care Trust v. XB and YB* [2012] EWHC 1390 (Fam)) – a decision supported by the court. Provided the AD is properly completed and applicable to the situation the person is in, then these refusals are legally binding in the same way as a contemporaneous decision by someone with mental capacity.

ADs have a long history in common law (as 'living wills') and were given statutory force in England and Wales by the Mental Capacity Act 2005. (In Scotland the relevant legislation is the

Adults with Incapacity (Scotland) Act 2000, under which ADs are 'potentially binding'; Northern Ireland has no comparable legislation at present.) Various similar legally binding arrangements are available internationally (Negri, 2011). A valid Advance Decision that refuses life-prolonging treatment, according to the Mental Capacity Act 2005, must:

- 1 be a written document specifying which treatments are refused under what circumstances;
- 1 state that the decisions apply even if your life is shortened as a result;
- 1 be from a person over 18 and with the mental capacity to make these decisions (capacity is decision-specific and must be presumed unless there is evidence to the contrary); and
- 1 be signed in the presence of a witness who also signs it.

An AD offers a legal mechanism for ensuring that a person's life is not

extended with medical technologies against their – capacitous – wishes (Wilkinson, 2014b). An Advance Decision is not the same as Advance Care Planning and/or writing Advance Statements laying out wishes for end-of-life care (Henry & Seymour, 2008). Such planning tools are very helpful in providing a guide to carers, and they can cover a range of non-medical issues, such as preferences in food, music, TV programmes and clothing. Advance Statements must be considered by the people providing treatment when they determine what is in a person's best interests, but carers are not legally bound to follow them. This makes them very different from an AD, which is legally binding. If someone administers treatment knowing that the patient has refused it in a valid and applicable AD they could be charged with a criminal offence. Not everyone feels so strongly about treatment refusal that they want to ensure that it is legally binding – but for

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those who do, ADs (and not Advance Statements) are the appropriate mechanism.

Advance Decisions are for those who are confident that they are personally and ethically committed to prospective autonomy (i.e. to making decisions now about an unknown future). For those who are less sure, there is the alternative of granting a Lasting Power of Attorney for Health and Welfare (see box). A person granted this power would be able to make decisions for them (once their own capacity to do so is lost) that take into account the quality of life they are apparently experiencing at the time.

### Do Advance Decisions work?

To be effective in practice an AD must do the following (see Kitzinger, 2014):

- I Reflect the person's wishes. In reviewing draft and existing ADs, we have found that this is not always the case,

especially for those prepared by solicitors from a template or downloaded by the person from an internet source. Sometimes people have misunderstood terminology or have not been offered the opportunity to think through the various options and reflect on alternative scenarios.

- I Be available when needed. There is no national register (such as the organ donation register) where ADs can be lodged. As a minimum, an AD needs to be lodged with a GP and put on the individual's medical record; copies should also be given to other relevant healthcare providers, and to trusted family members and/or friends.
- I Meet with compliance by health care providers (or, if necessary, the courts). Healthcare providers can be very anxious about withholding or withdrawing treatment – even when a capacitous person refuses it, and still more when they are dependent on a

written document for the refusal. Nonetheless there is evidence that refusals will be respected, especially where family or friends support the AD. Several cases have now reached court and valid and applicable ADs have always been upheld.

### Supporting people in writing Advance Decisions

A YouGov poll (see [tinyurl.com/ppaaze3](http://tinyurl.com/ppaaze3)) revealed that 82 per cent of people in Britain have strong views about their end-of-life care, yet only 4 per cent report having written an AD. (Only healthy adults living in the community were polled – the figures are likely to be higher for older people with poorer health, often living in institutions, and/or those specifically planning for end-of-life.) This is partly because many people are still unaware that it is possible to make a legally binding decision about treatment in advance of losing capacity (Schiff et al., 2000) and partly because many people believe – wrongly – that 'next of kin' will be able to make end-of-life decisions on their behalf. In fact, family members (as such) have no decision-making power for adults in English law – and, in any case, surrogate decision making is notoriously inaccurate (Fagerlin et al., 2001).

Other reasons for the lack of uptake of ADs are avoidance and procrastination in talking about death and dying (Hirschman et al., 2008; Sachs et al., 1992) and the difficulties medical practitioners experience initiating end-of-life discussions (Morrison et al., 1994). There are also 'practical roadblocks', such as difficulties understanding the law, unclear procedures and complex paperwork (Castillo et al., 2011).

There is very little professional support for people wanting to write ADs. Although Advance Care Plans sometimes (not always) include information about ADs, it seems that they are rarely completed via this route. People often turn to doctors (primarily GPs) or solicitors for help with writing an AD,

## An alternative: Lasting Power of Attorney for Health and Welfare

Creating a Lasting Power of Attorney for Health and Welfare (LPA(H&W)) is an alternative way of taking primary responsibility for medical decision making out of the hands of clinicians. With an AD the person retains decision-making rights and exercises them prospectively, documenting their decisions in advance of losing mental capacity. With an LPA(H&W), the person appoints a trusted other (relative, friend or professional) to make decisions on their behalf, once they have lost mental capacity.

But not everyone has someone they trust to act as an LPA(H&W), and even if they do, many people worry about the burden it might impose on a loved one who is then charged with making difficult decisions on their behalf, or wonder whether the person would have the 'courage' to make a decision that allowed death in a situation where that might be their preferred outcome. There is also an important distinction between the basis for decision making, which can be ethically and practically consequential: an AD is based on what the person wants for themselves, whereas an LPA(H&W) authorises decisions based on the criterion of 'best interests'.

It is possible to have both an AD and an LPA(H&W) by drawing them up to cover non-overlapping decisions (this takes considerable care to get right).

For more information on LPAs – and application forms – visit [www.gov.uk/power-of-attorney/overview](http://www.gov.uk/power-of-attorney/overview)

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Psychologists have the right expertise base to provide support for people wanting to write ADs

but neither GPs nor solicitors can offer sufficient time or expertise – and they often lack the knowledge and communication skills required (Kitzinger, 2014; Wilkinson, 2014a). The main providers of help for people who want ADs are charities such as Compassion in Dying, Age UK, the Alzheimer's Society, the Motor Neurone Disease Association, and our own charity, ADA (Advance Decisions Assistance).

So what role for psychologists? Psychologists have the right expertise base to provide support for people wanting to write ADs, bringing professional skills in communication and counselling, and academic and professional knowledge in areas such as information processing, decision making, and mental health. But so far psychologists have been very little involved in this domain. Most research on ADs comes from disciplines other than psychology – medicine, nursing, medical ethics, philosophy and the law. There is some research from the US that explores psychological theory and empirical evidence relating to ADs – including psychological barriers to thinking about and planning for death (Pyszczynski et

al., 2006); communication problems in end-of-life conversations (Hickman, 2002); variable stability of treatment preferences (Ditto et al., 2005); 'false memories' for treatment decisions (Sharman et al., 2008); and failures in predictive capacity for end-of-life preferences (Ditto & Hawkins, 2005). However, there is very little research on – or practice-based evidence of – psychologists working with clients in a way that supports them in writing an AD. The charity we have set up is designed to fill this gap.

Our expertise on ADs was developed through our work in the Coma and Disorders of Consciousness Research Centre (cdoc.org.uk; see also the multimedia resource at [www.tinyurl.com/vandmcs](http://www.tinyurl.com/vandmcs)); through an ESRC-funded seminar series on ADs; and through collaborative

research with the charity Compassion in Dying to evaluate their services in relation to end-of-life issues (Wilkinson, 2014a). We provide CPD training to professional groups including care home staff, neurologists, independent mental capacity advocates and GPs. None of these groups is as well placed to offer individual, personalised support for ADs as are – at least potentially – psychologists. Psychologists taking on this role would need training in order to develop a sound understanding of the specific legal, ethical and medical issues, as well as some of the psychological and practical issues involved in hands-on work – for example, managing uncertain or fluctuating capacity and supporting assisted decision making, understanding different attitudes to risk and uncertainty, and supporting clients in conflict with family members or medical practitioners.

### Debate and opportunity

Advance Decisions have attracted significant philosophical and ethical debate. Ethicists have wrestled with the problem of whether the newly diagnosed dementia patient who writes an AD

## ADs for all?

It is not just those who are approaching their later years who may wish to write an Advance Decision. When we began discussing this article with the Editor of *The Psychologist*, Dr Jon Sutton, he enlisted our help to write his own. You can read his draft with the online version of this article, via <http://thepsychologist.bps.org.uk>. He said: 'I firmly believe that attitudes towards death and dying will be the major area of social change over the next 50 years. Loss of mental capacity scares me more than death, and I don't want to leave all the risk assessment to medical professionals. Writing my AD, with Celia and Sue, has been a learning curve and for now it remains a work in progress... I think I would find it valuable to hear readers' views.'

directing (for example) that she should not be given life-prolonging treatment for serious illnesses or not given a feeding tube if she stops eating, should have the moral right to determine what happens to the person she becomes in the future – especially if it turns out that this future person seems to the observer to be happy or content (Dresser, 1995; Dworkin, 1993). There are strongly opposing views and no consensus on this issue. But at a time when medical advances can now extend the lifespan beyond what many people desire (Gwande, 2014; Marsh, 2014), and when the *British Medical Journal* has launched a 'Too Much Medicine' campaign, there is no doubt that ADs are of renewed interest to governments and policy makers. For psychologists, this offers an opportunity to extend our skills into this new area and to make a positive contribution to supporting people's rights and choices in relation to their lives and to their deaths.



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