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Advance Decisions: do they work in practice?

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Advance Decisions (formerly known as 'living wills') have statutory force under ss 24–26 of the Mental Capacity Act 2005 in England and Wales. They allow people to specify which medical treatments they wish to refuse (eg clinically assisted nutrition and hydration) under specified circumstances (eg with advanced dementia) in the event that they subsequently lose the capacity to make or communicate those refusals themselves. To be effective in practice advance decisions must (1) reflect the client's wishes; (2) be available when needed; and (3) meet with compliance by health care providers (or, if necessary, the courts). This article lays out ways in which solicitors can assist clients on all three fronts. Solicitors who are aware of the findings reported here will be able to maximize the likelihood that a client's wishes for refusal of treatment will be respected.

An Advance Decision (AD) allows a person to set out a decision to refuse medical treatment in advance, to be used in the event that they lose the capacity to make those decisions in the future. ADs have statutory force under ss 24–26 of the Mental Capacity Act (MCA) 2005 in England and Wales and they are binding in common law in Scotland and Northern Ireland.

Sometimes people with terminal illness make decisions in advance that they do not want cardio-pulmonary resuscitation (CPR) if their heart were to stop, or those with early dementia diagnoses make decisions in advance that they do not want a feeding tube at the point at which their dementia has progressed to the stage that they are no longer able to swallow food for themselves. A 2013 YouGov poll found that 57% want only 'comfort care' at the end of life. Basically, many people want to be allowed to die 'naturally' rather than be subjected to every possible medical intervention – which sometimes saves life only to prolong the dying process.

The inclusion of ADs in the MCA 2005 was controversial, with some organisations (including the Christian Medical Fellowship and the Lawyers' Christian Fellowship) concerned about bringing in

'euthanasia through the backdoor'. The Act did not, however, change the law on euthanasia: an AD cannot legally require a doctor to actively kill a patient – as for example with a lethal injection or deliberate overdose. An AD simply extends the right that we all have (when we have the mental capacity to do so) to refuse treatments we do not want.

It is common ground that it is the absolute right of any competent adult to refuse medical interventions even if that refusal means they will die. Such refusals are valid whatever the person's reasons – good or bad, or for no reasons at all. But many of us (around one-in-three) will, at some point, not have the mental capacity to refuse treatment. We may be unconscious (after a stroke, cardiac arrest or traumatic brain injury) or we may have developed late-stage dementia, or be unable to communicate our wishes. ADs enable us to express our refusals in advance of losing capacity.

Anyone over the age of 18 who has the mental capacity to understand, retain and weigh the information relevant to their decisions can make an AD (s 24 MCA 2005). An AD refusing life-prolonging treatment is potentially a very simple

document to complete and doesn't require either a solicitor or a standard form. Although a number of different templates for ADs have been produced (the most comprehensive by the charity Compassion in Dying: www.compassionindying.org.uk) all that is required is a written, signed and witnessed statement (s 25(6)) about what the person wants to refuse under what circumstances, and a statement that this refusal holds 'even if my life is at risk' (s 25(5)).

For example, an AD might read like this:

I refuse all medical treatments or procedures/interventions (including but not limited to clinically assisted nutrition and hydration) aimed at prolonging or artificially sustaining my life if I am persistently unconscious and have been so for at least 4 weeks and there is little prospect of recovery in the opinion of two appropriately qualified doctors. I maintain this request even if my life is at risk.

As long as the person writing this was over 18, had signed it and had a witness signature, (and had mental capacity at the time that it was written, which is always the presumption s1(2)), then this is a legally binding document. This means that if he or she is subsequently in a vegetative state for 4 weeks and assessed as unlikely to regain consciousness, then the unwanted treatment being administered (maybe a ventilator, certainly a feeding tube) must at that point be removed.

This AD is of a type that many people might wish to complete since research shows that the majority (82% in a survey reported in Demertzi, A et al, 2011, 'Attitudes towards end-of-life issues in disorders of consciousness: A European Survey', *Journal of Neurology* 258: 1058–1065) do not wish to be maintained long-term in a vegetative state. This is commonly expressed in lay terms as not wanting to be kept alive as a 'vegetable' or a 'cabbage' (S Wilkinson 'An analysis of calls to the Compassion in Dying end-of-life rights information line' 2013, available at <http://www.compassionindying.org.uk/policy-research>).

To be effective in practice an AD must (1) reflect the client's wishes; (2) be available when needed; and (3) meet with compliance by health care providers (or, if necessary, the courts). Solicitors can assist

clients with all three issues. In what follows I draw on published and unpublished research conducted as part of my work with the York-Cardiff Chronic Disorders of Consciousness Research Centre and as convenor of the ESRC Advance Decision Seminar Series.

(I) Reflecting the client's wishes

An AD should reflect the person's own values about the quality of life they consider worthwhile. The word 'recovery', as used in the sample AD above, is a slippery concept. It is advisable to discuss with clients what level of 'recovery' they would consider acceptable.

For example, recovery from the vegetative state can mean regaining the partial and fragmentary consciousness that is characteristic of the 'minimally conscious state' which, some believe, is actually worse than remaining in a vegetative state (Demertzi, 2011; D Wilkinson and J Savulescu 'Is it better to be minimally conscious than vegetative?' (2012) 39(9) *Journal of Medical Ethics* 557–558). A majority of people (67%, Demertzi, 2011) do not wish to be maintained in a minimally conscious state. Members of families of people who have been kept alive in either a prolonged vegetative or minimally conscious state are virtually unanimous that they would not want this for themselves and – compared with the general population – this group is disproportionately likely to write an AD refusing life-prolonging treatments (J Kitinger and C Kitinger 'The "window of opportunity" for death after severe brain injury: Family experiences' (2013) 35(7) *Sociology of Health & Illness* 1095–1112).

Even recovery of full consciousness can result in what for some people is an unacceptable quality of life if it means living with profound multiple neurological and physical disabilities. Some people would rather refuse life-prolonging treatment from the moment of loss of capacity rather than risk survival with profound impairments (Kitinger and Kitinger, 2013).

It is advisable to amend the AD above to read 'recovery to a quality of life that I regard as worth living' and to encourage the client to think about what level of 'recovery' they consider acceptable and

incorporate this into the AD. For example (taken from real ADs):

- By 'a quality of life that I would consider worth living' I mean a return to normal independent living.
- The quality of life I would want is being able to recognise my family and friends and to take pleasure from their company.

Without a discussion of 'quality of life' issues, clients may be signing ADs which do not in fact reflect their wishes. A family member interviewed as part of our research (Kitzinger and Kitzinger, 2013) had signed an AD drawn up for her by a solicitor refusing life-prolonging treatment if she were ever to be diagnosed as in the 'permanent vegetative state'. In discussion it became apparent that she had not understood that this would mean waiting six months (after non-traumatic injury) or a year (after traumatic injury), which is the time scale for making such a diagnosis: in fact she wanted to refuse treatment much earlier, and also to refuse treatment if she were diagnosed as 'minimally conscious' (not mentioned in the AD). In another family a (healthy) husband/father had signed an AD, again drawn up by a solicitor, stating that he refused life-sustaining treatment if he were ever to be diagnosed as being in a condition of 'unconsciousness or coma from which it is unlikely that I will ever regain consciousness'. He subsequently sustained severe brain injuries in a road traffic accident, but did regain consciousness with profound disabilities, meaning that his valid AD is not applicable to his current circumstances. He is now trapped in what his wife considers to be a 'fate worse than death' – precisely the situation they had previously discussed and he had drawn up the AD to avoid. Many people hope, by writing an AD, not only to avoid persistent unconsciousness (or minimal consciousness), but also to avoid consciousness with significant loss of capacity. This is sometimes not reflected in the documents they have signed.

(2) Ensuring ADs are available when needed

ADs are needed at the point at which medical treatment is clinically indicated

and a person lacks capacity to give or to withhold consent for that treatment. This might be an emergency situation (e.g. a road traffic accident or sudden collapse) or it might be as a result of progressive degenerative disease (eg dementia or motor neurone disease). If an AD is not available (or not valid or not applicable) at the point at which a decision needs to be made, clinicians must make a 'best interests' decision. In best interests decision-making there is a strong presumption that it is in the patient's best interests to remain alive and treatment is likely to be given unless it is clearly futile or overly burdensome. For people who want to refuse particular treatments, then, it is important for their AD to be available at this point.

There is no central register for ADs. People with life-limiting conditions are likely, however, to be involved in Advance Care Planning of which ADs may be one component, thereby maximising the possibility of a treating health care team being aware of the person's wishes at the end of life. The charity Compassion in Dying carried out a systematic review of the evidence (mostly from the USA) on the extent to which medical treatment preferences laid out in preference tools (including but not limited to ADs) are respected. They found that medical treatment preference tools are an effective way of ensuring patients' wishes are respected when used in the context of planned end-of-life care. Even then, though, ADs do not always follow the patient from one hospital (or ward) to another, or are not communicated to the ambulance service.

Only around half of all Ambulance Trusts in the UK currently use an end-of-life care register and although most have a 'Do Not Attempt Resuscitation' policy, only half hold data on the number of ADs in their system (P Satherley & J Cartwright, 'End-of-life decision-making and ambulance services' (2012) 3(9) *Ambulance Today* 30–31). The charity Compassion in Dying is currently campaigning for a central register, but in its absence the onus for bringing ADs to the attention of the relevant professionals lies with the patient. Some people who have drawn up ADs with solicitors report that they have lodged them with their wills –

which may mean they are unlikely to be accessed at the appropriate time.

Until there is a more satisfactory system for logging ADs, clients should be advised to do everything possible to alert people to their ADs. This includes giving copies to friends and family, GP, other health care providers, the local hospital(s) and the ambulance service. This can meet with mixed success. Families may be reluctant to discuss end-of-life issues and, because ADs are still uncommon in England and Wales (only around 4% of the population has one: YouGov 2013), health care providers may be unfamiliar with them. One study found people reporting widespread ignorance on the part of medical professionals, including a registrar who 'didn't have a clue' what an AD was, and GPs who 'didn't want to be bothered', are 'not taking any notice', 'ignore' the AD, or refuse to discuss it (Wilkinson, 2013).

Many people with ADs are aware of these problems and wear products designed to convey medical information (such as the bracelets and pendants produced by MedicAlert or S.O.S Talisman) or use the Lions 'message in a bottle' scheme to try to ensure that information about their AD is readily accessible in their home. The emergency services are trained to look for this sort of information but in a pre-hospital emergency situation preservation of life takes priority over searching for an AD, or assessing the validity and applicability of an apparent AD. The Act provides that 'A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment' (s 26(2)) and that 'Nothing in an apparent advance decision stops a person (a) providing life-sustaining treatment, or (b) doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court' (s 26(5)). Especially when the person is unknown to the health care provider, it is likely that a general policy of treating first and asking questions afterwards will prevail.

The most that individuals can do in the system as it currently exists is to ensure as far as possible that everyone concerned is

aware of their AD and its contents.

According to Robert Cole, Head of Clinical Practice – MH for the West Midlands Ambulance Service NHS Foundation Trust:

'It might be better – since Advance Decisions are rare – to actually hold a conversation with someone. I get that in West Midlands. Before they write in with their Advance Decision they will ring me and they'll say "can I discuss it with you?" and right away to me that's somebody showing their strength of feeling and indicating how important it is to them. If enough people started phoning in and doing that then there would soon be a robust system put in place for all organisations I would hope.' (personal communication)

It seems quite likely under the current system that a patient with a valid and applicable AD might be resuscitated and/or given other life-prolonging treatment in an out-of-hospital setting because the AD is not available. At the point at which the patient arrives in the Emergency Department and is booked in, another opportunity arises for the existence of an AD to be identified but at present it is unclear whether, or how, hospitals log ADs. In our research, several people with ADs have reported handing them to hospital staff who seemed not to know what they were, and were baffled as to what to do with them. If, in the continuing absence of the AD, hospital treatment is initiated and the patient stabilised, at some point thereafter relatives and/or the GP will become involved and should be able to report on the existence of the AD such that treatment can be withdrawn (if appropriate) at that point.

Outside of the emergency situation, it seems that surgeons and anaesthetists may be receptive to ADs produced by patients during the consenting process for scheduled surgery (e.g. surgery designed to improve chronic health conditions or remove cancers). People who have discussed and lodged ADs with clinicians under these circumstances are usually reasonably confident that their AD had been placed in their records and would effect the treatment they received if it became relevant – at least in relation to this one-off surgical intervention. In our research the initiative for producing an AD

in this situation had come, in every case, from the patient rather than the medical professional. One woman whose brother had cancer surgery (without an AD in place) which left him in a PVS said that the surgeon did discuss the risks associated with the operation ('already frightening him half to death') and pointed out: 'So in hindsight, if they're going to make sure that they're warning people of every possibility, why don't they suggest that they write an advance decision – and maybe give them a leaflet regarding it.' Upcoming surgery is one of the motivations that bring clients to solicitors for assistance with wills, and this may also be a good opportunity to suggest an AD.

(3) Enhancing compliance with ADs

If a patient has made a valid AD which is applicable to the treatment under consideration then 'the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued' (s 26), i.e. his advance refusal has the same force as a contemporaneous capacitous refusal.

The first problem with compliance, as we have seen, is that health care providers may not be aware of the existence of an AD. Even if an AD is placed in their hands on arrival at the scene, they may not be sure that the patient is the signatory, and/or they may be torn between taking the time to read the AD and saving a life or preventing further deterioration. Some have advised that compliance in emergency situations would be maximised if, on the front page of the AD, patients attached a signed photograph of themselves and summarised their AD in a bullet-point list (eg, 'No CPR, No artificial ventilation').

It is particularly difficult for health care providers when it seems to them that the 'best interests' of the patient and the instructions of an apparent AD contradict one another, e.g. when an otherwise healthy and relatively young person with a reversible condition appears to have refused treatment. This is the sort of situation in which the validity or applicability of an AD is particularly likely to be called into question. Health care providers sometimes raise (legally) spurious grounds for suggesting that an

AD might not be valid – for example demanding evidence that the person had mental capacity at the time that they wrote it (which should be presumed in the absence of evidence to the contrary) or pointing to the date of a signature of a few years earlier as indicating that the AD may have 'expired' (some ADs now incorporate the phrase that the AD 'is valid indefinitely unless I specifically revoke it'). In order to overcome these concerns an AD needs to be not only a legally valid document, but also a persuasive one.

As part of my research, consultants were asked to comment on a set of eight different ADs. An intensivist who reported feeling 'bullied' into acting against his better judgment by the legalistic tone of these documents said that he would be more likely to do as the documents requested if patients used the words 'please' and 'thank you'. Another consultant commented on this sentence from one AD:

'I offer the health-care team my heartfelt thanks for respecting my sincerely held wishes, as expressed in this advance decision.'

This is, he said, 'a good point which increases the likelihood of compliance'. A retired GP, recognising that doctors are sometimes antagonised by what they experience as legal coercion used in an attempt to over-ride their clinical judgment, has written his own AD in deliberately 'personal' language:

'In writing my AD, I wanted to "humanise" this – changing it from something technical mired in legal and medical jargon to a sort of "autobiographical" document which expresses the values I try to live by and want to die by. So, I personalised the document, whilst still acknowledging its formality.'

Solicitors may then need to do more than simply produce legally water-tight documents. It may also be necessary to encourage clients to 'personalise' their ADs, explaining to their future and possibly as-yet-unknown health care providers why they have chosen to refuse particular treatments, how these refusals are underpinned by their deeply held values and beliefs, and even acknowledging the

pain this may cause the health care team. For example (from two different ADs):

'I recognise that it is a decision that some people will find hard to understand or accept. If you are currently a member of my healthcare team and feel unable to accept my decision to refuse treatments, please can you pass my care over to someone else who is willing to respect my decision. Thank you!'

'I thank my family and any professional carers for their support – and hope that knowing that they have respected my prior expressed wishes will help them face the dilemmas/distress it may cause them personally.'

These displays of empathy and use of courtesy terms are not of course legally required. But health care providers are not lawyers, and if the intention is to make an AD effective – in the sense that its refusals of treatment will be honored – then it needs to be written in terms which speak to the people responsible for honouring those refusals.

The Compassion in Dying AD template has a section called 'Value Statement and additional directions' which is designed to:

'... give you an opportunity to express your values and beliefs . . . [This could] help health care professionals understand what you consider to be an acceptable quality of life or recovery for example. . . . These directions are advisory only and while they should be taken into account do not legally bind the health care team.'

In my experience people are generally enthusiastic about filling in this portion of the AD. One young woman provides a list of experiences that 'fill me with horror' by way of indicating the sorts of circumstances under which she would want to refuse life-prolonging treatment:

- 'The thought of being in pain and unable to communicate it, or painkillers not working because of brain damage;
- The thought of any isolation and loneliness which I subjectively experienced;
- Any awareness of the loss of my abilities and previous life, and

consequent subjective experiences of grief or loss; and

- Any suffering of my family and friends.'

A middle-aged woman records:

'Independence, autonomy and intellectual competence and making my own choices are very important to me. I fear pain, confusion and powerlessness far more than I fear death. I do not wish those I love to become full-time carers if I cannot meet them with emotional and mental engagement and recognition. I would want them to go forward with their lives with joy.'

An older man writes:

I acknowledge the distress my death may generate in my family and friends. I am acutely aware some people whom I value may want to care for me should I become incapacitated; however, my underlying view is we all have to die sometime. Often, death takes us away from those we love at unexpected times. Part of life is accepting death – it is a natural law. In the words of Emily Dickinson's poem, "I put away my labor, and my leisure too, for his civility"; death can be a very civil visitation. The omission of treatment, or – particularly – pre-emptive action to influence the time of my death, has the potential to aid, if not to ease, the civility of a farewell to friends and family. This is a positive statement. I value life. I have learned on most days. I think I have given to others in some small ways, and received from many. I hope my wishes can be understood by those who matter to me; that you might see my death as a kind of gift – to add to our experience during our brief presence on this Earth as we travel life's journey.'

Perhaps surprisingly, health care providers generally like these value statements. They 'give voice' to the patient – a voice which is elsewhere submerged under legal language and tick boxes. They provide evidence of patients' personal philosophies, their reasons for making the choices they have – indirectly addressing the issue of each patient's capacity at the time of making the AD, and rendering their choices more credible. It also helps, if a patient's capacity

may be in doubt, to include a witness (eg a GP or psychiatric social worker) confirming their capacity at the time of making the AD. Most importantly, in terms of making ADs effective, these statements reveal the patient's wishes, feelings, values and beliefs – as required for the 'best interests' decision-making (s 4(6)) with which health care providers are more familiar. When health care providers are concerned that adherence to the instructions in an AD may not be compatible with the patient's best interests, the values statement can tilt the balance. This section of the AD displays the patient's strongly held wishes, feelings, values, and beliefs thereby (potentially) enabling health care providers to consider them as part of 'best interests' and thus to arrive at a 'best interests' decision identical to the one which is, in any case, legally mandated by a valid and applicable AD. Although this is a somewhat circuitous route to enhancing compliance with ADs (by increasing the probability that 'best interests' decision-making arrives at the same outcome), it seems likely to be effective.

The use of ADs (actual or apparent) to inform best interests decision-making has featured in several court cases, most recently in *Westminster City Council v Manuela Sykes* [2014] EWHC B9 (COP). Ms Sykes, an 89-year old woman with dementia wished to return home, rather than being deprived of her liberty by being compelled to reside in a nursing home. In her 'living will' Ms Sykes had specifically refused medical interventions aimed at prolonging her life, but she was not being deprived of her liberty in order to subject her to any such interventions. This meant that her AD was not strictly applicable to the decision at hand. According to District Judge Eldergill:

'That said, the existence and terms of the Living Will are relevant to the court's consideration of her best interests. This is because it is an expression of her wishes, feelings,

beliefs and values made by her when she had capacity. The document indicates in general terms that she prioritises quality of life over the prolongation of life.'

The patient's views as expressed in her 'living will' were used, in conjunction with other evidence, to rule in favour of allowing her a one-month 'trial period' in her own home. So even when ADs are not applicable to a particular decision, they can be helpful to health-care providers in arriving at best interests decisions concordant with the person's views.

Conclusion

In sum, the current situation with ADs is very mixed. Very few people have them. Those who do may find that their ADs do not in fact accurately reflect the decisions they believe they have signed up to. Due in part to their rarity and in part to the absence of a national repository, it is difficult to ensure that completed ADs are available when required and health care providers lack confidence in dealing with them. Increasing the likelihood of compliance with their instructions requires not just legal accuracy, but a design that enables health care providers to identify their key content and the signatory's identity quickly, and a more detailed content that encourages them to take a 'person-centred' approach which puts the patient's own values, wishes and beliefs centre-stage. At present it seems that nothing can guarantee that a person's wishes for refusal of treatment will be respected as a result of their AD, but solicitors who are aware of these findings can maximise that possibility.

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