

Further information

Your GP should be able to talk to you about making an ADRT and talk you through the specifics of treatment you might wish to refuse.

There are many resources on the internet. A particularly good source is Compassion in Dying. They have a ADRT pack available on <https://compassionindying.org.uk/library/advance-decision-pack/> and they also have an online form which can be personalised and which takes the person through the steps to make a legally binding ADRT.

AgeUK also provide information and advice. Their information on ADRT can be found at <https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/advance-decisions/>

The Alzheimer's Society have information on ADRTs here: https://www.alzheimers.org.uk/info/20032/legal_and_financial/131/advance_decision_living_wills/8

They also have information on making advance statements of wishes and the difference between this an ADRTs here: https://www.alzheimers.org.uk/download/downloads/id/2664/advance_decisions_and_advance_statements.pdf

MyLivingWill is a charity that provides advice on decisions towards the end of life. The website allows creation of a personalised ADRT online. The inter-relationship between the statement of wishes and preferences is explored and integrated with the ADRT, and the complex interaction between the ADRT and LPA for health and welfare is described. Court of Protection confirmed that the website conforms to the MCA. www.mylivingwill.org.uk

References

Department for Constitutional Affairs. 2007. Mental Capacity Act 2005 Code of Practice. London. TSO.

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Advance Decisions to Refuse Treatment



Suggestions on the value and use of ADRTs in society

Foreword



This information leaflet is part of a series of materials designed to help all of society understand the Mental Capacity Act (2005) and in particular, how it can both promote individual choice and protect those who have impaired capacity. I want to thank the members of the National Mental Capacity Forum Leadership Group who provided advice and support in the writing of the guidance.

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Introduction

We all like to make our own decisions. But what happens if for some reason a person is not able to make a decision about their own medical treatment because of illness or because they are unconscious?

The Mental Capacity Act 2005 (MCA) provides mechanisms which allow the person to authorise others to make decisions on their behalf, including Lasting Powers of Attorney (LPA). The person can make an LPA which will deal with property and affairs and/or an LPA dealing with health and welfare matters. There is a legal process to follow and a fee to pay. We would strongly advise making an LPA as it is a very good way of ensuring that someone can act on the person's behalf if they are not able to.

The MCA also allows the person, if they have capacity, to plan ahead for decisions about medical treatment; using a tool called an Advance Decision to Refuse Treatment (ADRT). This will only come

into force once the person loses capacity to make their own choices. This can then become a legally binding decision and clinical staff must take it into account. 'Capacity' means being able to make one's own decisions. This leaflet will provide information about ADRTs and points towards further information.

A recent case¹ highlighted the power of ADRTs even though in this case the ADRT was 'lost'. The family of an 81-year-old woman received £45,000 after a hospital kept their mother alive for 22 months even though she had made an ADRT refusing life sustaining treatment. The hospital had lost the ADRT within a "thick pile of medical notes". - It is a reminder to make sure you tell people you have made an ADRT.

It is a good idea to make both an ADRT and LPA so that your own wishes can be acted upon.

¹Payout after woman was kept alive against her will. <http://www.bbc.co.uk/news/uk-england-coventry-warwickshire-42240148>

Making an ADRT

Life sustaining treatment; there are special rules to follow to make an ADRT legally binding in respect of life sustaining treatment. The person's wishes must be written down either by the person or someone else if the person cannot write them down themselves. The document must be signed by the person or by someone directed by the person if the person cannot sign. The person must sign in the presence of a witness who must also sign the document in the person's presence. The document must have a statement within it which states that the ADRT is to stand even if the person's life is at risk.

Life sustaining treatment could include things such as being fed by tube or having a machine breathe for the person.

ADRTs which are not about life sustaining treatment can be made verbally but it is a good idea to write these down too. This lessens the opportunity for confusion as to whether the person have made an ADRT or not.

It is a good idea for the person to discuss their intentions with a medical professional such as the person's GP, but it is not a requirement to do so. The person does not need to justify why they are making the decision.

Remember: ADRTs which are made and then not discussed will not work as no-one will know of their existence.

It is essential that if the person makes an ADRT, they tell significant people in their life that they have done so and where to find a copy if it is in writing. The sorts of people to tell might include the person's GP, spouse or partner, parents or children or anyone who might be contacted in the event they have an accident. The person can ask their GP to add the ADRT to their 'summary care record' which is an electronic system which is available to all medical professionals 24 hours a day. It is also possible to carry a wallet or purse sized card which will notify anyone finding the person in circumstances where they are not able to communicate, that there is an ADRT in existence. In the case mentioned in the introduction the woman's adult children did not know she had made an ADRT and it was the GP who eventually told the hospital that she had one. If the children had known, it might be that the existence of the ADRT would have been brought to the hospital's attention much earlier.

Next of Kin

It is important to remember that the individual considered to be the person's 'Next of Kin' does not have decision making powers about treatment unless they hold a Lasting Power of Attorney: Health and Welfare. For more information on decision making see the companion leaflet Next of Kin: Understanding decision-making authorities on the NCPQSW website. Please see <http://www.ncpqsw.com/financial-scramming-publications/nok/>

What does the law say?

The law is supported by a document called the Code of Practice. For an ADRT to be legally binding the person must be 18 and have capacity to make the ADRT. The person can make it using "layman's terms". It can be altered or ended at any time providing the person has capacity to do so. It is a good idea to regularly review the ADRT and update it where necessary to ensure it accurately meets the person's needs.

The ADRT also must be both "valid" and "applicable" (see below). In addition, if the ADRT is about life-sustaining treatment there are some other actions the person must take (see 'Making an ADRT').

What is Validity?

There are three reasons why an ADRT may not be valid, these are –

1. that the person has withdrawn it whilst s/he had the capacity to do so, or
2. Since making an ADRT, the person has also made a Lasting Power of Attorney (LPA) for welfare and has given the Attorney the power to make the relevant treatment decisions, although the LPA will need to show that the ADRT is not valid because of this or they should follow the ADRT, or
3. That the person has acted in an inconsistent way since making the ADRT.

If none of these three things are evident anyone providing the person with treatment would need to act as per the ADRT and to do otherwise would not be lawful, even when acting would make the difference between saving a life and not.

What is Applicability?

There are also three reasons why an ADRT may not be applicable

1. the treatment being offered may not be the treatment that is specified in the ADRT, or
2. the circumstances specified in the ADRT may not be relevant to the situation, or
3. there may be reasons for believing that there are now circumstances which the person could not have possibly anticipated at the time they made the decision, and if they had known that may have altered their decision.

What ADRTs cannot do

ADRTs cannot be used to demand treatment or certain types of treatment. Neither can the person use an ADRT to confer decision making power on someone else. They will need a Lasting Power of Attorney for this. See <https://www.gov.uk/government/organisations/office-of-the-public-guardian>.

The person cannot refuse interventions designed to keep them clean and comfortable nor the offer of food and fluid by mouth. Finally, they cannot use an ADRT to demand something illegal such as assisted death. The key to thinking about an ADRT is to remember that they do exactly what their title suggests: Advance Decision to Refuse Treatment.

Treatment decisions without an ADRT

If there is no ADRT and/ or a LPA for health and welfare and the person subsequently lose the capacity to make one, if a significant medical issue occurs a decision will need to be made about the person's care. That decision could not be made by a member of the person's family. In the first instance the clinical staff should consult with the family and loved ones to see if an agreement about what should happen, in the person's best interests, can be reached.

If no agreement can be made, then an application to the Court of Protection would almost certainly be necessary. This may involve legal and court fees. The Court might make an order which they judge to be in the person's best interests, considering what they have been told by those who know the person's views and wishes. But of course, this may not be precisely what the person would have wished. The existence of an ADRT and LPA will prevent this.

Clinical staff

Clinical staff, who are having discussions about treatment with patients, especially in the context of advance care planning, should consider making a note of the patient's wishes. In this instance this might include not only an ADRT but also an advance statement of wishes which might cover areas which fall outside medical treatment. Advance statements are not legally binding but judges have been known to place great weight upon them².

Clinicians need to be aware that assuming an ADRT is valid and applicable as discussed above, it must be followed. Failure to do so might result in an offence being committed. Proceedings could also follow by the clinician's registration body.

Even if an ADRT is considered to be neither valid nor applicable it will still point strongly towards what the patient themselves would have wanted and may act as an advance statement for the purposes of any best interest decisions and may guide discussions between clinical staff and loved ones.

²RGB v Cwm Taf Health Board & Ors [2013] EWHC B23 (COP)