



**Huntington's
Disease
Association**

Huntington's disease

**Advanced decision to refuse
treatment**

Introduction

An Advance Decision to Refuse Treatment (ADRT) is a legally binding statement refusing specific medical treatment in clearly defined circumstances. If applicable and correctly made, it will remain legally binding even after you have lost the ability to give or withhold consent.

In the past, this type of statement was not legally defined and may have been referred to as a 'Living Will', an 'Advance Directive' or an 'Advance Refusal of Treatment'. In England and Wales, the law around ADRTs is now set out in the Mental Capacity Act 2005. If you have withheld consent for a particular treatment, a doctor cannot lawfully give it.

An ADRT is a powerful expression of your wishes as they relate to your future health care. If completed carefully and in the necessary detail, it can enable you to take control of your future treatment now and will even apply if you need treatment to sustain your life. In circumstances where you have lost capacity, and your wishes are not known, doctors will usually look to provide treatment and sustain your life, unless it is futile or harmful.

What should I put in my ADRT?

An ADRT must:

- Be specific about what treatment you refuse, in what circumstances. You need to demonstrate an understanding of the consequences of your decision
- Be made by an adult aged 18 years or over
- Be recorded in some form (writing, transcribed for you, video)
- Be made when you have the mental capacity to make these decisions

An ADRT does NOT have to be:

- Completed by or with a Doctor – but this usually helps make it clear and easier to apply
- In writing – but this is likely to help them be clear and unambiguous, and shared
- Witnessed – unless it is to apply to decision about treatment to sustain your life
- Accompanied by a statement that you have mental capacity - but if this may be doubted, ask for a confirming statement or assessment from a professional

- Explained - an ADRT does not have to give any reasons why you refuse the treatment. This is your right

An ADRT cannot:

- Be applied unless you are shown to lack mental capacity to make the decision
- Compel clinicians to give particular treatment - this is always a medical decision
- Refuse social care
- Refuse food and water unless given by artificial means, as this is considered treatment
- Be overruled by your next of kin or others, unless they were later granted the Power to make these decisions by you (see LPAs)

There are extra rules that apply to ADRTs that refuse life sustaining treatment

- You must record these decisions in writing
- They must be signed and witnessed
- You must state that you understand this decision will apply even if life is at risk

- Tell your loved ones and professionals supporting you. It would be helpful for any statements to be dated and reviewed regularly

If you make an ADRT that is not legally binding, as you have not followed the guidance, but it clearly states your wishes, the decision-making doctor will still have to consider these views when making treatment decisions.

What is meant by ‘mental capacity?’

The law says everyone has the right to make decisions for themselves unless someone has proven they cannot. To be considered unable to make decisions you must be shown to be unable to understand, retain, or use and weigh the relevant information, or you must be unable to communicate that specific decision. If you can make decisions, you do not need to provide ‘proof’ that you have the necessary mental capacity to make an ADRT.

What if I change my mind?

If you change your mind, you will need to record any updates or cancelling statements, in the same way you did when you made the initial ADRT.

An ADRT can be modified as your situation changes and you can change your mind at any time while you still have capacity. Once you lose capacity, you cannot formally update or remove it.

If you lose capacity but knowingly act or express wishes that contradict the ADRT, this might give the Doctor concerned enough cause to not follow it and act in your best interests.

You should ensure that you record any changes in your views and that you keep relevant individuals informed. The Huntington's Disease Association (HDA) can help you to make an ADRT by providing you with a form which allows you to clearly state your wishes. The form includes review dates to ensure that the document remains accurate and applicable.

Complex choices about end-of-life care are difficult and these decisions can seem overwhelming. It can help to discuss these issues with your Specialist HD Adviser who can provide you with information to help you to make informed choices. If you wish to make an ADRT, they can help you use medical language if you wish, to make your wishes clearer. Writing an ADRT is always best, so it can be easily shared. Ensure that all those involved are given copies (electronic or on paper) with any accompanying information. The

Specialist HD Adviser in your area can help you with this.

What else could I do?

The following may be done in place of, or as well as making any ADRTs:

- Talk about your wishes to your GP, Consultant and others involved in your care
- Consider making a Lasting Power of Attorney (LPA) – see below
- Discuss your wishes with your loved ones to help them understand what you want and avoid difficult situations for them later
- Make other statements about what is important to you personally and in your health care and what outcomes you would prefer. While not legally binding, these will help others make decisions for you

Lasting Power of Attorney (LPA) for Health and Welfare

If you would like to appoint a representative to make decisions for you in the future, you can grant this person Lasting Power of Attorney for Health and

Welfare. (They can also be granted for Property and Financial Affairs). For more information see the Office of the Public Guardian website, at the back of this factsheet.

If you wish, you can grant the Attorney complete control over decisions for your care, or limit them by stating on the application specifically which decisions they will have the power to make (social care, health care, accommodation, life sustaining treatment, etc.) In this way, you can choose to make ADRTs that still apply, as well as having the Attorney for other issues. Once the application is completed, it must be registered with a statement that you have the necessary mental capacity.

The process for registering a LPA currently costs a maximum of £110, but you can apply for a discount if you have a low income and low savings.

Other sources of information and advice

The Mental Capacity Act 2005 Code of Practice

(Guidance on ADRTs in Chapter 9)

Read it online here:

<https://www.gov.uk/government/organisations/office-of-the-public-guardian>

Office of the Public Guardian

Phone: 0300 456 0300

Email: customerservices@publicguardian.gsi.gov.uk

Compassion in Dying -

Phone: 0800 999 2434 or 0207 479 7731

www.compassionindying.org.uk

Fact sheets available from the Huntington's Disease Association:

- General information about Huntington's disease and the Huntington's Disease Association
- Predictive testing for Huntington's disease
- Talking to children about Huntington's disease
- Information for teenagers
- A young adult's guide
- Eating and swallowing difficulties
- Huntington's disease and diet
- The importance of dental care
- Communication skills
- Behavioural problems
- Sexual problems
- Huntington's disease and the law
- Huntington's disease and driving
- Advice on life assurance, pensions, mortgages etc.
- Seating equipment and adaptations
- Checklist for choosing a care home
- Advance Decision to Refuse Treatment (ADRT)
- A carer's guide
- Challenging behaviour in Juvenile Huntington's disease
- A brief guide to Juvenile Huntington's disease for children's hospices and palliative care services
- A teacher's guide
- A young person with Juvenile Huntington's disease at school

All fact sheets can be downloaded free of charge from our website www.hda.org.uk or ordered by phone 0151 331 5444 or email info@hda.org.uk

For a publication price list/order form, membership form, details of our Specialist Huntington's disease Advisers and local Branches and Support Groups, please phone 0151 331 5444 or email info@hda.org.uk

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