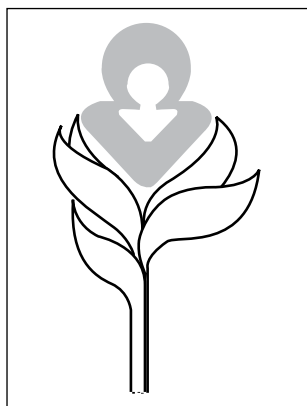


# Huntington's Disease Association



## Advanced Decision to Refuse Treatment (ADRT)

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### Fact Sheet

## **Introduction**

An Advance Decision to Refuse Treatment (ADRT) is a statement where you can say in advance what your wishes are regarding medical treatment. In the past this statement may have been referred to as a Living Will, an Advance Directive or an Advance Refusal of Treatment.

An ADRT is a powerful expression of your wishes as they relate to your future health care. An ADRT is a set of instructions documenting someone's wishes about refusing medical care that is intended to sustain life, and it is used if a person becomes unable to make decisions or communicate them.

An ADRT helps you to plan your future health care decisions and applies to all adults over the age of 18 years. It is useful because it gives some control over decision-making relating to health care and treatment.

An ADRT only applies to the refusal of medical treatment. The clinical decision to administer treatment lies with the physician and not with the individual therefore it is not possible to use an ADRT to make a statement relating to the treatment an individual would like to receive.

In England & Wales an advance refusal of treatment is legally binding as long as

- You are an adult aged over 18 years
- You made your refusal when you were mentally capable of making the decision.
- You intended your refusal to apply in the kind of situation, which later arose; and you understood the consequences of your decision(s) in the event of that kind of situation.
- It was your informed decision and not made under the influence of someone else.

Every competent adult has the right to accept or refuse medical care for any reason, or no reason, and an ADRT helps to protect this right. It can relieve some of the responsibility for making decisions from family, friends, and health care staff. Communicating wishes about future care helps to ensure that people with H.D. face the end of their lives with dignity and with the same values by which they have lived. Thinking about decisions relating to future care is complex and can have an emotional impact on everyone involved. For some people it can help them to feel that they are in control of decision-making and that they have dealt with their affairs in advance.

An ADRT can be modified as a person's situation changes and they can change their mind at any time whilst they retain capacity.

## **Capacity**

In order to make an ADRT you need to be deemed “competent” or to “have the necessary capacity” to make decisions; this is determined by a doctor and requires that you

- Understand and remember information about treatment
- Believe the essential information about treatment
- Are able to weigh the information to arrive at a decision.

An ADRT is a powerful expression of your wishes relating to your future care. To make sure that your ADRT is effective, it is wise to discuss it with your GP, Hospital Consultant, family members and care professionals. This will show your awareness, the decision-making process you have gone through, and that you have made the decision yourself with an understanding of the consequences.

Complex choices about end-of-life care are difficult and these decisions can seem overwhelming. It can help to discuss these issues with your Regional Care Adviser who can provide you with information to help you to make informed choices. The Huntington's Disease Association can help you to make an ADRT by providing you with a form which allows you to clearly state your wishes. When you have written your ADRT you need to make a number of copies and ensure that they are given to individuals involved in your care as discussed previously. The Regional Care Adviser in your area can help you with this.

You can change your mind at any time whilst you are deemed mentally capable of doing so. You should ensure that you record any changes in your views and that you keep relevant individuals informed. The HDA form includes review dates to ensure that the document remains active.

### **Lasting Power of Attorney (LPA).**

If you would like a representative to make decisions about your health in the future you should create a 'Personal Welfare' Lasting Power of Attorney, for more information see fact sheet 12. The LPA is a formal document which needs to be registered, once this is done it will invalidate any ADRT.

What to do if you already have a Living Will or Advance Directive  
The ADRT was introduced in the Mental Capacity Act, the Act states "The Advance Decision must include a clear, specific written statement from the person making the Advance Decision that the advance decision is to apply to the specific treatment even if life is at risk".

If you already have an Advance directive / living will and this is not clearly stated you will need to add the following statement "The decisions set out in my Advance Directive / Living Will will apply, even if my life is at risk as a result".

You will then need to circulate this to the people who are holding your document.

*There are a number of organisations available, which can provide you with further information on the subject of end of life decision-making and ADRTs*

**The Department for Constitutional Affairs**

Selbourne House  
54 Victoria Street  
London  
SW1E 6QE  
0207 210 8500  
[www.dca.gov.uk](http://www.dca.gov.uk)

**Dignity in Dying (formally The Voluntary Euthanasia Society)**

181 Oxford Street  
London  
W1D 2JT  
0207 479 7730  
[www.dignityindying.org.uk](http://www.dignityindying.org.uk)

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## **Fact sheets available from the HDA:**

- General Information about Huntington's Disease and the HDA
- Predictive Testing for Huntington's Disease
- Talking to Children about Huntington's Disease
- Information for Teenagers
- 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 Service
- A Young Person with Juvenile Huntington's Disease at School

All Fact sheets can be downloaded for free from our website:  
[www.hda.org.uk](http://www.hda.org.uk) or ordered direct from Head Office

For a publication price list/order form, membership form, details of our Regional Care Advisers and local Branches and Groups, please telephone, email or write to:

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