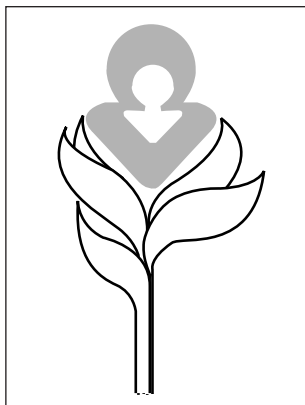


# Huntington's Disease Association



## Advance Directive or “Living Will”

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# Advance Directive or “Living Will”

## Introduction

An Advance Directive “Living Will” is a statement where you can say in advance what your wishes are regarding medical treatment. This statement may be referred to as a **Living Will**, an **Advance Directive** or an **Advance Refusal of Treatment**. It is clearer to use one term and for the purposes of our discussion we will refer to the term **Advance Directive**.

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

An Advance Directive 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 advance directive 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 advance directive 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 Advance Directive 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 to feel that they are in control of decision-making and that they have dealt with their affairs in advance.

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

### **How is it different from an ordinary will?**

A will refers to your last will and testament and is a statement relating to your funeral arrangements and what happens to your property after your death. If you want to make a will you can do so with the help of a solicitor.

### **Capacity**

In order to make an Advance Directive 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.

A living will is a powerful expression of your wishes relating to your

future care. To make sure that your advance directive 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 advance directive by providing you with a form which clearly states your wishes. When you have written your advance directive 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.

### **What is a health care proxy?**

It can help to have an advocate who will champion your health care decisions and to speak up on your behalf and this person is referred to as a health care proxy. Your health care proxy can be anyone that you know and trust and the role can be shared by more than one person. However, you must discuss your wishes in full with them, and they must agree to act on your behalf.

### **Health Care Proxy Criteria**

- A person(s) who is prepared to act as your health care proxy
- A person(s) who knows your wishes with regard to your treatment
- A person(s) who is prepared to express your wishes about medical treatment.

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

**The Terence Higgins Trust**

52-54 Grays Inn Road

London

WC1X 8JU

0207 831 0330

0845 1221 200

[www.tht.org.uk](http://www.tht.org.uk)

**The Department for Constitutional Affairs**

Selbourne House

54 Victoria Street

London

SW1E 6QE

0207 210 8614

[www.dca.gov.uk](http://www.dca.gov.uk)

**The Voluntary Euthanasia Society**

13 Prince of Wales Terrace

London

W8 5PG

0207 937 7770

[www.ves.org.uk](http://www.ves.org.uk)

## ***Acknowledgements***

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**Jackie Burke Regional Care Adviser 2005**



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

1. All about the Huntington's Disease Association
2. General Information about Huntington's Disease
3. Predictive Testing for Huntington's Disease
4. Talking to Children about Huntington's Disease
5. Information for Teenagers
6. Eating and Swallowing Difficulties
7. Huntington's Disease and Diet
8. The Importance of Dental Care
9. Communication Skills
10. Behavioural Problems
11. Sexual Problems
12. Huntington's Disease and the Law
13. Huntington's Disease and Driving
14. Advice on Life Assurance, Pensions, Mortgages etc.
15. Seating, Equipment and Adaptations
16. Checklist for Choosing a Care Home
17. Advance Directive or "Living Will"

## **Booklets**

*Huntington's Disease in the Family* (1997)

A booklet produced for young children

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

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