



**Huntington's  
Disease  
Association**

# **Huntington's disease**

**Huntington's disease and the law**

## Huntington's disease and the law

People with Huntington's disease and their families have a number of difficult issues to consider when coming to terms with their diagnosis. The predictive test offers people at risk the unique opportunity to plan for a future in which Huntington's disease may well be a reality and a chance to anticipate future difficulties which arise as a result of the disorder. One area in which people can take control and make decisions in advance is that of the law. In this leaflet we will discuss various aspects of the law which we hope will enable you to consider some of the issues involved.

### Making a will

**What is a will?** A will is a legal document which indicates the wishes of the deceased regarding the disposal of their assets upon their death. A will determines who should be left items, property and money upon the death of another and the document indicates named executors, age of inheritance, trust arrangements etc.

If you do not make a will the law will decide who inherits and the law is very specific. The effects of a deceased person pass first to their married spouse, then to their offspring, surviving parents and finally to surviving siblings. If you wish to make alternative

arrangements you must make a will. The law is not sympathetic to an individual's informal requests.

Do it yourself wills as found in newsagents' shops are not recommended as often people underestimate the extent of the goods they possess and if your intentions are complicated there may be some debate regarding your wishes in the event of your death.

People thinking about making a will ought to consult a solicitor. It need not be expensive; a standard will can cost as little as £60 and a couple can make a will together for £100. The more complex your requests the more expensive it becomes. Legal aid may be available in some cases and anyone can make a will.

## **Lasting power of attorney**

Lasting Power of Attorney (LPA) is a legal document introduced by legislation in 2007. It enables people to decide in advance who they would like to deal with their affairs for them if they are unable to in the future.

### **Two types of LPA's can be created:**

A 'Property and Affairs' LPA: this allows you to choose someone to make decisions on your behalf regarding your finances or property. A 'Property and Affairs' LPA is relevant when a person has property, money, shares, bank or building society accounts, pensions and any other financial interests; if a person is in receipt of

DWP benefits only an appointee system is available via the DWP and Power of Attorney is not necessary.

**A 'Personal Welfare' LPA:** this allows you to choose someone to make decisions on your behalf regarding your healthcare and welfare.

**In both types of LPA there will be a 'donor' and an 'attorney'**

**The donor:** The person who makes the Lasting Power of Attorney is the "donor", anyone can be a donor providing they are over 18 years and mentally capable.

**The attorney:** The attorneys is someone who can act on behalf of a donor. Attorney(s) can be anyone chosen by the donor providing they agree to assume this role. The attorney must be over the age of 18 years and in the case of the 'property and affairs' Lasting Power of Attorney (LPA) must not be bankrupt when he or she signs the LPA. The donor can choose more than one attorney as long as this is clearly stated on the documentation relating to the case.

If the donor gives general authority to act on his/her behalf in relation to 'property and affairs', then the attorney will be able to sign cheques, withdraw money, buy and sell shares or property; the attorney would be authorised to undertake any financial transaction the donor may have undertaken themselves.

If the donor gives general authority to act on his/her behalf in relation to 'personal welfare', then the attorney will be able to refuse or consent to treatment on the donor's behalf and make decisions about where the donor lives.

Restrictions and conditions can be built in to the LPA so the donor must consider very carefully what powers he or she wishes to give the attorney(s).

## Choosing an attorney

The person you ask to act as your attorney should be someone you know well and trust, it does not have to be one individual and could be all or some of your family acting together to assure your best interests. The attorney(s) do not have to live locally but should be in touch with the donor to ensure they are acting in his/her best interest. In some cases, when there are no family members or friends available, the attorney may be appointed from your solicitor's firm or from your bank. If you decide to appoint a professional as your attorney you will be expected to pay fees for their services.

**Lasting Power of attorney (LPA)** should be considered in good time in order that both the donor and the attorney understand and agree to the arrangement. LPA attorney should not be thought of

as a crisis solution and the donor must be deemed to have capacity to appoint their attorney.

The donor can cancel or revoke the Lasting Power at any time whilst he/she remains mentally capable. However Lasting Power cannot be revoked if the person is deemed to lack capacity until the Court of Protection confirms the revocation (see below).

## **Setting up a lasting power of attorney**

The form for LPA is available online from the Office of the Public Guardian website.

[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk) or by telephone: 0300 456 0300 or via your solicitor.

You can fill in the forms yourself and set up your own Lasting Power of Attorney or you can employ a solicitor to help you. Solicitors will charge a fee to do this. Some people are entitled to legal aid and your solicitor has a duty to tell you if this is the case. The Solicitors Regulation Authority (phone: 0870 606 2555) can help you find solicitors who specialise in LPAs.

When completing the form, you must make sure you complete all sections correctly, if there are any mistakes the forms will be returned and you will have to pay the fees again.

## **Registration of lasting power of attorney**

The Lasting Power of Attorney can be registered as soon as you have created it, or it can be registered when the attorney(s) believe(s) that the donor is becoming mentally incapable.

When creating an LPA, the donor can name people who they wish to be notified when registration takes place. To register an LPA the attorney(s) must give notice to these named persons using form LPA001. The application must then be made using the form LPA002 to the Office of the Public Guardian.

If the donor has listed people to be notified, these people have five weeks to make an objection to the registration.

There is a registration fee of £150. This applies to both the 'property and affairs' LPA and the 'personal welfare' LPA, so if you are applying for both there will be a charge of £300. You may be exempt from the fee if you are in receipt of certain benefits, are on a low income or if the payment would cause you hardship.

## **When do the powers of the attorney begin?**

Once registration is complete the 'Property and Affairs' LPA may begin with immediate effect if this is the wish of the donor. A 'Personal Welfare' LPA can only be

used if the donor lacks capacity to make decisions themselves. Medically there is a capacity test available which can determine when an attorney needs to step in.

## **Existing enduring power of attorney**

Existing enduring power of attorneys' which were set up before the 1 October 2007 are still valid, and can still be registered now if it was created before 1 October 2007. There is a fee of £120 to register an EPA.

If you wish, an existing EPA can be revoked and an LPA set up instead, this can only happen if the donor still has mental capacity. Alternatively, you can keep an EPA for financial matters and create an LPA for 'Personal Welfare'.

## **Court of protection**

The Court of Protection is an office of the Supreme Court; its function is to manage and administer the property and affairs of individuals in certain circumstances:

- When that person is unable to look after their interest themselves.
- When there is no one else available to assume the role as their attorney.

- When an individual is deemed to have lost the capacity to make decisions, mental capacity is determined medically.

Court of protection is a formal arrangement administered centrally via London; it is intrusive, expensive and can be very upsetting for those involved with the individual. There are some cases however when there is no alternative and where court of protection must be used in order to provide a legal framework of support for an individual's affairs.

## **Advance Decisions to Refuse Treatment (ADRT)**

An Advance Decision to Refuse Treatment (ADRT) is a statement where you can say in advance what your wishes are regarding medical treatment. Please see our Fact Sheet relating to this for more details.

If the donor has created an ADRT then the attorney cannot make decisions in relation to the treatments which were specified on the ADRT, unless the LPA was made after the ADRT and the donor gave the attorney authority to refuse or consent to that treatment.

The issues discussed in this leaflet are intended as an introduction to some of the legal decisions which may affect someone with Huntington's disease. The Huntington's Disease Association advise individuals to

consult a solicitor or their local Citizen's Advice Bureau for further information specific to their circumstances.

## **Useful Addresses**

### **Office of the Public Guardian**

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

Tel: 0300 456 0300

### **Central Citizen's Advice Bureau**

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

### **Solicitors Regulation Authority**

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

### **Community Legal Advice**

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

Tel: 0845 345 4 345



## 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](http://www.hda.org.uk) or ordered by phone 0151 331 5444 or email [info@hda.org.uk](mailto: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](mailto:info@hda.org.uk)

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