

Planning for the Future: A Guide for Individuals and Families

This is a booklet intended to guide you in making decisions about your future. In the later stages of Huntington's Disease, you may be less able to communicate your views relating to your care and treatment. You may find that discussing and documenting your feelings in advance allows you to retain a sense of control over your illness.

This booklet is not a legal document but will hopefully give you and your family some guidance as to what options are available to assist you in planning for your future.

Planning for the Future may include:

- Talking to those close to you about your wishes and preferences
- Appointing a Power of Attorney
- Making an Advance Directive (Living Will)
- Decisions about brain donation for research purposes

Any of these decisions about your future must be made while you still have the mental capacity to make informed choices. For this reason the earlier you are able to start discussing these issues the better.

Power of Attorney

While an individual has the capacity, he or she can appoint a Power of Attorney under the Adults with Incapacity (Scotland) Act 2000. This is a legal document prepared by a solicitor. There is a charge for this but you may be entitled to legal aid however qualifying conditions will apply. A Power of Attorney gives a trusted person such as a family member, the power to make certain decisions or take certain actions on your behalf, should you lose the ability to make decisions for yourself.

If there is any doubt over an individual's decision making capacity, a Doctor may be asked to carry out an assessment of capacity before the Power of Attorney is appointed.

The powers given can relate to financial and/or welfare matters. Financial matters you might need someone to manage for you may include looking after bank accounts and paying bills or dealing with any property that you may have. Welfare decisions may include the Power of Attorney being consulted and consenting to medical treatments and other decisions regarding your care and wellbeing.

When appointing a Power of Attorney you will be able to state what powers you wish the person to have should they be called upon to make decisions for you in the future. The person you choose should be someone who knows your values, beliefs, preferences and wishes. This will allow them to carry out their role with the confidence that any decisions they make are what you would have wanted.

You can allow your Power of Attorney to deal with certain property or financial matters at any time, but welfare Power of Attorney will only come into effect in the event that you become unable to make decisions for yourself.

Key Points:

- You can appoint more than one Power of Attorney, either to act jointly or each deal with different powers. You can also name a substitute Attorney who can act in the event that your designated person is no longer able to carry out this role.
- Any person who is over the age of 16 who has the capacity to do so can be a Power of Attorney.
- The Power of Attorney is obliged to fulfill their role by ensuring that your best interests are being met. This is overseen by the Public Guardian.
- You can make changes to or revoke your Power of Attorney at any time while you still have the capacity to do so.

Advantages of having a Power of Attorney.

A Power of Attorney is relatively quick and easy to arrange and can be tailored to suit your individual requirements. It also gives you the choice as to who will make decisions for you, allowing you to have an element of control in your future by giving this responsibility to a person you know and trust.

A Power of Attorney is proactive in that it can be put in place before it is needed and used after someone loses capacity to make decisions. If, however, you do not have this in place and are no longer able to make decisions for yourself, there are other provisions to enable one person to legally act on your behalf:

Legal arrangements available to deal with circumstances when there is no Power of Attorney in place.

- **The Appointee Scheme.** Under the benefits system, if someone loses capacity to manage their benefits, a family member or friend can apply to be the named person who can deal with your social security benefits or state retirement pension.
- **Authority to Intromit with Funds.** If you do not have the capacity to manage your bank account, an individual with an interest can apply to the Public Guardian under the Adults with Incapacity (Scotland) Act 2000 for authority to access the account. Any funds accessed must be used for your benefit and have to be authorized by the Public Guardian.
- **Appointment of a Welfare or Financial Guardian.** If there is no Power of Attorney in place and consent is needed to make an important decision on your behalf, which you do not have the capacity to make, an application may be made to a Sheriff to appoint a legal Guardian. This may be a relative or friend, but can also be the local Authority social work department. The Guardian will help with ongoing decisions that you are unable to make.
- **Intervention Order.** In certain cases where a one off decision needs to be made such as selling your house, a sheriff can grant an Intervention Order to allow someone to make this decision on your behalf.

Advance Directive

In most situations, you have the right to make decisions about your medical treatment. Based on the information you receive, as well as your values and beliefs, you can weigh the risks and benefits of proposed treatments. You decide which treatments you want and which to refuse. There may, however, come a time when your illness prevents you from being able to make these decisions.

Some people have certain views about the types of treatment they would not wish to have at a certain stage in their illness. Making an advance directive, sometimes known as a living will enables you to record your decisions not to receive life sustaining medical treatment. This means that your medical team and others will know your views and wishes at a time when you may be unable to communicate them. As a result your family and friends are not left with difficult decisions and uncertainty regarding your wishes.

These decisions may include whether you would choose to be fed artificially should you have difficulty swallowing and not be able to meet your nutritional needs. In Huntington's Disease artificial feeding is most commonly administered through a percutaneous endoscopic gastronomy (PEG) tube. A PEG tube provides a way of getting food and fluids directly into your stomach. (See picture below).



For further information you may wish to read our information booklet on PEG feeding which is available from the Scottish Huntington's Association.

Other decisions may involve receiving repeated antibiotics for chest infections or receiving cardiopulmonary resuscitation (CPR). Some individuals feel that under certain circumstances which reflect their quality of life, they would not want such treatments and wish interventions at that stage of their illness to focus on supporting their comfort and peace. These decisions are very individual and are based on your own personal views and values. It may be helpful to take time to consider your own values by completing the **values history form and/or statement (see appendix 1 and 2)** as this will help others understand more fully your decision making process. This will also give you the opportunity to express any additional personal preferences relating to your future care. You may wish to get help to complete these forms from another person such as a family member, friend or your HD Specialist.

Although in Scotland it is not a legally binding document, your advance directive should be taken into account by your medical team as long as the following criteria are met:

- You were mentally capable at the time of making your advance directive
- You were fully informed about the nature and consequences of your advance directive when making it.
- Your advance directive is the most recent expression of your wishes.
- You were not pressurised or influenced into making the advance directive by anyone else.
- You intended the refusal to apply in the situation that has arisen.

Your advance directive will only be used if there comes a time when you are unable to make or communicate decisions. Otherwise you will be fully consulted regarding any treatment decisions.

Whilst your advance directive can be used to state the types of treatment you wish to refuse, it cannot be used to demand treatments that a doctor may feel are inappropriate. Neither can it be used to refuse basic nursing care such as basic hygiene, pain relief or being offered food and drink by mouth. Also, as the law in Scotland stands at this time, you cannot request euthanasia.

Making an advance directive?

An example of an advance directive is included in appendix 3 of this document and this is something you may wish to complete following discussion with your family and health care team. It is not necessary to contact a solicitor although you may wish to do so. Other examples of advance directives are available, see useful contacts.

Once you have completed your advance directive, it is important that your family and health care team are aware that you have one and it is recommended that a copy is lodged with your GP and hospital notes.

Once completed it is important that your advance directive is reviewed on a regular basis to ensure that your wishes have not changed and the advance directive is still valid. Any review should be dated and signed. It is recommended that it is reviewed at least annually.

While you still have the capacity to express your wishes you can change or revoke your advance directive at any time.

Brain Donation/ Organ Donation

Individuals with Huntington's disease who wish to donate organs after their death should add their name to the NHS organ donation register. This can be done online at www.organdonation.nhs.uk or be telephoning 0300 1232323.

Some individuals with Huntington's disease may wish to make a contribution towards research into the cause and cure of the disease by donating their brain tissue after death. Specific consent and arrangements are required for brain donation and if you would like further information regarding this you can contact the MRC Centre for Neurodegeneration Research in London for an information pack. Tel: 02078480290, email brainbank@iop.kcl.ac.uk

USEFUL CONTACTS

Scottish Huntington's Association: www.hdscotland.org Tel 0141 848 0308
E-mail: sha.admin@hdscotland.org

Mental Welfare Commission: www.mwscot.org.uk Tel: 0131 222 6111
E-mail: enquiries@mwscot.org.uk

Office of the Public Guardian: www.publicguardian.gov.uk Tel: 01324 678300
E-mail: opg@scotcourts.gov.uk

Patients Association Helpline: www.patients-association.org.uk Tel: 0845 608 4455
E-mail: helpline@patients-association.com

MRC Centre for Neurodegeneration Research: www.iop.kcl.ac.uk/brainbank Tel: 020 7848 0290
E-mail: brainbank@iop.kcl.ac.uk

NHS Organ Donation Register: www.organdonation.nhs.uk Tel: 0300 1232323