

Future planning

It can be helpful to think about important decisions about your future and care ahead of time, and you may wish to consider them with your family, friends and/or HD Specialist.

When you have Huntington's disease, the kind of support you need from others will change over time. Letting those close to you know how you would like to live as your condition changes can help to make sure you receive the type of care you want throughout your life. If you find the prospect of having these conversations upsetting or daunting, you can speak to your HD Specialist for support and guidance.

1. Power of Attorney

As Huntington's disease symptoms change, it can become more difficult to make decisions about complex matters such as those concerning your medical treatment or finances. This may be due to problems with your memory or speech which make it harder to make, remember or communicate your plans. As a result, you may no longer have the ability (also referred to as capacity) to make these decisions on your own.

A Power of Attorney is a legal document, usually drawn up by a solicitor, which gives someone else the authority to make decisions on your behalf. Most people choose to appoint someone who knows them well, such as a close friend or family member. You can also appoint a solicitor to act as your attorney if you do not know anybody that you would wish to undertake this role.

Without appointing a Power of Attorney, the person making decisions on your behalf may not be someone you would have chosen yourself. Having

one in place may give you peace of mind that these decisions will be in good hands.

When can I appoint a Power of Attorney?

You can appoint a Power of Attorney so long as you can demonstrate that you have the mental capacity (ability) to do so. Your solicitor may ask your doctor for a report confirming your capacity. It is a good idea to set up your Power of Attorney in plenty of time, before changes in your symptoms could make this more difficult.

What decisions can my attorney make?

In Scotland, there are different types of attorney. A welfare Power of Attorney can make decisions about your welfare (such as medical treatment and housing) and a continuing Power of Attorney is able to make decisions about your finances. A combined attorney can make decisions about both matters. Your attorney will only make decisions for you once you can no longer do this on your own, although you may choose to allow somebody to help you manage your money earlier on.

Can I appoint more than one person to be my attorney?

Yes. Some people like to choose one person to deal with welfare matters and another to deal with financial matters. Other people like to appoint one or several people as combined attorneys.

Are there fees involved?

Yes. Solicitors will charge a fee to draw up your Power of Attorney document. If you are on a low income or receive certain benefits, you may be able to have some or all of these fees paid for you via Legal Aid. There is also a fee to register your document with the Office of the Public Guardian where the documents are kept. You can apply for a fee exemption if you receive certain benefits. Finally, your doctor may charge a fee to provide a medical report to your solicitor, so check with your surgery.

2. Anticipatory care planning and advance directives

You may already have opinions about what you would like your future care to look like.

An **anticipatory care plan** is a document outlining your likes and dislikes and what is important to you. This may include things like your preferred place of care (e.g. at home or within a care home), who you would like to visit you, what foods you dislike and your religious beliefs.

Scottish Huntington's Association provides a template which you can use to document your anticipatory care plan (ACP). Please contact your HD Specialist to access the template. They can also help you to work through this if this is your preference.

You may also have opinions about certain types of life-sustaining medical interventions that you would **not** want to consider. These may include things like an artificial feeding via tube (PEG) or receiving CPR. If this is the case, then you may wish to consider making an **advance directive (sometimes called a living will)** in which you state what treatment(s) you wish to refuse in the future. You can also specify if there are particular instances in which you would like your decision to apply.

Although neither document is legally binding in Scotland, they can help those involved in looking after you to make decisions in keeping with your values and preferences. Make sure to share a copy of your documents with your GP and other people involved in your care once you have completed them – you will still be able to review them and make changes at a later date.

3. Wills and funerals

Making a Will enables you to set out what you wish to happen with your possessions and finances after you pass away. You can also choose the person or people that you would like to be responsible for distributing your estate (the executor[s]). If you die without making a Will, your affairs may be distributed in a way, or by someone, that you would not have chosen yourself. You can write a Will yourself but many people choose to ask a solicitor to draw one up to ensure it is legally valid.

Speaking to those close to you about wishes you have in relation to your funeral can alleviate uncertainty after you pass away. Funerals can be

expensive, so it is also helpful to think about how it will be paid for, for example via a pre-payment plan.

Useful links

Find a solicitor near you at [LawScot.org](https://www.lawscot.org).

Find out more about making a will at [Citizens Advice](https://www.citizensadvice.org.uk).

Information about funeral planning and costs at [MyGov.Scot funeral planning](https://www.mygov.scot/funeral-planning).

[Contact a Scottish Huntington's Association HD Specialist](#)

[Scottish Huntington's Association Financial Wellbeing Service](#)

[National and Regional Care Frameworks for Huntington's Disease](#)

[Sign up for regular updates from Scottish Huntington's Association](#)

Updated January 2022