

Planning for the future

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- Power of Attorney (POA)
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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.

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)
- Completing an anticipatory care plan
- Making a will, considering life assurance and making funeral plans

Talking to those close to you about your wishes and preferences

The most important aspect of planning ahead is ensuring that those closest to you are aware of your values and wishes. This can be a difficult thing to talk about but if you are able to do so it can give important information for those who might help make decisions for you in the future. It may be helpful for you to write down some of your thoughts and your HD specialist can help you with this. This can be anything that is important to you, ranging from what activities you enjoy to how you would like to be cared for.

Power of Attorney (POA)

A POA is a written document, giving someone else authority to take actions or make decisions on your behalf. As long as you have the capacity to do so, you can choose the person(s) you want to act for you and decide what powers you wish them to have.

These powers 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.

For more detailed information, the following website may be helpful:

www.citizensadvice.org.uk/

Making an Advance Directive/Living Will

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 if you are unable to make decisions or communicate them. As a result, your family and friends are not left with difficult decisions and uncertainty regarding your wishes.

Although in Scotland it is not a legally binding document, your advance directive should be taken into account by your medical team. You may wish to complete this if you have strong views regarding decisions such as artificial feeding or cardiopulmonary resuscitation at the later stages of your condition.

Anticipatory Care Plan

This is a written plan which aims to support those living with a long term condition to plan for expected changes in their condition. It is another way of supporting individuals to think ahead and adopt a positive approach to staying as well as possible. The plan will summarise discussions between the person involved and their healthcare professional and should record the actions and interventions required following a clinical deterioration or change.

Many NHS Boards will have a template they use to make an Anticipatory Care Plan, with headings, so you can fill in the answers. The headings are likely to include:

- Key people: write down the names of the people (including friends and family) who are involved in your care
- Emergency Contacts: write down who to contact if you are feeling unwell. You can ask your GP, HD specialist or other care professional to help you with this
- Notes: you, your family, or healthcare staff can write down important relevant information about your care
- Hospital admission dates: keep a record of each time you are admitted to hospital, and when you return home
- Thinking ahead: thinking about situations or problems that may occur in the future, write about your wishes for your future care

Life Assurance

When planning ahead, individuals often give some thought to buying life assurance.

Life assurance provides a cash lump sum in the event of the death of the person with life assurance. It can be comforting to know that funds can be made available to loved ones or families after death.

It can be difficult for people with Huntington's Disease to get life assurance without paying high premiums. There are some plans available for the over 50's however where you don't need to have a medical or answer questions about your health.

Our Financial Wellbeing Service can help with advice about this. hdscotland.org/getting-specialist-financial-advice/

Making A Will

By making a will you are showing care and concern for your family as well as directing what happens to your property and possessions after your death. Perhaps equally importantly, in a will you choose the person or persons you wish to deal with your affairs and you reduce the possibility of distressing family arguments after your death. More information about writing a will is available from the Citizens Advice Scotland by visiting:

<https://www.citizensadvice.org.uk/scotland/relationships/death-and-wills/>

Funeral Planning

Many people die without making any plans for their funeral. For family or close friends who are left behind, arranging a funeral can be stressful if they don't know exactly what type of funeral service a person wanted or how they would have like it carried out.

If you tell your family or friends what you want, your funeral is much more likely to reflect your wishes. It may also be one less thing for your family or friends to worry about.

Funerals can be expensive so you may want to pay for your funeral in advance by taking out a funeral pre-payment plan. You can find out more from your local funeral director or the NAFD at www.nafd.org.uk/ It's best to look into prices first. Make sure that you know what services are included in the price as these can vary.

We have highlighted some of the areas you may wish to consider when planning for the future but there may be other things that are equally important to you. Although this can be difficult to talk about, people often find that talking to their family and the professionals involved in their care means that they feel a greater sense of control over their future.