Huntington's Disease Association

Huntington's disease:

Planning for the future guide

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Introduction

Huntington’s disease progresses gradually over time, often for many years until the end of a person’s life. People with Huntington’s will likely find that it becomes more difficult for them to be independent and to communicate effectively.

It is important to clarify any preferences about treatment and care to family and carers ahead of time. Settling practical, financial and emotional matters early on may also make things less stressful later.

Whilst it is understandable that someone may find it difficult to plan for the end of their life, it can be reassuring to know that there is a plan in place and that wishes will be fulfilled.

This guide provides some information about some of the important aspects to consider when planning for the future.

Life insurance

Any serious health condition can affect the type of insurance that a person is able to access, so it makes sense to find out the facts so that a person can ensure that they're adequately covered. The insurance industry aims to offer a fair service based on the risk level of any applicant.

The amount a person must pay for insurance is affected by factors like age and any pre-existing conditions.

When applying for insurance a person must answer all questions honestly or a claim will not be valid. Whilst insurers do ask about family history, there are rules in relation to asking about genetics.

The government and the Association of British Insurers (ABI) have developed the 'Code on Genetic Testing and Insurance' which explains how insurers can use genetic test results. The commitments made by the Association of British Insurers are outlined below.

Code of genetic testing and insurance

1. Insurers will always treat applicants fairly. They will not require or pressure any applicant to undertake a predictive or diagnostic genetic test in order to obtain insurance. Insurers will not treat any applicant differently if they have had a predictive genetic test, except as detailed below.

2. Insurers will only ask applicants to disclose the result of a predictive genetic test for Huntington's disease in applications for life insurance cover which totals over the financial limit of £500,000.

3. Insurers will not ask an applicant to disclose the results of a predictive genetic test if it's taken after insurance cover has started, for the duration of that cover, only states the results of a blood relative, or was obtained exclusively in the context of scientific research.

4. If an insurer does ask an applicant to disclose the result of a predictive genetic test, they will not impose disproportionate terms, conditions or exclusions related to that result.

5. Insurers will provide all applicants with clear information before an application is completed, ensuring that they explain what a person will and won't have to disclose, and how their insurance decision may be affected if they voluntarily disclose any favourable predictive genetic test result.

6. If a predictive genetic test result is given to an insurer by the applicant, either accidentally or voluntarily, an insurer may take it into account if it is to the applicant's benefit. If the result is unfavourable to the applicant, the insurer will ignore the result unless Commitment two applies.

The above commitments mean that someone who has a family history of Huntington's is likely to pay a higher premium than someone who doesn't. If a person goes on to test positive for Huntington's this should not affect the premium as it is only necessary to inform the insurer about the test result when applying for life insurance that exceeds £500,000. However, if a person receives a negative test result they should be able to take out a new policy and benefit from a lower premium.

More information can be found on the ABI website at:

www.abi.org.uk

Mortgage

It is unlikely that Huntington's disease will affect whether somebody is able to get a mortgage. Some mortgage providers may recommend taking out life insurance when taking out a mortgage, but this is not usually a compulsory requirement.

Driving

People who hold driving licenses must inform the DVLA if they develop a notifiable medical condition, or if their condition worsens in the time that they hold a license. Huntington’s is a notifiable medical condition, so the DVLA must be contacted if the condition is becoming an issue. A CN1 form can be used to let the DVLA about a person's medical condition and can be found here:

www.gov.uk/government/publications/cn1-online-confidential-medical-information

The DVLA do not need to be informed if somebody has had a positive predictive test for Huntington’s, but isn’t showing any symptoms. If the person is showing symptoms it doesn’t mean that they will automatically lose their license, but they will need to have regular medical assessments to check that they are able to drive safely. After these checks, decisions are usually communicated within six weeks, although the DVLA will contact the person if it is going to take longer.

The DVLA may take the following steps:

- Contact the person’s doctor or consultant.
- Arrange an examination.
- Arrange a driving assessment, eyesight test or driving test.

If a person’s doctor or other medical professional decides that they can no longer drive, due to the Huntington’s, the person must surrender their license to the DVLA.

The Citizen’s Advice Bureau can also provide advice on this matter.

www.citizensadvice.org.uk

If somebody is concerned about a person's driving ability they can write to the below address. The DVLA are unable to act on anonymous letters, but signed communications will be treated confidentially and concerns acted upon.

Drivers Medical Group, DVLA, Swansea, SA99 1TU

www.gov.uk/contact-the-dvla

0300 790 6806

The following websites provide more information on driving with Huntington’s and how to inform the DVLA of any issues.

www.gov.uk/contact-the-dvla/y/driving-and-medical-issues
www.gov.uk/huntingtons-disease-and-driving

Power of attorney

There may come a day when it is no longer possible for a person with Huntington's to manage their own finances, or to be responsible for matters regarding their welfare, and at this point they will need somebody to help.

For help with benefits, a person can appoint a friend or family member and ask them to liaise with the relevant benefits department on their behalf.

In the long term it is sensible for a person to choose somebody that they trust and to grant them Lasting Power of Attorney (LPA). This means that this person can step in to make decisions if they no longer can. They should act to carry out the wishes of the person that they have LPA for. A person granting LPA to someone must be over 18 and have mental capacity (the ability to make their own decisions). The application forms are available online or in paper format from the Office of the Public Guardian (OPG), and can be found at:

www.gov.uk/government/organisations/office-of-the-public-guardian

A person may choose to enlist a solicitor or advice agency for help with filling out the forms. Taking professional advice can prevent problems later on, especially when unsure of the process or if the situation is complex. A solicitor will charge to help fill out the forms and their fees may vary. It is wise to contact a few solicitors to get an idea of fees and services.

There is a cost to register an LPA, although some people are able to get reductions or exemptions. The government guide on lasting power of attorney, including information about reductions and exemptions is available at

www.gov.uk/power-of-attorney

There are two types of LPA:

- **Power of Attorney for property and financial affairs** - A person may want their LPA to start taking over their property and financial affairs whilst they still have capacity. They can then continue to use this power in the future.
- **Power of Attorney for health and welfare** - This is only used if someone has lost the capacity to manage their own health and welfare. It enables someone to make decisions affecting care, like choosing between different kinds of treatments, or when choosing residential care.

> *"Setting up an LPA was easier than I thought. We were able to fill in the forms online over several weeks so there was plenty of time for discussion with my family."*

If a person is unable to make decisions about their financial or welfare matters, and they don't have a lasting power of attorney then the Court of Protection will make decisions on the person's behalf. Fees will vary depending on the circumstances of the case, but it can be very expensive.

Further information on the Court of Protection can be found at

www.gov.uk/courts-tribunals/court-of-protection
☎ 0300 456 4600

The Citizens Advice Bureau website also has information to help

www.citizensadvice.org.uk

Making a Will

It is important for everyone to make a Will. A Will is a legal document that sets out a person's wishes on what they would like to happen to their money, property, possessions and investments (known as their estate) after their death.

If someone doesn’t have a Will it means that the person is intestate and inheritance is decided by a set of rules. This may not be how the person wished their money and possessions to be distributed.

More information can be found at

www.gov.uk/inherits-someone-dies-without-will

As a member of the National Free Wills Network, we can offer you the opportunity to have a simple Will written or updated free of charge, through a network of solicitors, local to you, all across the UK.

If you choose to leave a gift to the Huntington's Disease Association in your Will, the gift will cost you nothing during your lifetime but could one day make a difference to the lives of families living with Huntington’s disease across the UK. Whilst it would be wonderful if you choose to leave a charitable gift in your Will, there is no obligation to do so.

You can make a self-referral on our website. If you have any questions, please email wills@hda.org.uk.

hda.org.uk/get-involved/donating/leaving-a-gift-in-your-will

Choosing where to be cared for

Being in a residential or nursing home is one option, but it is not the only option. Some people are able to stay at home with a care package co-ordinated by social care, their local hospice, or the NHS until the end of their life.

Unforeseen circumstances, such as a carer becoming ill, may cause initial plans to change. Having a backup plan can help, should problems arise.

One option to consider is day care or care by a hospice, either as an inpatient or via a home visiting team (known as 'hospice at home'). It is advised to make contact with a local hospice in order to meet the staff and talk to them about what help and support they can offer, even during the earlier stages of the illness. This way a plan can be put in place for future care.

Hospice care can offer a calm supportive environment during the end of a person's life, whilst also providing support to the family. Many people are surprised by how welcoming and pleasant hospices are, and this can alleviate some of the stress and worries that a person may be feeling. A referral can be made to a hospice team by a GP or contact can be made directly.

Hospice UK, the national charity for hospice care can help find an appropriate hospice. They can be found at

www.hospiceuk.org

Advanced care planning

When somebody begins to share their wishes and preferences for their future care with their family, friends or healthcare team they are participating in Advance Care Planning (ACP). ACP should be a process, not a single event, and should happen at a pace that suits the person with Huntington's. Topics and decisions that a person may want to consider, include:

ACP considerations

- Where they would prefer to be cared for and how this may affect the treatment options available.
- Their wishes and preferences in relation to future treatment and care, and the feelings, beliefs and values that may influence these. This may include basing their decisions around faith and religious beliefs.
- The people that they would like to be involved in decisions about their care.
- Interventions that may be undertaken or considered, such as CPR (resuscitation) or artificial feeding.
- Where they would like to die and what they would like to happen after they die. This includes considering if they would prefer to be buried or cremated and if they would consider organ or brain donation. This also includes what they would like to happen at their funeral, in terms of music, flowers, etc.
- Anything else that is important to them.

Further information can be found here

- www.nhs.uk/conditions/end-of-life-care
- www.compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-care-planning/making-acp

Advance decision to refuse treatment (ADRT)

It is a good idea to make decisions about specific treatments and interventions before reaching the later stages of Huntington's. Some people don't want certain kinds of treatment or intervention, and in this case they may want to put in place an Advance Decision to Refuse Treatment (ADRT). This was previously known as a 'living Will'. An ADRT can only be made by someone who has capacity.

An Advance Decision to Refuse Treatment (ADRT) is a legally binding statement refusing specific medical treatment in clearly defined circumstances. If applicable and correctly made, it will remain legally binding even after a person has lost the ability to give or withhold consent.

An ADRT is a powerful expression of a person's wishes in relation to their future health care. If completed carefully and in the necessary detail, it can enable a person to take control of their future treatment. In circumstances where a person has lost capacity, and their wishes are not known, doctors will usually look to provide treatment and sustain life, unless it is futile or harmful. Some of the specific issues that may need an ADRT are detailed below.

ADRT considerations

- **Clinically assisted nutrition and hydration** - When a person's swallowing becomes difficult they may not be able to eat or drink enough. There is an increased risk of choking and it is likely that they'll begin to lose weight. In this case, some form of artificial feeding may be recommended. Different types of feeding carry different levels of risk, benefit, discomfort and effort. It may help to talk to a clinician to learn more. See later section about tube/PEG feeding.

- **Cardiopulmonary resuscitation (CPR)** - an invasive intervention which can cause injury. It's a good idea for a person to discuss with their loved ones and specialists whether they think they would want to be resuscitated, and under what circumstances. This can then be documented in their record or advance care plan.
- **Antibiotic treatment -** Antibiotics may be prescribed to fight infection.

An ADRT needs to be written down and signed by the person with Huntington's, as well as a witness. We have a template that can be used.

It can only be made by somebody who is considered to have capacity. The law says everyone has the right to make decisions for themselves, unless it has been proven that they cannot. To be considered unable to make a decision it must be shown that a person cannot understand, retain, or consider the information that they need to make that decision.

The following may be done in place of, or as well as making any ADRT:

- Talk about wishes with a GP, Consultant and others involved in a care capacity.
- Consider making a Lasting Power of Attorney (LPA).
- Discuss wishes with loved ones to help them understand and avoid difficult situations for them later.
- Make other statements about what is important personally and in relation to health care, preferred outcomes such as a place of care. While not legally binding, these will help others make these important decisions.

> *"I had very strong views on certain aspects of my future care and wanted to make sure my views were heard and respected."*

Tube / PEG feeding

What is tube or PEG feeding?

Despite best efforts, sometimes it becomes increasingly difficult to meet nutritional needs by mouth. This difficulty can include problems with getting enough food to the mouth, chewing and swallowing food as well as staying hydrated. This can cause problems with safety such as choking, increased risk of chest infections as well as dignity. When a person can no longer eat safely and/or they continue to lose weight, it may be that a healthcare professional discusses the possibility of tube feeding, also known as PEG feeding (Percutaneous Endoscopic Gastrostomy). This can be difficult to deal with, especially if someone is also struggling with thinking and speaking challenges.

Tube feeding is a way of providing the body with the nutrition and hydration it needs. It provides a liquid form of nourishment that is delivered into the body through a flexible tube. The nutrients are similar to those someone would get from normal food, and are also digested in the same way. It contains all the nutrients someone would need on a daily basis, including carbohydrates, protein, fats, vitamins, minerals and water. The tube also provides a route for medication administration, although is not solely fitted or used for just that.

Making a decision about PEG feeding

It is important to discuss and record preferences about what will happen in the future earlier on in the disease. If a person knows that they do not want to be tube fed in the future it is important that they record this in an Advanced Decision to Refuse Treatment (see earlier section on ADRT). This is a legally binding document and the person making it must have ‘capacity’, meaning they understand the decisions fully, before making them. The person must then make sure their GP has a copy as well as any key people involved in their care (such as family and / or their Lasting Power of Attorney for Health and Welfare).

If PEG feeding is being considered for a person who no longer has capacity to make this decision and they have a Lasting Power of Attorney for Health and Welfare (LPA), the attorney/or attorneys should be asked to help in the decision making process on behalf of the person, providing the health or social care professional is aware of the existence of the LPA. If the person does not have an LPA in place, a doctor may ask family members for their opinion on the placement of a PEG as part of making a best interest decision. A best interest decision takes place at the end of a series of discussions, usually in a meeting called a best interest meeting, about the person’s wishes and values if known, alongside the risks or benefits of having a PEG fitted.

When helping in the decision making process, family members and attorneys often feel huge pressure. It is important to remember that any best interest decision made will be a joint decision between them and the person’s care team. If this matter has been discussed previously with the person with Huntington’s disease, family and /or attorney's will be able to base their decision on the person's wishes. If the person's wishes are unknown, it is important to take time over the decision. The following points should be considered when making a decision about tube feeding.

Tube feeding considerations

- Is the person getting enough food to keep them healthy and well?
- Are meal times distressing for the person and the family or carers?
- Does the person get lots of chest infections because the food they swallow is going down the wrong way into their lungs?

- Does food get stuck in the person's throat and make them cough, choke and have difficulty breathing?
- Will the anatomy, health and movement of the person with Huntington’s allow for the fitting of a PEG? The local surgeon responsible for the fitting of the PEG will be able to advise on this as sometimes it may not be possible
- Will the person accept the PEG and be able to accept the support needed to manage the PEG? (i.e. comply with the feeding regime and keeping the site clean)?
- Will a PEG cause them distress and will they injure themselves in trying to remove it? People with severe chorea may find that the area around the tube becomes sore or tender from the repeated involuntary movements of the arms and legs touching or pushing against the area around the tube. Some may find the site so irritating that they tug at the tube, which loosens it. They may injure themselves or even remove the tube.
- When deciding whether or not to fit a PEG, it is important to consider the major contribution it may have in extending life. If the person is no longer able to communicate or actively participate in life, they may continue to live because they are being fed through the tube.

Thinking about these decisions makes a person confront their own emotional and spiritual beliefs. Everyone is different and each person’s journey with Huntington’s is unique. It is important to remember that what is right for one person may be different for the next.

PEG procedure

Having a PEG fitted is usually a straight forward surgical procedure done under sedation and with a local anaesthetic in hospital. A tube is passed down the nose into the stomach and a small cut is made in the stomach to pull the tube through to the surface. The tube is then cut to the right size and a tiny balloon is used to keep it in place inside the stomach with a cap added to keep it in place outside the body. The person may have to stay overnight in hospital, but usually they are allowed home the same day. Liquid food and fluids can then be fed through this tube straight into the stomach.

When a PEG has been fitted it may be possible to carry on eating and drinking as long as the person chooses and are able to. Continuing to eat and drink will depend on how safe the swallow is, the capacity of the person, and the recommendations of a Speech and Language Therapist.

Feeding at risk

Although this section focuses on tube feeding, it may be that the lasting power attorneys, family and care team decide in the best interest process that tube feeding is not the right decision for the person and that ‘feeding at risk’ may be the most appropriate and compassionate way ahead.

Feeding at risk means still assisting the person to feed through the mouth, even in the presence of weight loss and swallowing difficulties. This decision should be discussed and the implications fully considered, for example how to deal with repeated chest infections, what to do about hospital admissions and also how this can be carried out safely for the individual.

Removing a PEG

Once a PEG is fitted, it can only be removed if the person with Huntington’s has capacity to say they no longer want it, or they have documented clearly in an ADRT that they want the PEG to be removed at a certain stage of the disease or if a doctor and the clinical team decides it is no longer in the person’s best interest to have the PEG. If a relative is being consulted in making this decision for the person with Huntington’s disease, it is because the doctor does not feel the person has capacity to do this for themselves.

Voice banking

People with Huntington's disease may find that their speech becomes affected over time, making it harder to communicate. They might also find that communicating with other people becomes more tiring.

There are many different types of communication aids that can help, some of which use synthesised voices. Through voice banking, it's possible to create a personalised synthesised voice that is based on a person's natural voice. To do this, a set of phrases are recorded and these can then be used to say any word, phrase or sentence.

There are a number of ways to do this and a number of companies who can help. As technology in this area is advancing rapidly, we advise speaking to a Speech and Language Therapist or with your local Specialist Huntington's Disease Adviser for up to date information and advice.

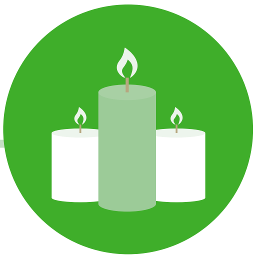
Memory boxes and keepsakes

Memory boxes can be a good way of passing on memories and a person’s sense of identity to loved ones. They can contain letters and CD or DVD recordings, as well as messages, photographs, souvenirs and gifts. Anything that a person considers important can be included.

A person may also want help from loved ones when putting together their memory box. They particularly may want their children or young relatives to help. There are also digital apps to help record messages for children and other loved ones such as 'Record me now'.

www.recordmenow.org

Planning a funeral



A typical funeral using a funeral director costs around £4,800, and a cremation around £3,750. Some people plan in advance for their own funeral by adding to a savings account or a funeral plan. Some insurance plans have a payout for funeral costs.

Funerals don’t have to be expensive. There are plenty of alternative ways to commemorate the end of a person’s life. A person may choose to have their body cremated or buried with no-one present with a separate memorial service or commemorative event for people to remember and celebrate their life. This can take any form and can be designed to fit a certain budget.

The Good Funeral Guide produces a useful fact sheet about this, as well as some useful pointers for thinking about planning a funeral.

www.goodfuneralguide.co.uk

Please also see our form, **Funeral wishes - Celebrating your life in your own way,** designed to help a person document their wishes to share with their loved ones.

Organ and brain donation

If a person chooses to donate their organs or brain they may be used to save somebody’s life. They could also be used for research into Huntington’s disease.

If a person would like to do this, it is important that they ensure that their family or friends are aware of their decision so they support this when the time comes.

In accordance with current organ donation laws in England and Wales, all adults are considered to have agreed to be an organ donor when they die unless they have previously registered a decision not to donate. This is sometimes referred to as 'deemed' consent'. Deemed consent will not apply if the person belongs to an excluded group, including those under the age of 18 years, those visiting the country and those that have lived in the country for less than 12 months prior to their death.

Further information about organ and tissue donation, deemed consent and the process to opt out can be found at:

www.organdonation.nhs.uk

If a person would like to donate their brain to research, further information about how to do this can be found on the Human Tissue Authority website.

www.hta.gov.uk

Support from the Huntington's Disease Association

Specialist Huntington's Disease Advisers (SHDAs)

Our Specialist Huntington's Disease Advisers have a background in health or social care and are knowledgeable about Huntington’s disease. They operate throughout England and Wales and support the person with Huntington’s, their carers and any professionals involved in their care. To get in touch with a local Huntington's Disease Adviser, contact us at:

☎ 0151 331 5444
e info@hda.org.uk

Huntington's disease Youth Engagement Service (HDYES)

At the Huntington's Disease Association, we have a Youth Engagement Service (HDYES) who work with young people whose families are affected by Huntington’s. This confidential service is for anyone aged 8-25 living in a family affected by the disease. Contact us to get in touch with a Youth Worker:

☎ 0151 331 5444
e info@hda.org.uk

Local branches and support groups

It can really help to meet people who know what you’re going through. Many people find comfort in meeting others who face similar challenges as they can relate to each other’s experiences. There are volunteer run Huntington's Disease Association branches and support groups all over the country. Groups meet for a mixture of social activities, information sessions, fundraising and awareness raising – and always a good chat. Further information can be found on our website.

Website

Our website offers practical advice and sources of help and support, including downloadable information guides. It also holds information about online and in-person events, webinars and activities and details of local branches and support groups. Additionally, the website hosts an online message board for people to access peer support, information and advice.

- www.hda.org.uk
- hdmessageboard.com

Social media and mailing list

We have a number of social media channels that we share stories, resources, events, webinars, and announcements on frequently. They offer a way for the Huntington's community to interact and connect with each other. We also have a YouTube channel with lots of videos and webinar recordings to help people catch up on anything they've missed.

- @hda_tweeting
- @hdauk
- @hdauk
- @hda_uk
- Huntington's Disease Association
- Huntington's Disease Association

We also regularly send out information about the charity, events and updates by email to those signed up to our mailing list. To join, visit our website:

- www.hda.org.uk/get-involved/join-our-mailing-list

Membership

Huntington's Disease Association membership is free for people with Huntington's and their families. Members receive regular eNewsletters and other communications from the charity, meaning they are among the first to hear about our work, news, events and opportunities to get involved. Members are eligible to vote at our Annual General Meeting and receive a copy of our Annual Report and Summary of Accounts. To find out more about becoming a member, please contact us or take a look at our website:

www.hda.org.uk/get-involved/membership

Resource library

The following charities, organisations and information sites may be able to provide further information and guidance on the topics covered in this guide:

Organisation	Contact details	Support
Huntington's Disease Association	0151 331 5444 info@hda.org.uk www.hda.org.uk	Advice Support resources Online forum
Association of British Insurers (ABI)	www.abi.org.uk	Advice Information
Gov.uk	www.gov.uk	Advice Information Support resources
The Citizens Advice Bureau	www.citizensadvice.org.uk	Advice Information Support resources
Hospice UK	www.hospiceuk.org	Advice Support resources
NHS	www.nhs.uk/conditions/end-of-life-care	Advice Support resources

Compassion in Dying	www.compassionindying.org.uk	Advice Support resources
DVLA	www.gov.uk/contact-the-dvla 0300 790 6806	Advice Support resources
Record Me Now	www.recordmenow.org	Support resources
The Good Funeral Guide	www.goodfuneralguide.co.uk	Advice Support resources
NHS Organ Donor Register	www.organdonation.nhs.uk	Information
Human Tissue Authority	www.hta.gov.uk	Information

Notes

Get in touch

For advice and support or to speak to a Specialist Huntington's Disease Adviser

email **info@hda.org.uk**

phone **0151 331 5444**

www.hda.org.uk

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Registered charity no. 296453

A company limited by guarantee.
Registered in England no. 2021975

Design and print by the Huntington's DIsease Association

Published September 2022 - First edition

We'll be there