Huntington's Disease Association

Huntington's disease:

A young adults' guide

Contents

Introduction

Huntington’s disease is a rare disease which is caused when somebody has a faulty gene in their DNA. DNA is like instructions that a person inherits from their biological parents, which tells their cells what to do. Every child conceived naturally to a parent who carries the faulty Huntington’s gene has a 50% chance of inheriting it.

This guide is intended to provide further information to young adults affected by Huntington's disease, whether they have or are at risk of the condition or they have a loved one that is. It contains further information about the condition, support available and practical matters to consider.

Support from the Huntington's Disease Association

It can be very difficult, emotionally and practically, to live with Huntington's disease. Even living with the risk of Huntington's can be challenging.

It may be a fairly rare disease, but it's important to remember that other people have also been through similar circumstances and will have shared experiences. Seeking out information and support can be really helpful and comforting. There are a number of different ways to access support and information from the Huntington's Disease Association which are outlined further below.

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 Huntington's Disease Association branches and support groups all over the country which are run by volunteers who have a link to Huntington's. Groups meet for a mixture of social activities, information sessions, fundraising and awareness raising – and always a good chat. Further information about local branches and support groups can be found on our website.

www.hda.org.uk

Membership

Membership is free for people with Huntington's and their families. Members receive regular communications from the charity, making them 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.

Events

Each year at the Huntington's Disease Association we run a number of in-person and online events to provide useful advice, support and guidance to people affected by Huntington's disease.

Our events aimed at young adult's aim to address issues which are most important to young adults, such as testing for Huntington's, having children, medical research, and insurance. People who attend find the topics useful, but they most appreciate the opportunity to talk to and hear from other young adults in a similar situation.

The charity also holds an annual family conference for people of all ages. The event features a mix of speakers and workshops. Further information about our events 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 events, webinars and activities and details of local support. Additionally, the website hosts an online message board for people to access peer support, information and advice.

www.hda.org.uk
hdmessageboard.com

WhatsApp group

We have a WhatsApp group specifically for young adults. Please contact us at the Huntington's Disease Association for further information on how to join this group.

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 for people to 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

Support from other organisations

Huntington's Disease Youth Organization (HDYO)

Known as HDYO, this is an international not-for-profit organisation providing support for young people around the world affected by Huntington’s disease. Further information can be found at:

www.hdyo.org

Specialist clinics

Across England and Wales there are clinics that specialise in helping people with Huntington’s disease. Through these clinics a person may be able to access genetic counsellors, neurologists, neuro-psychiatrists, specialist nurses, psychologists and physiotherapists. Some clinics also offer the option of becoming involved in research. The Huntington’s Disease Association are able to help with finding an appropriate clinic.

Genetic services

Genetic services are often linked to specialist clinics and are there to guide people through the process of genetic testing and options for having a family A Specialist Huntington's Adviser can help find the right clinic for a person.

Counselling

People in any challenging situation can find it useful to talk to someone about their feelings, and may prefer to talk to a professional, instead of to friends and family. GPs are able to make referrals to counsellors. A counsellor may not know specifically about Huntington’s, but can still help to work through the issues that a person may be encountering. A list of local counselling and psychotherapy services can be found on the British Association for Counselling and Psychotherapy (BACP) website:

www.bacp.co.uk

Life Insurance, mortgages and travel 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.

Life insurance

The amount a person must pay for life 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

Mortgages

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.

Travel insurance

When applying for travel insurance it is incredibly important to be honest about any disabilities or conditions. It is likely that declaring a disability or condition will increase the cost of cover.

This does not apply to somebody who has genetic risk, but no diagnosis of their own, as they do not have to declare this to an insurance company when looking for travel insurance.

More information can be found at

www.moneyadviceservice.org.uk

Employment

When a person discovers that they have Huntington's disease they may become concerned about how this will affect their current job or future employability.

Looking for work

At the stage of a job interview, whilst all questions should be answered honestly, it is important to remember that it is not mandatory to give information about a health issue unless an employer specifically asks about it.

Someone may feel that they don't want to voluntarily offer information about a health condition, as they are worried that they could be treated differently. Someone with Huntington's may also be concerned about telling others as there is so little awareness of the disease.

Managing at work and rights

People often worry most about work if they are concerned that they are showing early symptoms. Each person will have a different relationship with their employer and their colleagues, and this will affect how they feel about sharing personal information. All employers must comply with the Equality Act 2010, which addresses unfair treatment and helps achieve equal opportunities in the workplace, as well as in wider society.

It may vary from person to person at which point they feel comfortable to share that they have Huntington's with their employers. However, once they have shared this, they are able to communicate specific problems they may be having. The employer is then able to work towards solutions.

If a person works in a noisy office with constant distractions, like phones ringing, it may help them to move to a quieter space. Adding more structure to the day, for instance only taking phone calls at certain times, could also help.

If a person finds that they are exhausted by the time they get to work, due to their journey during rush hour being stressful, they could ask for more flexible working hours.

There are possible solutions to a number of issues, and employers should be happy to work to find these in order to accommodate a valuable employee.

For support and advice in relation to work, the Brain Charity's employment support service has useful information for both employees and employers.

www.thebraincharity.org.uk

ACAS also run a helpline and can provide useful information

www.acas.org.uk

☎ 0300 123 1100

Further information can also be found about working with a disability on the government website

www.gov.uk

Our Specialist Huntington's Disease Advisers at the Huntington's Disease Association can also talk to an employer about what they can do to help an employee affected by the condition.

Being a carer

Many young people at risk of, or affected by Huntington's, also care for loved ones with the condition. Being a carer can have a big impact on a person's life and the decisions they make. For example, many people feel guilty about studying, moving out or thinking about their own future, and instead focus mainly on their caring role.

Caring for someone can be tiring and stressful. It can also be incredibly emotional, especially if a person is living at risk of developing Huntington's themselves, or have had a positive or negative result.

People with Huntington’s often become dependent on one particular person. This is often a family member who they feel very comfortable with, so naturally they often prefer this to professional carers coming into their home. This also means that it may be the person that they ‘take things out on.’ People will often be much harsher on their family members than professionals and this can be really tough.

This dependency can make family carers reluctant to get outside help in, but it is really important to know about the support available. In England and Wales, people with a disability can have an assessment from Social Services to see what support they may be entitled to, and have a care plan set up that is appropriate to their needs. Financial support may also be available for the person with Huntington's and / or their carer

Our Specialist Huntington's Disease Advisers can provide support, information and advice on caring for someone with Huntington’s. They can also provide training to Health and Social Care professionals involved to provide a better understanding of the condition.

There is a 'Carer's guide' and further information about caring for people with Huntington's on our website:

www.hda.org.uk

Living with Huntington's

Every child conceived naturally to a parent who carries the faulty Huntington’s gene has a 50% chance of inheriting it. It can be very stressful for somebody who knows that they are at risk of Huntington’s.

Some people want to know for certain whether or not they have the faulty gene, whereas others would rather not know, until or unless they get symptoms.

Deciding whether to have a genetic test may be a difficult decision to make as it could impact the rest of the person's life and learning the result could affect others in their family. It is a personal choice.

Living with the risk of Huntington’s means facing some particular challenges, emotionally and practically, which most people don’t have to face. It is important to know that there is help and support available from both the Huntington's Disease Association and many other organisations. It can also be hugely helpful to meet others in the same situation.

We have a 'Genetic Testing guide' and further information on our website about the testing process, options for having a family and the support available if for anyone who receives a positive result or tests negative for Huntington's disease:

www.hda.org.uk

Testing positive for Huntington's disease

When somebody finds out that they are positive for Huntington’s, they may need some time to process what this means. The clinics that offer the test should have genetic counsellors to support people through their results. Our Specialist Huntington's Disease Advisers at the Huntington's Disease Association are also able to give help and support.

Many people in this situation worry that a stumble or fall or a moment of forgetfulness, may be the start of symptoms, and this can cause a lot of anxiety.

Regardless of whether someone has begun to show symptoms or not, it can be better to seek support earlier, rather than later. It is important to tackle issues head on, in order to stay in control of the situation.

There is information and advice on testing positive on our website:

www.hda.org.uk

Testing negative for Huntington's disease

People who have had a negative test and who now know that they do not carry the faulty gene, may also struggle to cope. Sometimes people have lived their whole lives thinking they would get Huntington’s. When they discover the test was negative they feel that they should be happy, but also feel that they have lost a huge part of their identity.

It’s also common that a person may feel guilty after a negative test, especially if their siblings have tested positive or remain at risk. People who have had a negative test may still want to maintain a role in the Huntington’s community through support groups, fundraising and research.

There is further information and advice on testing negative on our website:

www.hda.org.uk

There is also a private Facebook group (Kim's Friends) available for people who have had a negative test for Huntington’s. This group can be accessed via our website or by joining the group directly in Facebook.

If symptoms have begun

Although there is currently no cure, there are many ways to get help with the symptoms and challenges of living with Huntington's. It can be helpful to implement lifestyle and practical changes that might make life easier.

There are also different types of care that can be accessed at different times. These include:

- **Social care** help with things like washing and dressing, which can be arranged privately or through the Adult Social Services department of the local council.
- **Medical care** from healthcare professionals, the involvement of Neurologists, Neuropsychiatrists, Dietitians, Speech Therapists and other professionals can also enable someone to manage their symptoms more effectively and positively. Access to medical care is usually through the GP. The Huntington's Disease Association can provide a GP with extra information about Huntington's.

Living well

Healthy living is important for everyone, regardless of whether they have Huntington’s disease or not. Focusing on living a healthy life can lead to improved mental health, increased ability to cope through tough times and a greater feeling of control over one's life.

Day-to-day life is busy and most people have to juggle many things, like long work hours, relationships, family commitment and social lives. It’s very important to take time out for relaxation and self-care. This is especially important for somebody who is living with Huntington’s disease.

> "I have had symptoms of Huntington’s for the last three years. I have continued to go to my Pilates class with my friends and it has helped with my core strength, as well as allowing me to relax and reduce my temper outbursts. My teacher has adapted my exercise programme over time to better suit my needs. My consultant at the Huntington’s disease clinic always comments on how well I walk and my family remark on how calm I am after classes. I credit all of this to taking time out to attend Pilates.”

Building up reserves in the brain

There is a well-known phrase: ‘use it or lose it’. A less familiar term is ‘neural reserve’, or brain resilience. The 'use it or lose it’ principle refers to doing things now, in order to build up the capacity to be stronger in the future.

Imagine a man who decides to try to ride a unicycle. His first try is not good; he manages just two rotations of the pedals before falling off. This difficult action of riding a unicycle has, however, resulted in different cells throughout the brain firing, which leads to a kind of circuit of neurons activating together.

He then decides to have a go the next day. Again, this network of neurons fire together and this time, connect a bit more strongly. After this he then decides that he will train every day to ride a unicycle. By doing this, he strengthens his neuronal network every single time.

How does this connect to Huntington’s disease? An increasing number of studies have shown that an ‘engaged lifestyle’ one that includes different activities that exercise the brain - has considerable long-term benefits.

‘Engaged lifestyle’ refers to anything that uses the brain, from riding a unicycle, seeing a new film, playing video games, travelling, socialising with friends, or attending a dance class.

Every time a person does something that activates their brain, they are training it to be stronger. There is a connection between how brains have engaged in the past and the strength of those brains in the future. Knowing this can empower a person to make changes to their life today that will help later in life.

Physical activity and physiotherapy

Benefits of physical activity can include improved mood, improved concentration, cardiovascular conditioning and improved strength, balance and coordination.

Taking part in physical activity is one way that people at risk of or living with Huntington's can have some control over the potential symptoms.

Physiotherapists can prescribe exercises and activities that are appropriate for an individual's specific needs. The 'Physiotherapy Working Group' of the European Huntington's Disease Network suggest that people who are at risk of Huntington's, or at the early stages of the disease, participate in a regular exercise routine. They also suggest that people structure their day to encourage ongoing physical and mental activity. Incorporating activities like daily stair climbing, walking to work, playing cards and doing puzzles can help to keep the mind and body healthy.

More guidance can be found on the European Huntington's Association website

eurohuntington.org/active-huntingtons

Talking to people about Huntington's disease

It can be difficult to talk to people about Huntington’s. It’s a rare disease so most people don’t know much about it and won’t know the symptoms or understand what it means for a person’s future. It is possible a person may not have heard of it at all. It can help a lot to have honest conversations, to share worries and talk openly about specific problems and fears. It’s also helpful to have friends both within, and outside of, the experience of living with Huntington’s.

Approaches to take when talking about Huntington's

Planning in advance what to say can make discussing Huntington’s with somebody who doesn’t know a lot about it much easier. A person with Huntington’s may also decide that there are certain details that they would like to keep private. It is likely that somebody learning about Huntington’s will have questions to ask.

It can be really difficult to describe Huntington’s, as everyone’s symptoms are different. Outlining that there are physical and behavioural symptoms, as well as changes to the mood, could be a good place to start. A person may find it most important to focus on the symptoms that they are personally affected by, especially symptoms affecting their behaviour.

Understandably, it is upsetting for someone to find out that their friend or family member has Huntington’s and they may want to know how they can help. Feeling as if they are helping, even in a small way, may help them deal with the situation. Some people may be good listeners, whereas others may be keen to do something more practical, like fundraising.

A person with Huntington’s may want to share with friends and family little ways in which they can make life easier. For instance, telling them that when enjoying a coffee in a café, it may be easier to leave conversation until after finishing the drinks, may help them understand ways in which they can make helpful adjustments. Asking them to assist when choosing food from a menu, as making decisions can be hard, may help them understand Huntington’s more, whilst allowing them to help where possible.

Some friends and family of people with Huntington’s may want to read the information on the Huntington’s Disease Association website. This can help them better understand how they can help.

Being surrounded by friends and family can prove invaluable when going through difficult times. A person with Huntington’s may want to associate with people who have a good understanding of Huntington’s, as well as those without. People who are able to relate to what they are going through can act as a great comfort, whilst people who aren’t as associated with Huntington’s can act as a distraction or escape.

There are many sources of support, such as online communities, message boards, events and local Huntington's Disease Association branches. Friends and family are also welcome to contact the Huntington's Disease Assocation for more information about Huntington’s.

Research

A worldwide effort is underway to advance therapeutic options to either slow down or prevent Huntington's. At the same time, there is a significant amount of research looking at ways in which specific symptoms of Huntington's may be treated.

CHDI Foundation Inc.

CHDI is a private, not-for-profit research organisation. They work with an international network of scientists to discover drugs that can be used to either slow the progression or delay the onset of Huntington's.

European Huntington's Disease Network (EHDN)

EHDN is a nonprofit research network committed to advancing research, facilitating the conduct of clinical trials, and improving clinical care in Huntington's. The Network provides an infrastructure for large scale clinical trials on Huntington's throughout Europe.

www.ehdn.org

HDBuzz

HHDBuzz is a website that brings the latest news about Huntington's disease research to the global Huntington's community, written in plain language, by Huntington's scientists.

www.hdbuzz.net

Enroll-HD

Enroll-HD is a clinical research platform and the world's largest observational study for Huntington's disease. It is a resource for the entire Huntington's community, including families, clinicians, researchers, advocates, and anyone else who has a connection to or an interest in the condition. Researchers use this information to learn more about the disease, understand why and when symptoms appear, and try to find new treatments. For further information, visit:

www.enroll-hd.org

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 Support resources
Money Advice Service	www.moneyadviceservice.org.uk	Advice Support resources
The Brain Charity	www.thebraincharity.org.uk	Advice Support resources
ACAS	www.gov.uk	Advice Support resources
European Huntington's Association	eurohuntington.org/active-huntingtons	Advice Support resources

European Huntington's Disease Network (EHDN)	www.ehdn.org	Information Research
HD Buzz	www.hdbuzz.net	Information Research
Enroll-HD	www.enroll-hd.org	Research

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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