



**Huntington's  
Disease  
Association**

# **Huntington's disease**

**A young adult's guide**

## **Introduction – by Matt Ellison**

During my childhood I watched for many years, as my father slowly progressed with Huntington's disease. During these years my father received plenty of support from various sources. However, support for me, as a young person from a family affected by Huntington's disease, was very limited and often overlooked.

My experience of growing up around Huntington's disease was not that long ago. That's why it is encouraging to see how much has changed in recent years. The importance of supporting young people has been recognised, and young people are no longer being overlooked. The HDA is now reaching out to young people on various levels such as, networking sites, forums, conferences, summer camps and their website. In fact, the HDA go to great lengths now to make sure there is support available for young people.

This guide provides you (as a young person) with a wealth of information/advice about Huntington's disease and the issues that arise specifically for young people. The guide also contains a comprehensive list of the support that is now available to you as a young person impacted by Huntington's disease. I hope it is helpful!

## **Huntington's disease - an overview**

Huntington's disease is an inherited disease that affects the brain, resulting in changes in behaviour, thinking and emotions. These changes happen over a number of years. Symptoms can start at any age, but

in most people the first symptoms start between 30 and 50 years old. Everyone with Huntington's is different in terms of when the symptoms start and which symptoms they will present with.

It is estimated that about 1 in 10,000 people have Huntington's; however recent research has suggested that the incidence may be higher than this.

Huntington's gets its name from George Huntington, an American doctor who was the first person to write about the disease in 1872. At the time it was called Huntington's Chorea. Chorea comes from the Greek word 'to dance' because of the involuntary movements he saw. Now it is called Huntington's disease as not all the changes are physical, and not everyone has involuntary movements.

## **Diagnosis**

When a neurologist is diagnosing someone as having symptoms of Huntington's (this is different to predictive testing, see below), they will rule out other diseases that could cause similar symptoms first. Thyroid or hormonal diseases have similar symptoms to early Huntington's so even if someone has a family history of Huntington's these need to be ruled out.

A neurologist would then ask about family history. For example, if people know of Huntington's in their family or if there is a chance that a parent / grandparent may have had Huntington's but it was misdiagnosed e.g. as Alzheimer's or Parkinson's disease.

Finally, a neurologist would carry out some neurological and psychological tests; they may also use brain scans.

## Treatment

There are a number of medications which can help to control the symptoms of Huntington's. Drugs are available for involuntary movements, anxiety, depression etc. There are also many therapists who can help (e.g. Physiotherapists for balance problems)

## Support available

**The HDA youth worker** – The HDA has two dedicated specialist youth workers who can support you, (one each to cover the North and South regions across England and Wales respectively). They can be contacted via our Operations team, on 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk)

**The HDA advisory service** – There are HDA Specialist HD Advisers (SHDAs) across the country. The SHDAs all have backgrounds in either health or social care; they are there to support you and the person you are caring for. This could be just having someone to chat to and off-load, or it could be helping you to access other support if you don't know how to do this or where to look. You can find your local SHDA by looking on the website [www.hda.org.uk](http://www.hda.org.uk) or calling the HDA Operations team, on 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk)

**HDA website** – Our website is a valuable source of information for young adults. There are sections for young adults, young carers, teenagers and children, along with a wealth of further information for families and health professionals. ([www.hda.org.uk](http://www.hda.org.uk))

**HDA message board** – The HDA also has an online message board where you can find support from people in similar situations. This is a great way of getting support if you find it difficult to get to a group or if you feel you would prefer to remain anonymous. You can access the message board via the HDA website [www.hda.org.uk](http://www.hda.org.uk)

**HDA annual events** - The HDA runs an annual conference for young people (18-35 years) with Huntington's in the family. The topics covered are similar to those in this booklet, and most people find that the chance to meet other people in a similar situation is very valuable – see below. Each year the HDA also holds its Family Weekend and AGM; this is a conference for people of all ages. For further details of either of these events contact the Operations team on 0151 331 5444.

**HDA branches and support groups** – The HDA has branches and support groups across the country; these are run by volunteers who have a link to Huntington's. They all evolve in their own way and form to meet the needs of the people who use them. Branches are slightly more formal than support groups as they have a committee, but the main aim of both is to come together with people who understand your situation. Once again, contact details

of any local branches or groups are available by calling the HDA Operations team, on 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk)

**HDA membership** – The HDA has free membership for people with Huntington's, their friends and families. By subscribing you will receive a twice-yearly newsletter to keep you up to date with HDA events and research. Contact the Operations team 0151 331 5444 if you wish to become a member.

**Specialist clinics** – Across the country there are specialist clinics for Huntington's. They all run differently, but have some of the following: genetic counsellor, neurologist, neuro-psychiatrist, specialist nurse, psychologist, therapists (e.g. physiotherapist). Some clinics also offer the option of becoming involved in research. Clinics may be useful for a variety of people who have Huntington's in their lives – not just for people who are symptomatic.

**Genetic services** – These are often linked with the specialist clinics, they guide people through the process of predictive testing.

**HDA youth conference** - The HDA holds an annual conference for young adults; this is normally the last weekend in March at a central venue. The conference is ever evolving but is based around the issues which are most important for young adults, such as testing for Huntington's, having children, research, insurance etc. There is normally a mix of speakers and workshops.

Most people who attend find the topics useful but they most appreciate the opportunity to talk to other young adults in a similar situation. If you would like to get information about the next conference, keep an eye on the website or contact Head Office to register your interest.

### **Feedback from a young adult about the conference:**

“The opportunity to come and meet with others whose lives are affected by Huntington’s has quite literally been a life changing experience. Before this weekend I thought I was the only one with this weight and burden. I saw no point in working, I saw no future. This weekend has changed that – I’ve heard about the hope for the future, I’ve spoken with people who have tested positive for Huntington’s but are making a difference both in their own lives and in the Huntington’s community – I am determined to be one of those people.” (AB aged 28)

**HDYO** – This is a website designed by young people with Huntington’s in their lives for young people with Huntington’s in their lives. It is an excellent resource. [www.hdyo.org.uk](http://www.hdyo.org.uk).

## **Predictive testing for Huntington’s disease**

Huntington’s is a hereditary disorder caused by a faulty gene. If one of your parents or another relative has Huntington’s then you will probably be worried about the likelihood of developing the disease yourself. Living with the knowledge that you are at risk can be very worrying. You may feel that you would

prefer to know for certain whether or not you have a copy of the faulty gene.

A DNA test can now be carried out which will usually give you this information. In very rare circumstances the result may not be able to tell you if you will develop symptoms or not. Although the test is available, it does not mean you should have it. You need to consider very carefully whether the test is right for you. If you have only just discovered that you are at risk, then be careful not to rush into making a decision. Once you have been given your test results, you can't change your mind about whether or not you wanted to know.

Only you can make the decision about whether you want to be tested and you usually need to be over eighteen years of age before it will be performed. Parents, partners and other family members may pressure you one way or the other, but it remains your decision.

Testing is available at Regional Genetics Clinics, which are located throughout the country. A list of these centres is given in our fact sheet 'Predictive Testing.' You can ask your GP to arrange an appointment for you.

You can attend a genetics clinic even if you have not decided whether or not to take the test and going to the Genetics clinic does not mean that you are obliged to take the test, but it does give you the chance to talk over all the implications and any concerns you may have. Each clinic follows an agreed

counselling procedure or 'protocol' which is usually spread over at least three sessions, to help you decide. You can withdraw at any time. Follow-up counselling after the test should be available.

## **Having children**

Knowing that you are at risk of Huntington's may affect your decision about having a family of your own. Some people decide never to have children at all, whilst others go ahead on the grounds that the children are likely to have many years of normal life before developing the disease (if they get it at all).

Couples at risk to Huntington's may find it difficult to adopt although they may be able to undertake fostering. IVF (in vitro fertilisation) and AID (artificial inseminations by donor) may also be considered.

Your decision to have children may depend upon the results of genetic testing. If testing shows you don't have the faulty gene then you can't pass it on to your children.

If you do have the faulty gene, then your unborn children can be tested to see if they have inherited it. If you do not know if you have the faulty gene, and you do not want to take the test yourself there is a different type of prenatal test which can be performed using linkage analysis.

If you are considering this option, do discuss it at the Genetics Clinic well before embarking on the pregnancy.

Preimplantation Genetic Diagnosis (PGD) offers another alternative to testing for Huntington's in pregnancy (prenatal testing); this is an option for people who have had a positive predictive test, or couples who are at risk to Huntington's, where there is genetic material available from the affected parent. PGD gives a couple the chance of conceiving a pregnancy that should be unaffected by Huntington's. PGD involves the couple undergoing IVF treatment even if they are a normally fertile couple. These embryos are then tested for Huntington's before they are implanted in the woman's womb. Only embryos without the Huntington's mutation are chosen for replacement. The hope is that the couple will be successfully pregnant with a baby that is not at risk of inheriting the Huntington's gene.

## **Huntington's and insurance**

The insurance industry is based on risk. It aims to offer a fair service based on the risk level of any applicant. Premiums are higher for many reasons, e.g. age, smoking etc but also for health – this will be based on someone's current health and family history. When applying for insurance all questions need to be answered honestly, otherwise a claim will not be valid in the future. While insurers do ask about family history, there are rules in relation to asking about genetics.

Since 1997 the Association of British Insurers (ABI) have agreed certain (time limited) rules which insurance companies have to follow in relation to genetics and insurance. The period of time, while they

have agreed to follow these rules, is called a moratorium. The key obligations of insurance companies during the moratorium are:

No insurer will request that an applicant undertake a genetic test in order to take out insurance. That, in relation to Huntington's, they can only ask for a test result if you are applying for:

- Life insurance in excess of £500,000
- Critical illness in excess of £300,000
- Income protection in excess of £30,000 per annum

Very few people wish to take out insurance at these high rates.

This means that people who have a family history of Huntington's will have to pay higher premiums than someone who doesn't have Huntington's in the family. If someone has a positive test the rates will continue to be high but if they have a negative test they will be able to take out a new policy and benefit from the lower premiums.

In relation to mortgages, while it is recommended that people take out life cover when taking out a mortgage this is not usually a compulsory requirement.

## **More Information**

HDA Factsheet: Advice on Life Assurance, Pensions, Mortgages, etc\* (available from the HDA website)

Association of British Insurers <http://www.abi.org.uk>. Use the search facility on the site to search for genetics and insurance information.

## **Being a Carer**

If you are reading this booklet it is likely that there is someone in your family who has Huntington's, and you may well have a caring role now, or have been a carer in the past. You may not see yourself as a carer but as a son or daughter, brother or sister – but when you look objectively at the situation you are providing some sort of a caring role.

Caring can have a big impact on your life and decisions you make. For example, you may feel guilty about leaving the person you care for if you are going to study or move in with a partner – you may think that you shouldn't think about your own future; but focus on the person you are caring for.

Caring for someone in the family can be difficult, tiring and stressful. It can also be incredibly emotional especially if you are at risk for Huntington's yourself or have had either a positive or negative test result.

Caring can also have its good times, when you see the person enjoy themselves and it seems like it's all worthwhile.

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 would prefer this to a stranger coming

in to 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 you feel bad about trying to get outside help in, but it is really important to know about the support available. In England and Wales people with a disability may have an assessment from social services to see what support they are entitled to, and a care plan maybe set up for them which is appropriate to their needs. Sometimes asking for professional help seems overwhelming, or even embarrassing if you think your situation is different to every else - you may wonder how carers coming in would cope with your loved one especially if they have some unusual behaviours.

It can be a good idea to contact your local Specialist HD Adviser for support. They can help you navigate your way through the care system and can support the professionals with information about Huntington's. If carers start coming in to the home, they can offer training to them so they get to understand Huntington's.

The social worker can also advise if there are benefits that you or the person you care for may be entitled too. Social workers can also assess whether the person may actually be better off in residential care. Sometimes this can seem like a massive stepping stone and, again, a time when people often feel guilty. However, people who have dreaded their loved one moving out often look back and say that it has been a

relief – and that they are able to spend more quality rather than quantity time together.

As a carer there is a lot of support available and the HDA ‘carer’s guide’ goes through a number of issues in relation to caring for someone with Huntington’s. This is available on-line at [www.hda.org.uk](http://www.hda.org.uk) or by calling Head Office to request a copy.

## **Relationships**

As a young adult with Huntington’s in the family, you may be worried about forming relationships, especially with a potential partner. You may wonder about when you would raise the issue of Huntington’s, how you would tell someone about it, and how they would react.

You may be worried about the future – that you might become a burden to the person you love. Sometimes it seems really hard if a partner says they will love and care for you forever, no matter what – but you don’t want them to have to do this.

People often feel that it is better to talk about Huntington’s openly in the early stages of a relationship to gauge how someone will cope with the information, and so they don’t feel that it’s something that is hanging over them and worrying them as they become closer to someone.

You tend to know your friends quite well and have an idea of who to tell and who not to tell. You may have different friends who you feel you can rely on for

different things. From a friend's point of view, they probably want to support you and may need you to guide them as to how they can do this. They may be scared of saying the wrong thing or asking silly questions – they may want some information on the disease that they can look at so they get an idea of what Huntington's is. Friends and family are always welcome to contact the HDA to gain information – clearly, the service is confidential and no individual would be discussed without their prior agreement, but general information and advice can be given. A friend may be glad of a way to help - this could be coming along to an appointment with the genetic counsellor with you, just being there to speak to, or getting involved in some fundraising.

If you sometimes feel low and this makes you step away from social activities you may want to discuss this with a friend. You may want to say that sometimes you could do with a push from them to get out and have some fun.

Many people have found it really useful to build up a social network of other young adults who have Huntington's in their lives. When you're talking to others in a similar position it can be a relief to not have to explain what Huntington's is and why things can be difficult – you are automatically with people who understand. There are HDA and HDYO Facebook pages which you can join, where you will find many other young adults with Huntington's in their families. Another great place for support is the HDA message board on the website, where people share information and support.

Some people also find it good to have people in their lives who don't know about Huntington's. This may be colleagues at work - people who perhaps aren't your best friends, but this allows people to have a space 'away from Huntington's'.

## Coping

It can be incredibly hard to cope with the fear of living at risk, or with having a positive test for Huntington's. People may fear becoming a burden, becoming like their parent, passing on the gene, losing cognitive abilities.

People worry that a trip or fall, a moment of forgetfulness, or arguments may be the early symptoms of Huntington's. Whether or not the stressor is a result of Huntington's it must be addressed, not avoided.

People who have had a negative test can also struggle to cope. Sometimes people have lived their lives thinking they would get Huntington's, when they have a negative test they feel they should be happy, but also feel that they have lost a huge part of their identity. Others feel guilty after a negative test, especially if siblings have tested positive or remain at risk. People who have had a negative test can find that maintaining a role in the Huntington's community can be a good coping mechanism (e.g. support groups, fundraising, research etc).

People - in any situation - can find it useful to talk to someone about these feelings, and it doesn't always

seem appropriate to talk to friends. You can talk to your Specialist HD Adviser, you can ask your GP to refer you for counselling, or you can also contact your closest specialist clinic to see if there is support they can offer.

Again, one of the key ways people find they can cope is by talking to others in a similar situation; this may be at a local support group (contact us for more information), the HDA and HDYO Facebook pages and websites, the on-line message board (at [www.hda.org.uk](http://www.hda.org.uk)) or coming along to the youth conference.

## **Work and Huntington's**

Young adults can have concerns in relation to their work and Huntington's. At the stage of an interview it is important to remember that you only have to give information about a health issue if an employer asks you i.e. you have to answer all questions honestly but you do not have to offer information if the question isn't asked.

Most people feel they don't want to voluntarily offer information about a health condition as they are worried that they might be treated differently. Also, in relation to Huntington's people are often concerned about telling people as there is so little awareness of the disease.

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 employees and their colleagues, and this will affect how they feel about giving information to an employer, but all employers need to comply with the Disability Discrimination Act (DDA).

If you are speaking to an employer about Huntington's it is worth thinking things through first; if you just tell an employer that you aren't coping then it might be difficult for them to see how they could help you, but if you can give specific issues and preferably come up with solutions then this will be more constructive.

For example, if you are in a noisy office, with phones going all the time, emails coming in all the time and colleagues making requests all the time, you may struggle with doing all these things at once and you may want to ask your employer if you can structure your day better so you only get calls at certain times, only check your emails twice a day or similar. Or, if you find you are exhausted by the time you get to work because rush hour is so stressful, you may wish to ask for more flexible working hours. There are possible solutions to a number of issues and employers are usually happy to work through these to keep a good employee.

For support in relation to work, the Working Life Service <http://www.neurosupport.org.uk/working.html> has useful information for both employees and employers. There is also a large amount of information about working with a disability at [www.direct.gov.uk](http://www.direct.gov.uk)

## Looking after yourself – and building neural reserves

Modern day life is busy. Young adults often have to juggle many things – studying, long work hours, relationships, family commitments, social lives. It's very easy to get caught up in the momentum of life and to forget to step back and think “where am I in all of this? Who is looking after me?”

General principles of looking after yourself apply to everyone. We've all heard the mantras ‘eat healthily’, ‘get enough exercise’, ‘use your brain’, ‘sleep well’, ‘take time for relaxation’, and so on. However, did you know that these principles can be especially relevant for young people who are at risk of having the Huntington's gene?

Healthy living can benefit everyone in the short-term, leading to better mental health, a greater sense of control over one's life, and a better ability to cope when the going gets tough. It's very important to take time out for relaxation and ‘me time’. And if things do start to get too much, there are people who can help, such as your GP, a counsellor or a Specialist HD Adviser. The long-term benefits of healthy living are where people at risk of Huntington's can also really see the advantages.

There is a phrase you've probably heard: ‘use it or lose it’. A less familiar term is ‘neural reserve’. How do these link together? The ‘use it or lose it’ principle refers to doing things now so you build them up to be strong into the future. Imagine a man who has a go riding a

unicycle. His first try is ridiculous; he manages a few rotations of the pedals before falling off. This difficult action of unicycling has results in different cells throughout the brain firing, which leads to a kind of circuit of neurons firing together. Mr unicyclist then decides to have a go the next day, and again this network of neurons fire together and connect a bit more strongly. He then decides that he will train in unicycling and does it for an hour each day, in the hope of qualifying for the Olympics. OK, well maybe he's dreaming! But one thing is for sure – this neuronal network has strengthened every single time he has ridden his unicycle.

How is this man's unicycling relevant to us? Well, an increasing number of studies have shown that an 'engaged lifestyle' has considerable long-term benefits. The fun part is that 'engaged lifestyle' refers to anything that uses the brain, from unicycling to studying, seeing a new film, playing X-Box, travelling, having a belly laugh with a friend, doing a new dance class. The list goes on. Any time you do something that activates your brain, you are training it to be stronger.

There is a connection between how we engage our brains now and the strength of our brains in the future. Knowing this can empower us to make changes to our lives today that will help us later on down the track.

# Exercise and Physiotherapy

## Why exercise and why physiotherapy?

Exercise has been shown to have many benefits in individuals of all ages and health status. Some of these benefits can include improved mood, concentration, cardiovascular conditioning, and improved strength, balance and coordination, to name just a few.

For people at risk for Huntington's, or those in the early stages of the disease, such benefits can significantly impact their quality of life and participation in activities that are meaningful to them.

Participation in exercise is one of the few ways that individuals at risk of Huntington's can have some control over the potential effects of the disease process.

Current research is underway in Europe and the U.S. in people with early-mid stage Huntington's to determine the possible benefits of various types of physiotherapy-led exercise programs. Physiotherapists are trained in understanding the effects of movement disorders such as Huntington's and are experts in exercise prescription. Physiotherapists can help individuals at risk for Huntington's to understand the potential physical motor symptoms, the progression of the disease, and can prescribe exercises and activities that are appropriate for an individual's specific needs.

## So, what can you do now?

The Physiotherapy Working Group of the European Huntington's Disease Network (EHDN) has made the following recommendations for individuals who are at risk for Huntington's, or at the early stages of the disease:

- Seek consultation from and develop relationship with qualified physiotherapist who can provide advice on appropriate physical activity and address any postural or musculoskeletal impairments that are amenable to change (e.g. poor posture, muscle imbalances)
- Participate in regular exercise routine (see recommendations below).
- Structure your daily environment to encourage ongoing physical and mental activity (e.g. daily stair climbing, walk to work, playing cards, and puzzles)

## Basic guidelines for a recommended fitness programme

- Trunk mobility & flexibility exercises (e.g. yoga or pilates exercises)
- Endurance/cardiovascular training (recommended 30 min 3-5x/wk; e.g. walking, swimming, stationery bike)
- Balance exercises
- Strength training/core stability

## **Questions?**

Members of the Physiotherapy Working Group of EHDN are specialists who are experts in physiotherapy for people with Huntington's. For further information, contact Lori Quinn by email, at [QuinnL1@cardiff.ac.uk](mailto:QuinnL1@cardiff.ac.uk) or Monica Busse, at [BusseME@cardiff.ac.uk](mailto:BusseME@cardiff.ac.uk).

## **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 Disease.

## **EHDN – European HD Network [www.euro-hd.net](http://www.euro-hd.net)**

EHDN is a platform for professionals (health care professionals and scientists) and people affected by Huntington's and their relatives to facilitate working together throughout Europe. The Network provides an infrastructure for large scale clinical trials on Huntington's throughout Europe

## **Where can I find out more about research?**

The UCL website has information on Huntington's research and a very useful booklet

[http://hdresearch.ucl.ac.uk/wp-content/uploads/hd\\_therapies\\_ucl.pdf](http://hdresearch.ucl.ac.uk/wp-content/uploads/hd_therapies_ucl.pdf)

HD lighthouse is an American website which explains the latest Huntington's research in language which is easy to understand [www.hdlighthouse.org](http://www.hdlighthouse.org)

**HD Buzz:** HDBuzz 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. It provides easy-to-understand digests of scientific papers and conference reports that are free to read and share. [www.hdbuzz.net](http://www.hdbuzz.net)

## **How can I get involved in research?**

Enroll-HD is a worldwide observational study for Huntington's disease families. It monitors how the disease appears and changes over time in different people, and is open to people who either have Huntington's, or are at risk. It aims to collect clinical information about individual people and their health over time. Researchers use this information to learn more about the disease, understand why and when certain symptoms appear, and try to find new treatments for it. If you would like to know more about Enroll-HD or how you can get involved, visit [www.enroll-HD.org](http://www.enroll-HD.org)

## Fundraising

Fundraising is a really positive way to get involved in the Huntington's community and enables the HDA as a charity to continue running. Many young people in England and Wales have participated in hundreds of fundraising events from a 5k run (or walk as the case may be) to marathons and treks overseas. It can be a great way of raising awareness and having fun at the same time.

There are also less involved opportunities to raise money for the HDA, such as switching your search engine to [www.giveasyoulive.com](http://www.giveasyoulive.com) and selecting the HDA. If you are interested in fundraising for the HDA in any way, why not look online in the fundraising section for ideas and more information.

## Further Information

### Books

**Learning to live with Huntington's disease:** One family's story. Sandy Sulaiman – Chapter 3, The Older Son's story. Chapter 5, the daughter in Law's story, Chapter 4 The younger Son's story

**Huntington's and Me: A guide for young people** – available from Head Office at a cost of £10.50, this is aimed at teenagers

### Factsheets

**Predictive testing for Huntington's disease** - HDA  
**Advice on life assurance, pensions, etc** – HDA

## **Web resources**

[www.HDBuzz.net](http://www.HDBuzz.net)

[www.HDYO.org](http://www.HDYO.org)



## Fact sheets available from the Huntington's Disease Association:

- General information about Huntington's disease and the Huntington's Disease Association
- Predictive testing for Huntington's disease
- Talking to children about Huntington's disease
- Information for teenagers
- A young adult's guide
- Eating and swallowing difficulties
- Huntington's disease and diet
- The importance of dental care
- Communication skills
- Behavioural problems
- Sexual problems
- Huntington's disease and the law
- Huntington's disease and driving
- Advice on life assurance, pensions, mortgages etc.
- Seating equipment and adaptations
- Checklist for choosing a care home
- Advance Decision to Refuse Treatment (ADRT)
- A carer's guide
- Challenging behaviour in Juvenile Huntington's disease
- A brief guide to Juvenile Huntington's disease for children's hospices and palliative care services
- A teacher's guide
- A young person with Juvenile Huntington's disease at school

All fact sheets can be downloaded free of charge from our website [www.hda.org.uk](http://www.hda.org.uk) or ordered by phone 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk)

For a publication price list/order form, membership form, details of our Specialist Huntington's disease Advisers and local Branches and Support Groups, please phone 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk)

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