Huntington's Disease Association

Huntington's disease:

A Juvenile Huntington's disease guide

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What is Juvenile Huntington's disease?

If someone develops symptoms of Huntington's before the age of 20, this is known as Juvenile Huntington's disease - sometimes also referred to as JHD or Juvenile-onset Huntington's.

Juvenile Huntington's is quite rare; about 5% of people with Huntington's disease will have Juvenile-onset. This means that dealing with it can be quite an isolating experience for the person and their family, and meeting others in the same situation can help.

People with Juvenile Huntington's can sometimes experience symptoms that don't feature in adult Huntington's. This is particularly the case for those who are young children when they begin to develop symptoms. They are less likely to have the involuntary movements common in Huntington's, known as chorea. They're more likely to experience muscle contractions and stiffness, making their movements slower and more difficult. They may also develop epilepsy.

Mood changes, such as feeling frustrated or angry and finding it hard to manage behaviour, are a common symptom in people who develop Huntington's in their teens. This can often be the first sign of the illness. However, many children and young people with Juvenile Huntington's do not have these problems, and it's important to remember that these symptoms may relate to other causes and not be due to Huntington's.

These are just a few of the possible symptoms – someone with Juvenile Huntington's may not experience them all, or may experience different ones. There are many different kinds of help and support available to reduce symptoms and their effect on someone's life.

The genetics of Juvenile Huntington's disease

Huntington's disease is a rare disease which is caused when somebody has a faulty gene in their DNA. DNA is the biological instructions that a person inherits from their parents which tells their cells what to do. Genes control cells by producing proteins and different genes make different proteins. Chromosomes are threadlike structures which store the genes. Each human cell contains around 25,000 pairs of genes, stored on 23 pairs of chromosomes.

The Huntington's gene determines whether a person could develop Huntington's disease, and is stored on chromosome pair four. The Huntington's gene provides the code for the Huntington's protein. Everyone has two copies of the gene – one inherited from each parent. if a person inherits a faulty copy of the gene from a parent they will develop the condition.

If the child or young person of someone with the Huntington's gene starts to show symptoms, a diagnostic blood test may take place to see if they have Juvenile Huntington's. As Juvenile Huntington's is so rare and the symptoms hard to recognise, they can be mistaken for something else, and this can make the actual diagnosis more difficult. Not knowing can be stressful, and it is important for the family to access support at this time.

Key facts about genetics and Juvenile Huntington's

- If somebody has Juvenile or adult Huntington's disease, this means they have inherited a faulty version of the Huntington's gene from one of their parents, and the recipe for the protein that the gene produces is incorrect.

- The faulty version of the gene repeats a particular coding sequence known as CAG (cytosine-adenine-guanine) too many times - a bit like adding too much of one ingredient in a recipe.

- If a person has 40 or more CAG repeats, it is certain that they will develop Huntington's at some point. If they have more than 60, it is highly likely that they will get Juvenile Huntington's, meaning they will start to experience symptoms before the age of 20. Not everyone with a high CAG count develops Juvenile Huntington's.

- If a person does develop Juvenile Huntington's, it is more likely that the faulty gene came from their father, as CAG repeats tend to be more unstable when passed on from a man. It is thought that this is because the gene becomes more unstable in sperm.

- Every child conceived naturally to a parent who has the faulty gene has a 50% chance of inheriting the disease.

- Juvenile Huntington's is what's known as an 'autosomal dominant disorder'. Autosomal refers to a gene that is dominant and is not on the X or Y chromosome. This means that if one copy of the gene is faulty it dominates over the normal copy.

Symptoms of Juvenile Huntington's disease

The faulty version of the gene that causes Huntington's disease produces too many repeats of a particular piece of genetic code. The protein this produces damages neurons instead of helping them to develop. This causes them to function poorly and reduce in number over time which is when symptoms begin to appear. In the case of Juvenile Huntington's, the gene produces an even larger number of repeats than with adult Huntington's, which causes symptoms to appear earlier, before the age of 20.

Huntington's disease and Juvenile Huntington's affect both the brain and the body. The parts of the brain affected include areas called the basal ganglia and cerebral cortex. These areas are responsible for different types of activity, including movement, learning, thinking, planning, motivation, and emotion.

The ways that Juvenile Huntington's will affect a person's body and the speed at which these changes will happen are different for different people. Not everyone experiences the same symptoms, and symptoms change over time as the disease progresses. However, changes to the body may occur faster in some young people. Access to care that fits the person's needs and adapts as required can make a huge difference.

In some ways, symptoms of Juvenile Huntington's are similar to those of the adult disease, but there are some key differences. As with adult-onset Huntington's, Juvenile Huntington's symptoms can vary from one person to another. They mostly affect three main areas - movement, thinking and behaviour.

However, children and young people affected by Juvenile Huntington's are less likely to experience involuntary movements, known as chorea, that often characterise the adult illness, and are more likely to be affected by muscle contractions and stiffness.

Epilepsy (seizures) is also more common in Juvenile Huntington's, particularly in children. Different types of symptoms generally occur at different stages of the illness. Often the first indication that someone has Juvenile Huntington's is a change in their thinking or behaviour. For example, they may experience difficulty concentrating and following instructions, and there may be a noticeable drop in their performance at school, college or work. Family members and teachers may not initially interpret these changes as an illness at all.

Not all behavioural changes, however, may be directly caused by the disease. Children of families affected by Huntington's may also be experiencing disruption and difficulties in their home life, which might also impact their behaviour, or they may be facing other challenges in their lives.

A person must be 18 years or older to have the genetic test for Huntington's. As the symptoms of Juvenile Huntington's can resemble those of other diseases such as autism, depression or attention deficit disorder (ADD), the illness can be misdiagnosed or remain undiagnosed for some time. This is particularly true where a family history of the disease is not known.

If a young person develops Juvenile Huntington's, there are many ways that they can get help and support with their symptoms to help them cope in school and improve their quality of life.

Early stages of Juvenile Huntington's disease

Changes in behaviour or a drop in school performance are often the first noticeable symptoms of Juvenile Huntington's disease.

- It may become harder to concentrate, learn new things, follow instructions and remember things.
- It may take longer to respond to questions and perform tasks.
- It might be harder to start tasks. Sometimes this can be misinterpreted as lethargy or laziness.
- The person may start to feel more frustrated, impatient, irritable or angrier than normal.
- The person may start to experience stiffness in their limbs. Their movements may slow down and they might find that they start to stumble or walk unevenly.

These are just a few of the possible symptoms. Not everyone will experience them all or they may experience different ones. Some young people with Juvenile Huntington's may find that their symptoms progress more rapidly than adults with Huntington's.

Many symptoms can be greatly helped with extra support at home and in school. As Juvenile Huntington's is so rare, it's important for schools to have information to help them understand the disease and how best to provide support. For example, it may help to have longer to eat or to have frequent snacks throughout the day to help maintain weight.

Middle stages of Juvenile Huntington's disease

Symptoms of the middle stage of Huntington's often revolve around changes in muscles and movement, although changes in behaviour may also become more significant and challenging.

- Muscles may start making involuntary contractions and may become stiff and rigid.
- Movements may slow down and arms and legs may become clumsy.
- There may be changes in speech, as it may become more difficult to form words. Speech therapy and specialist equipment can help with this.
- It may become difficult to swallow, making eating difficult, and this may cause weight loss. Support from a speech and language therapist and dietitian can help to make sure weight is maintained.
- Behaviour may change as feelings of anger, frustration, or depression become more intense. This can be incredibly challenging for both the young person and those around them. It doesn't happen to everyone but it's more likely to happen if symptoms started developing in teenage years.

Everyone's journey through Juvenile Huntington's is unique. Not everyone will experience all these symptoms, and some people may experience them at different stages. This means that care will need to be tailored to meet individual needs and will need to change and evolve as required.

Later stages of Juvenile Huntington's disease

The nature of Huntington's is such that gradually, often over a period of many years, the disease progresses until the end of life. Later on, difficulties may increase with the following

- Weight loss and nutrition
- Speech and swallowing
- Movement and stiffness
- Communication

It is important to pay attention to the symptoms that are causing the greatest difficulty, emotionally or practically, at the time. Sometimes the psychological and emotional sides of living with the disease are more of a problem than the physical side. It can be mentally difficult to cope with having a serious illness, and extremely frustrating to not be able to do things that could be done easily before.

There are many different kinds of support and help available to help manage symptoms and live as well as possible. Practical and emotional support is also available for carers and families of people affected by Juvenile Huntington's. In the later stages of the disease more care and support will be needed.

Support from the Huntington's Disease Association

Getting the right information and support is vital. The possibility that a child may have Juvenile Huntington's disease can cause a lot of stress, and finding out that a child does have the disease is understandably upsetting.

Because Juvenile Huntington's is very rare, health professionals, schools and the general public are not always aware of it or knowledgeable about it. So in addition to managing symptoms, the person with Juvenile Huntington's and their family may feel isolated at times. The Huntington's Disease Association can provide information and advice, help families affected by Juvenile Huntington's disease to access support and help connect them with others affected by the condition and facing similar situations.

Specialist Huntington's Disease Advisory Service

At the Huntington's Disease Association, we have a Specialist Huntington's Disease Advisory service run by advisers who have a background in health or social care and are knowledgeable about Huntington's disease. There is an experienced Specialist Adviser on Juvenile Huntington's and a Youth engagement team. They operate throughout England and Wales and can give advice on accessing other support services, or simply act as somebody to talk to. For further information or to speak to an adviser, contact us at:

- 0151 331 5444
- info@hda.org.uk

Juvenile Huntington's disease activity weekend

Our Juvenile Huntington's disease activity weekends run annually and are aimed at families affected by Juvenile Huntington's. The weekend offers an opportunity to meet others in a similar situation, whilst also having a great weekend full of exciting activities. It provides the opportunity to find out more about Juvenile Huntington's, from both other families affected and healthcare professionals with expertise in Huntington's disease. The whole family is welcome on the weekend, including brothers and sisters. More information is available on our website.

Events

Each year at the Huntington's Disease Association we run a number of events to provide useful advice, support and guidance to people affected by Huntington's disease and Juvenile Huntington's disease. This includes our Juvenile Huntington's disease activity weekend. Further information about our national and local events can be found on our website.

Website

Our website offers practical information and sources of help and support. It also has information about events and activities that you can attend and get involved in. Our website can be found at:

- www.hda.org.uk

Message board

We have an online message board for people to share support, information and ideas. This is a great way of finding support for people who are unable to attend groups and events, or if they wish to remain anonymous. The message board can be found at:

- 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 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 and provide us with your preferred contact details:

- 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.

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 can be found on our website.

Support from other organisations

Young people with Juvenile Huntington's and their families need plenty of support to help them at different stages. As the disease progresses, symptoms and needs change too. There are a number of healthcare specialists, organisations and funding that may be accessed as the condition progresses.

Neurologists

A neurologist is a doctor who specialises in conditions that affect the brain, spinal cord and nerves. Having a neurologist, paediatric neurologist, or another doctor who specialises in Huntington's disease can be a huge help. Depending on their age, children and young people with Juvenile Huntington's are usually referred by their GP to a paediatrician, and then to a paediatric neurologist, or to a neurologist.

Physiotherapists ('Physio')

Physiotherapists help people to maintain and restore movement and function in their muscles through things like massage, exercises, and advice. Some physiotherapists won't have met someone with Juvenile Huntington's before, but they will look at their symptoms and decide how they can be managed. A physiotherapy programme for young people with Juvenile Huntington's will focus on keeping the range of motion in the joints and on supporting independent mobility. It should also help to prevent the muscle contractions that cause the stiffness many young people with Juvenile Huntington's experience. A referral to a physiotherapist may come from social services or a GP.

Occupational Therapists ('OT')

An Occupational therapist will help a young person affected by Juvenile Huntington's to move around, carry out normal everyday activities and do the things that matter to them. They will identify any difficulties that the young person is experiencing and will provide practical solutions. As the disease progresses, equipment and mobility support may become necessary, and an occupational therapist can help with this. A referral to an occupational therapist may come from a specialist clinic or a GP.

Speech and Language Therapists ('SALT')

Speech and language therapists help people who have difficulties with communicating, eating, drinking or swallowing. A speech and language therapist can help to keep up speech and swallowing ability for as long as possible and introduce tools to improve communication as it deteriorates. Young people with Juvenile Huntington's tend to perform much better with speech when they have an early referral to a speech therapist. A referral to a speech and language therapist may come from a specialist clinic or a GP.

Dietitians

Dietitians provide advice about diet and nutrition. Many people with Juvenile Huntington's start to lose weight. If eating becomes difficult or an individual is experiencing weight loss, a dietitian will help by setting up a high-calorie diet to keep weight up. They can also help with advice around foods that are easy to eat. A referral to a dietitian may come from a specialist clinic or a GP.

Palliative care teams

Palliative care teams provide holistic care and support for people who have a condition that can't be cured, as well as providing support for family and carers. They will often be able to offer support at any point of a person's condition. Different healthcare professionals provide palliative care support, but there are also some healthcare professionals and teams who specialise in palliative care.

Local councils

Councils have a duty to provide certain services to families with disabled children, under the Children Act 1989. Some services are free of charge, but a council may ask for a contribution towards others. Help available may include: care at home, short breaks, holiday play schemes, financial help, or the provision of equipment and adaptations to the home. To get this help, a person must contact the social services team at their local council. A social worker should then assess the family's needs, including health, social care and education, and give advice on what to do next.

If a person's home needs to be adapted to meet their needs, they may be able to get a Disabled Facilities Grant from their local council to help with the costs. An occupational therapist can help to decide what adaptations will work best.

Support groups

Living with Juvenile Huntington's can feel quite isolating at times for young people affected and for their families and carers. Connecting with other families in the area with disabled children can be a big help. Local councils can provide information about local support groups. Online forums, like the 'Huntington's Disease Youth Organisation' and the Huntington's Disease Association's message board, can also help people connect with others going through similar experiences.

NHS – continuing healthcare funding

If a person's medical needs are very high, they may meet the criteria for fully funded NHS care. This is known as NHS continuing healthcare or NHS children and young people's continuing care. This means that a person will receive the care and support they need at no cost.

Respite care

Having a break can be very important for people living with Juvenile Huntington's, and their families. Depending on the situation, funding for respite care may be available through social services. A social worker should be able to advise if someone is eligible for funding. There are different kinds of respite care options, varying from activity-based holidays to more traditional care in residential care homes. A local Specialist Huntington's Disease Adviser (SDHA) can help find out what's available locally.

Carer's Assessment

The families of disabled children aged under 18, can be assessed by their local authority to find out what their needs are as a family unit, and to see what kind of support they may be entitled to.

GP Carer's register

Some GPs have a carer's register, and anyone acting as a carer can ask to be added to it. When a GP is aware that someone is a carer they can take extra steps to ensure that they are coping and can provide a safe space for them to share their feelings. They can also advise on local organisations and carer's services that may benefit both the carer and the young person affected by Juvenile Huntington's.

Living well with Juvenile Huntington's

People with Juvenile Huntington's, and those around them, may find that keeping active and doing things that they enjoy helps them to cope with the big challenges of Juvenile Huntington's. Finding opportunities to make new friends will also help to combat feelings of anxiety and hopelessness, and may bring more joy and fun into life.

Young people with Juvenile Huntington's may find that activities help them to feel independent and give them a sense of achievement. Hydrotherapy may help to relieve certain Juvenile Huntington's symptoms such as stiffness, rigidity and muscular aches and pains.

Having Juvenile Huntington's doesn't mean that a person can't visit places or go on holiday. Transport staff should be able to offer assistance when travelling by train or plane. The 'Motability Scheme' can offer help with leasing a car for people who qualify for the right type of benefits or funding.

www.motability.co.uk

Some people may also be eligible for a Blue Badge which allows them to park near to their destination, often for free.

www.gov.uk/blue-badge-scheme-information-council

There are a wide range of charities who offer 'special days' for children with illnesses or disabilities, and some of these support

young adults too. These can provide an opportunity to take part in fun activities and to socialise with other young people. Huntington's Disease Association Specialist Huntington's Disease Advisers (SHDA) or Juvenile Huntington's Advisers can offer more information.

Some organisations provide holidays and short breaks for children with disabilities, either with or without their families. Social services, GPs or health workers can share a list of providers and may also be able to make a referral to some of the organisations.

Financial help

Having Juvenile Huntington's or caring for someone with Juvenile Huntington's can have an impact on finances, which can feel stressful at times. It may become increasingly difficult for the young person affected, and members of their family who look after them, to work or study. Meeting their care needs can also be costly.

There are different forms of financial help available to people living in England and Wales, from the Department of Work and Pensions (DWP), local councils and other sources. It's important to access all the help that the person with Juvenile Huntington's is entitled to.

Disability benefits

Aged under 16

Disabled people under the age of 16 should be entitled to a Disability Living Allowance (DLA) for children, if they meet the eligibility requirements. The amount of Disability Living Allowance that a person is entitled to is based on their care needs and mobility.

Aged 16 and over

Disabled people over the age of 16 may be entitled to claim benefits such as Personal Independence Payment (PIP). If they are not able to manage their own benefits, someone else can act as their 'appointee'.

Every family's circumstances are different, so it's a good idea to get detailed advice from an expert benefits adviser to calculate an

individual's full benefits entitlement. The local Citizens Advice bureau or Law Centre can often help with this. They can also help with filling in forms and can contact the Department of Works and Pensions (DWP) if necessary.

Help with equipment and adapting the home

A person with Juvenile Huntington's may be able to get help with equipment and adapting their home. For example, they may be able to get a Disabled Facilities Grant from their local council if their home needs to be adapted, to help with the costs. Usually, an occupational therapist can help decide what adaptations will be necessary. If council tax increases as a result of adaptations, for example after the addition of an extension, a person can apply to their council to have the increase removed, as long as the adaptation is as a result of their child's disability.

People with a long term illness can get certain products, services and pieces of equipment without being charged VAT on top of the cost of the items. The types of items covered include certain types of stairlifts, wheelchairs, adjustable beds, alarms, motor vehicles and building work. Suppliers can advise which items qualify for VAT relief, and will ask for a completed 'eligibility declaration' form.

Financial help for carers

A person who cares for someone with Juvenile Huntington's for more than 35 hours a week may be entitled to a Carer's Allowance. Claiming Carer's Allowance can affect the other benefits so it's important to get detailed advice from an expert benefits adviser to find out if it is worth claiming. The Citizens Advice Bureau can help with this.

www.citizensadvice.org.uk

Carer's Credit will ensure that a person who is caring for someone for more than 20 hours a week is still having their National Insurance contributions paid, just as if they were working during that time. This means that their caring role will not affect their future right to a state pension. Anyone receiving Carer's Allowance or Child Benefit for a child under the age of 12, should automatically get Carer's Credit. Carer's Credit can also be applied for by filling out a form.

Parents of a disabled child aged under 18, can be assessed by their local authority to find out what their needs are as a family unit, and what support may be appropriate.

Other grants

A wide range of grants are available, depending on a person's specific needs and situation:

- Turn2us offers a simple tool to search for grants that a person may be entitled to

  www.turn2us.org.uk

- The Huntington's Disease Association offers small grants for specific needs. Local Specialist Huntington's Disease Advisers (SHDA) can offer more information.

- Sheenam's Wish, a charity set up by a young woman with Juvenile Huntington's, provides small grants to other young people with the disease for them to do something fun.

  www.sheenamswish.co.uk

While coping with Juvenile Huntington's can be expensive at times, there are lots of different sources of help available.

Talking about Juvenile Huntington's

It can be difficult to talk to people about Juvenile Huntington's disease. On one hand, it's such a rare condition that most people haven't heard of it and may not know the symptoms, or understand what it means for the future. On the other, many people find it particularly difficult to talk about serious or life-limiting diseases when it affects a child.

It can be helpful for a person with Juvenile Huntington's and their family to have people they can have honest conversations with in order to share their worries and to talk openly about what the family is dealing with.

The Huntington's Disease Youth Organization (HDYO) provides support for children and young people around the world who have Huntington's in their family. Their website includes a section on talking about Juvenile Huntington's with children and young people.

- hdyo.org

The Huntington's Disease Association has an online message board where people living with Huntington's and Juvenile Huntington's are able to share thoughts, receive and give advice, and chat with other facing similar situations and challenges.

- hdmessageboard.com

Managing changes in behaviour

Families living with Juvenile Huntington's have shared their top tips below in dealing with changes in behaviour in young people with the condition.

Tips on managing behaviour

When a person finds that they disagree with a family member, it may help to...

- Walk away for 10 minutes (and come back calmer).
- Change the focus of the discussion from a negative to a positive (what they can do, not what they cannot do).
- Bring someone else into the room/home to deflect attention.
- Present choices.
- Take an indirect approach to a request.
- Use other people in the family to negotiate, or to help find a compromise.

What doesn't help...

- Confrontation.
- Trying to rationalise with the person.
- Expecting them to accept a different point of view.

If a planned event ends up being cancelled, it can cause distress. It may help to...

- Avoid mentioning events until very close to the time they will take place. Ensure that others also avoid subjects that cause excitement and could influence behaviour.
- Have a plan B in place, to avoid disappointment if plan A fails. Introduce both plan A and plan B as possibilities, ahead of time, clarifying that depending on certain factors, Plan B may be more likely to happen.

Everyone likes to have some control in their lives. It may help to...

- Give the person options and allow them to make some choices, e.g. what they will wear. When asking the person to make a choice, putting the possible options in front of them makes it easier than asking them to think abstractly.
- To reduce unsettled behaviour, have a routine and stick to it.
- ·Look after yourself by setting boundaries. If you give in completely, you lose yourself, so set boundaries beyond which you do not go, and be consistent.
- ·Not being too hard on yourself, celebrate the small successes!

Education and Juvenile Huntington's

Because the symptoms of Juvenile Huntington's disease change and evolve over time, the extra support needed at school may also change.

All schools are required under the Equality Act 2010 to make 'reasonable adjustments' for disabled children. These can include:

- Adding ramps or lifts.
- Changing how learners are assessed.
- Providing extra support and aids, such as specialist teachers or equipment.

It is the responsibility of local councils to ensure these adjustments happen. A school should be able to accommodate any special needs that a pupil has, at least initially.

As Juvenile Huntington's is such a rare disease, teachers are unlikely to have encountered any pupil with it before. The school may benefit from advice to ensure that they understand how best to help.

Getting assessed

Local councils can carry out an education, health and care (EHC) needs assessment. Local authorities are required to carry this out in accordance with the Children and Families Act 2014. This should lead to an EHC plan, which will explain the extra support that is needed.

Choosing the right school

Some schools are able to offer more help and support to pupils with additional needs than others. A person can ask to see a school's policy on special educational needs and disabilities (SEND), which should give an idea of what support they can offer.
There are lots of different things to think about when considering which school is right. These include:

- The current Juvenile Huntington's disease symptoms and how they are expected to develop.
- The availability of suitable schools in the area.
- How well a school is able to respond to the challenges of Juvenile Huntington's and whether they can meet the individual's specific needs.
- Whether the school will be able to adapt to changes over time, and if so, how long changes are expected to take.
- If considering a special needs school, whether a school for children with physical disabilities would be more appropriate than a school for children with learning disabilities.
- How the individual with Juvenile Huntington's, their family and siblings feels about the school.
- The opinions of main carers and professional advisers.

Transport

If a person is unable to walk to school because of their disabilities they may be entitled to free transport. It doesn't matter how far away they live, their council should provide transport suitable for their needs.

When to change schools

For many children and young people with Juvenile Huntington's, staying in a mainstream school may be the best option in the early to mid-stages of the illness, but it can become more difficult as

the disease progresses. However, it very much depends on each individual situation.

Moving to a special needs school can be a big step for everyone, so it's a good idea to think carefully about the best time to make such a change. Some children do better when they are with other children that are 'higher-functioning' than themselves, whilst others benefit from the experience of being one of the more capable ones in their peer group.

Home schooling for someone with Juvenile Huntington's is likely to be extremely challenging, as it can be quite isolating for both the child or young person and their parent-teacher. It's generally good to have a break by being apart from each other and with other people for a few hours a day. Many children respond very differently to teachers and therapists than they do to their own parents and the presence of other children can also be very motivating.

Getting the right school environment is important, and it can make a big difference to the young person's quality of life.

Becoming a young adult

Until the age of 18, the long-term health care of a child is the responsibility of child health and social care services. From 18 years onward, adult services usually take over. Between the ages of 16 and 18, there is a period of transition during which a child will start to have contact with the adult services.

Transition planning

Planning for this transition should begin as soon as it starts to become clear what the person's needs are likely to be from the age of 18 onward. The timing may be different for each person, but it typically starts at age 13 or 14.

Transition planning should be an ongoing process rather than a single event and should be tailored to suit the needs of the person with Juvenile Huntington's. The first step should be a 'transition assessment' carried out by the local authority to see what help the person will likely need and benefit from.

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
Motability	www.motability.co.uk	Advice Support resources Information
Blue Badge Sceme	www.gov.uk/blue-badge-scheme-information-council	Information Support resources
Turn2Us	www.turn2us.org.uk	Information Support resources Helpline
Sheenam's Wish	www.sheenamswish.co.uk	Grant information
Huntington's Disease Youth Organization	hdyo.org	Advice Support resources Online forum

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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Huntington's Disease Association

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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

Inspired by our community