



Huntington's  
Disease  
Association






# Huntington's disease: Teachers guide

A Teacher's guide for supporting a student with Huntington's disease in their family.



COMMUNITY  
FUND

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# Introduction

This simple guide aims to explain what a young person could experience being in a family with Huntington's disease and how to best support them. This guide can also be used for personal development to enhance your understanding of Huntington's disease.



# What is Huntington's disease?

Huntington's disease is a hereditary neuro-degenerative psychiatric disorder caused by a faulty gene in your DNA. If you have Huntington's, it affects your body's nervous system - the network of nerve tissues in the brain and spinal cord that co-ordinate your body's activities.

Huntington's disease can cause changes with movement, thinking and mood. Once symptoms begin, the disease gradually progresses, so living with it means having to adapt to change, taking one day at a time.

Huntington's is not something you can catch; it is inherited. Every child conceived naturally to a parent who carries the Huntington's gene has a 50% chance of inheriting it.

You can live with a faulty gene for years without any symptoms though at some point you will develop symptoms. Most people start to show symptoms between 30-50 years old.

You can have a predictive test to see if you have the gene from 18 but this cannot predict when you will show symptoms. There is currently no cure.

Living with Huntington's disease can be very challenging.



# Emotional support

Many young people find it very difficult to manage the changes that are happening to their parent or family member. People with Huntington's disease can be irritable, fixated, apathetic, repetitive, less able to engage in physical and social activities as well as being slower to respond and problem solve.

Young people also have to manage anxieties that they could inherit the gene and one day have Huntington's. For young people, it can feel like they are looking at their own future when with their parent.

Young people often fear not being understood or having to explain what Huntington's is, which can make it difficult for them to share. Families experience repetitive loss and bereavement as the person with Huntington's disease changes.

## How can you help?

- Improve your knowledge of Huntington's disease so your student feels more comfortable talking to you. The Huntington's Disease Association offers free training to school staff.
- Allow for regular opportunities to discuss how they are coping and feeling.
- Offer a key worker/mentor in the school.
- Be lenient and understanding if homework is not completed on time or they are late to school.
- Enable the student to stay in touch with home so they know that their parent is safe



# Isolation

Huntington's is a rare disease and awareness amongst the general public is low. Most of a student's peers will never have heard of the disease or be able to empathise with them. Sometimes the parent can no longer drive and can require high levels of care which their child may provide. This can make it difficult for the child to socialise with their peers due to logistics or guilt and fear of leaving their parent. This can sometimes show as a child not engaging with peers in lessons or during break times due to worry, anxiety or stress.

## How can you help?

- Show the student that you have an understanding of Huntington's and that you empathise with their situation.
- Make sure to monitor their behaviour and promote positive social interactions.
- Try a buddy system if they are not making friends.
- Refer them to services such as Young Carers.
- Contact the Huntington's Disease Association about allocating a youth worker.

# Social settings support



A lot of students do not want to 'stand out' as being different from their peers. Their parent or family member may come to school and may be moving around, losing balance, making noises, speaking differently or using a walking aid. Sometimes people with Huntington's are mistaken as being drunk due to lack of awareness and knowledge of the condition.

## How can you help?

- Give the student opportunities to speak about their feelings and potential embarrassment.
- Embarrassment also comes with guilt. Listen to this and do not judge. Explain that their response is perfectly normal.
- Organise a home visit for greater understanding of daily life.
- Deal with any reports of bullying or verbal comments made by other parents or students in a way that fits your policy but that the student is comfortable with.
- Create an option for a more discreet school pick up and drop off if required. This could include a later drop off time and pick up for students as mobility issues are common with Huntington's.
- Ensure that everyone is happy with any actions being taken.



## Financial support

Families can get into financial difficulty, particularly when the affected parent can no longer work. Sometimes the other parent or a family member has to give up their job to care for the affected parent or it may be a one member family.

Money is needed for school lunches, uniforms, shoes and travel to and from school as well as clubs and trips. Young people do not like to feel different and unfortunately, those with limited means are susceptible to bullying.

### How can you help?

- Offer subsidised school trips and travel.
- Increase the number of social activities in school for those on low income or having money problems.
- Assisting and helping the purchase of school uniform where possible for families with Huntington's.
- Offer appropriate financial support (FSM, Pupil Premium etc) to the family and review regularly to ensure this is up to date.
- You may need to help fill in forms and give support in accessing additional services as the cognitive effects of Huntington's disease can make this extremely challenging for people to manage and action.



# Genetics in the classroom



It is important to consider your student before using Huntington's disease as an example.

Huntington's disease is no longer on the curriculum and there are other genetic conditions such as Sickle Cell disease and Cystic Fibrosis that could be used.

If you have chosen to use Huntington's disease as your example, then here are some ideas on how you can create a positive learning experience for the student.

## Have a chat prior

- Have a chat prior to the module to outline what they could expect and how Huntington's disease will be taught. Try to gauge how much they know prior to any lesson to avoid any shocks.
- This could be achieved by showing them the lesson plans, speaking to other staff to gain a good understanding of student and family.
- Talk to their youth worker or contact the Huntington's Disease Association for advice.
- Set up a key member of staff where the young person can go for support and advice.

## Give a choice

- Allow the student to have a choice and think about what could be best for them. Tell them the options and then let them decide.
- Allow them to leave during the lesson if needed or have alternatives to the lesson prearranged.
- Some young people can be very proud and open about themselves and family. Perhaps they would like to contribute and be part of the lesson.

## Be mindful

- Be mindful that open conversations and questions could lead to unwanted and difficult topics being discussed.
- Allow the students to sit with a friend so they feel safer.
- Explain to the class about sensitivity beforehand.
- After talking to the affected student privately, make students aware people within the school are impacted by Huntington's disease without mentioning the specific student.
- Ensure you do not draw unnecessary or unwanted attention to the student.
- Make the student aware that Huntington's may come up in other lessons such as RE and ethics.
- Recognise Huntington's disease has effects on mental health too and is not simply just a genetic and physical disease.



# Support from the Huntington's Disease Association

## **Specialist Huntington's Disease Advisers (SHDAs)**

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

- 📞 0151 331 5444
- ✉ info@hda.org.uk

## **Huntington's Disease Youth Engagement Service (HDYES)**

At the Huntington's Disease Association, we have a Youth Engagement Service (HDYES) operated by youth workers 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. To get in touch with your local Specialist Youth Adviser contact us at:

- 📞 0151 331 5444
- ✉ hdyes@hda.org.uk







## Website

Our website offers practical advice and sources of help and support, including downloadable information guides. It also holds information about events and activities that you can attend and details of local branches and support groups.

-  [www.hda.org.uk](http://www.hda.org.uk)
-  [hdmessageboard.com](http://hdmessageboard.com)

## Social media and mailing list

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

-  @hda\_tweeting
-  @hdauk
-  @hdauk
-  @hda\_uk
-  Huntington's Disease Association
-  Huntington's Disease Association

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

-  [www.hda.org.uk/get-involved/join-our-mailing-list](http://www.hda.org.uk/get-involved/join-our-mailing-list)

# Other useful organisations



## Huntington's Disease Youth Organisation

HDYO is a fantastic online space where adults and young people of all ages can explore and further their knowledge about Huntington's disease. There are a number of interviews in which people talk about their experiences with Huntington's and offer an insight into their lives so people can have a better idea of what to expect.

 [www.hdyo.org.uk](http://www.hdyo.org.uk)

## Carers Trust

Carers Trust believes in a world where the role of unpaid carers is recognised and they have access to the quality support and services they need to live their own lives.


 [www.carers.org.uk](http://www.carers.org.uk)

## Young carer information

### The Children's Society

 [www.childrenssociety.org.uk/youngcarer/home](http://www.childrenssociety.org.uk/youngcarer/home)

The Children's Society campaign for change, promote best practice with central and local government, and work in partnership with key workers to support young carers.

 0300 303 7000

 [supportercare@childrenssociety.org.uk](mailto:supportercare@childrenssociety.org.uk)

 [www.carers.org.uk](http://www.carers.org.uk)


## Young Carer Info

 [www.youngcarer.info](http://www.youngcarer.info)

An online guide for young people to get support, know their rights and get advice online.

## Bereavement support


### Cruse


 0844 477 9400

 [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

 [www.cruse.org.uk](http://www.cruse.org.uk)

### Winstons Wish

 Freephone: 08088 0120 021

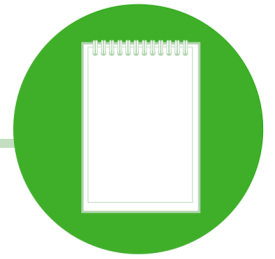
 Enquiries: 01242 515 157

 [info@winstonswish.org](mailto:info@winstonswish.org)

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

### NHS Directory

 [www.nhs.uk/livewell/bereavement/Pages/bereavement.aspx](http://www.nhs.uk/livewell/bereavement/Pages/bereavement.aspx)



# Notes





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## Get in touch

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

**info@hda.org.uk**

**0151 331 5444**

**www.hda.org.uk**

-  @hda\_tweeting
-  @hdauk
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## Huntington's Disease Association

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