Top tips for school staff working with a student affected by Huntington's disease
Contents

Introduction 3

What is Huntington's disease? 4

Emotional support 5

Isolation 6

Embarrassment 7

Money problems 8

Genetics in the classroom 9

Support from the Huntington's Disease Association 11

Other useful organisations 13
This brief and simple guide aims to explain what a young person could experience being in a family with Huntington's disease and how best to support them.
What is Huntington's disease?

Huntington’s disease is an illness 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 the 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. There is currently no cure.

Living with Huntington’s disease can be very challenging.
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, obsessive, apathetic, repetitive, less able to engage in physical and social activities as well as being slower to respond and problem solve.

Young people often fear not being understood or having to explain what Huntington’s is.

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 the student feels more comfortable talking to you.
- 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.
- Discuss whether contact via text or on the phone during the day would help ease anxiety.
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, get them to clubs and social events or they may have more care responsibilities and therefore cannot socialise as much as their peers.
- They may not engage with peers in lessons or during break times due to worry, anxiety or stress.

How can you help?

- Learn about Huntington's disease so you are better prepared to discuss it with the student if they want to. We offer training to schools about Huntington's disease and the impact it has on young people.
- 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.
- Make sure to monitor their behaviour and promote positive social interactions.
Embarrassment

- 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 or on drugs 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 this response is perfectly normal.
- Deal with any reports of bullying or verbal comments made by other parents or students.
- Ensure that everyone is happy with any actions being taken.
Money problems

- 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.
- Money is needed in school for lunches, uniform, 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 appropriate financial support (FSM, Pupil Premium etc) to the family and review regularly to ensure this 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 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 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 lesson to avoid any shocks.**

- This could be achieved by showing them the lesson plans - Speak 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.
Allow the student to have a choice and think about what could be best for them. Tell them the options and 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 a part of the lesson.

Be mindful that open conversation and questions could lead to unwanted and difficult topics being discussed.

- Allow the student to sit with a friend so they feel safer.
- Explain to the class about sensitivity beforehand.
- Ensure you do not draw unnecessary or unwanted attention to the student.
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

Specialist 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
✉️ info@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. Additionally, the website hosts an online message board for people to access peer support, information and advice.

www.hda.org.uk
hdmessageboard.com

Membership
Huntington's Disease Association membership is free for people with Huntington's and their families and it is easy to join. If you become a member, you'll receive a bi-annual newsletter with up-to-date information on events and research. To find out more about becoming a member, please contact us or take a look at our website.
Other useful organisations

Huntington’s Disease Youth Organisation

- www.hdyo.org

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.

Carers Trust

- www.carers.org

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.

Young carer information

The Children’s Society

- 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.

- Telephone - 0300 303 7000
- Email - supportercare@childrenssociety.org.uk
- Live chat – on their website from 10am-4pm, Monday-Friday
Young Carer Info

www.youngcarer.info

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

Bereavement support

Cruse

www.cruse.org.uk
0844 477 9400
helpline@cruse.org.uk

Winstons Wish

www.winstonswish.org
Freephone – 08088 020 021
Enquiries - 01242 515157
info@winstonswish.org

NHS directory

www.nhs.uk/livewell/bereavement/Pages/bereavement.aspx
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
@hda_tweeting
@hdauk
@hdauk

Huntington's Disease Association
Suite 24,
Liverpool Science Park IC1,
131 Mount Pleasant,
Liverpool, L3 5TF

Registered charity no. 296453
A company limited by guarantee.
Registered in England no. 2021975

Design and print by the Huntington's Disease Association
Illustration by Gawk Design www.gawk.design
Published October 2020 - First edition

We’ll be there