



Huntington's
Disease
Association

Newsletter

Winter 2019

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Supporting a Huntington's carer

Supporting a friend or family member who is a full-time carer of someone affected by Huntington's disease can sometimes be difficult and confusing. Should you offer the carer help? If so, what kind of help? Maybe you don't know how to talk to them about Huntington's or how to speak to their loved one who is affected by the disease? All of these thoughts are valid and understandable. We

asked two carers to give us their thoughts on how they would like to be supported by friends and family as a full-time carer of someone affected by Huntington's.

Who are our carers?

Steve, whose wife Sandy has Huntington's disease. Steve is 67 years old and originally from Bath, he used to work for the local government but retired in 2016 to become Sandy's full-time carer.

And, 65-year-old Heather from Longwell Green whose husband, Robin, was diagnosed with Huntington's in 2007. In 2014, Heather left her job as Community Liaison Manager at University of the West of England to become Robin's full-time carer.

As a carer for a loved one affected by Huntington's disease...

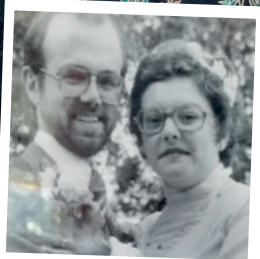
How do you hope your friends and family would support you physically or emotionally?

Steve – "We have a personal assistant who comes in for six hours on a Monday and Thursday – that's a business arrangement and I'm comfortable with that but I find it difficult to ask for help from friends and family.

Despite my outgoing persona, I'm quite a private person and I have always been very self-sufficient. I'm used to being the one that people tend to come to for advice and help. Even though people say that they are willing to help at any time, I still feel guilty about asking them. I'm not sure if I'm conscious about the burden that comes with looking after Sandy, a feeling of 'dumping' her once again or whether I still see it as a weakness



Steve and Sandy



Robin and Heather

on my part. Probably a bit of all three.

I am, however, beginning to recognise that I am opening up a little bit more to certain people – especially if they are in the Huntington's community themselves and find talking about my situation helpful."

What kind of things would you rather your family and friends didn't say or do concerning your caring role and Huntington's disease?

Heather – "I have a large group of family and friends but unless you are living with Huntington's, as Rob and I am, it is hard for people to know how to support you. You do not want to hear "he should now be in a home" when it is obvious he is not ready and we have plenty of help at home. The Bristol Branch are brilliant as they all fully understand what we are living with."

How do you hope people would act around and talk to your loved one with Huntington's?

Steve – "I hope that they would treat us as a normal couple, in my experience most people do. I've always been very open about Sandy's condition so I tend to take the initiative and tell people about Huntington's whenever the opportunity arises. Most people are quite interested to learn more and show a lot of respect for Sandy. Once people get to know Sandy, they realise that she has a wicked sense of humour, is not embarrassed about her condition and they tend to warm to her. She's seen as quite an inspiration."

Heather – "As for connecting with Robin, I tell people if they do not understand him, tell him, not me. His brain is fully functional and he can answer for himself with my help. Both of us like to be involved with people and he is very sociable."



Christmas with Steve and Sandy

"I've always been very open about Sandy's condition so I tend to take the initiative and tell people about Huntington's whenever the opportunity arises."

Steve



Holidaying with Robin and Heather

"Both of us like to be involved with people and he is very sociable."

Heather

What is the one thing you find most useful and supportive as a carer of someone affected by Huntington's disease?

Steve – "I've thought long and hard about this and thought 'what is it that makes my life easier?' and I finally plumped for information, in all its formats. I'm not the sort of person who worries about bridges I may have to build somewhere along the journey, I like to collect the tools and instruction manuals I may need in my bag, so that if I do have to build that bridge then I know how to do it. Be prepared – once a boy scout always a boy scout! I'm also very lucky that we have a very good neurological services team locally who have been able to help across a whole range of matters when I have needed it."

Heather – "Having a good care plan, community health centres and the services of carer personal assistants. Finally, respite, so I can be myself and cry if I want to, it has to be done sometimes."

Every person connected to Huntington's, whether they have the disease, are a family member, a carer or even a professional, are affected differently. We hope that this interview with Heather and Steve can give an insight into how you can support your friend or family member who are a full-time Huntington's disease carer.

 **If you have any further questions about Huntington's disease or are looking for support, you can visit our website, www.hda.org.uk, or contact us on 0151 331 5444 or at info@hda.org.uk**



Developments in research

There have been many developments in research over the past year and progress is moving at an amazingly fast pace. However, it may still feel slow for most people with Huntington's disease and their families. Below is a quick update on Huntington's research so far.

In May 2019, an IONIS trial was published that reported the first-ever humans to be given treatment to lower the huntingtin protein. This treatment was safe and has shown to lower the protein in people's brains. This was a massive breakthrough and the people in this study are continuing to receive an experimental treatment called GEN-EXTEND.

The breakthrough in the IONIS trial opened many doors and raised a multitude of questions - Will the treatment make an actual difference to people's lives? Does it make them any better or stop them from getting worse so quickly? To figure this out, GENERATION-HD was created! GENERATION-HD is a successful trial that was born out of IONIS' GENERATION-EXTEND trial yet it is now funded and coordinated by Roche. The trial has already recruited over 600 people with

plans to expand to 801 people. There are some people from the UK involved in this study but most are from the USA.

Immediately behind GENERATION-HD are two other trials, one run by Wave and the other UniQure. The Wave trial is fairly similar to GENERATION-HD. The difference is that the Wave drug only affects the mutated Huntington's gene whereas the GENERATION-HD drug targets both the normal and the mutated Huntington's gene. In theory, this sounds like a cleaner approach, but a lot more research must happen before we know for sure.

The UniQure trial, which is not recruiting in the UK, involves injecting a drug directly into the brain. This drug is packaged inside a non-dangerous virus which multiplies inside brain cells. The advantage of this approach is that the treatment may only have to be given once as the virus package keeps producing the drug inside people, however, this is a much more risky process.

Finally, ENROLL-HD, a global observation study! Enroll-HD aims to speed up the development of therapies for Huntington's disease

by collecting more uniform clinical data and biological samples to better understand the natural history of Huntington's. The study is building a comprehensive and valuable database of information which is available for use by Huntington's researchers worldwide. The study now has around 20,000 active participants and is linked to many other studies including brain imaging, studying spinal fluid and sperm cells. ENROLL-HD gives invaluable information about the whole biology of Huntington's. If more is known about how Huntington's normally affects people, then it gives researchers a much clearer idea about what might work to slow down, stop or even reverse the disease.

Although the current status of Huntington's research is extremely encouraging, there is still a long way to go. Once treatments are licenced to be used, questions such as accessibility and the cost of this will need to be addressed to ensure that all the people who need the drugs have access to them.


 **If you would like to learn more about research, visit www.hda.org.uk/research**

The fun of fundraising

Skydive

Have you always dreamt of skydiving? Are you looking for a new challenge in 2020? Join our #TeamHDA tandem skydive team and your dreams will come true in May 2020!

Our tandem skydive is taking place 16 May 2020 at Brackley Airfield in Northamptonshire. A tandem skydive means you will be harnessed to a professional parachute instructor at all times throughout the 10,000 feet drop.

 **For more information and to order your #TeamHDA Skydive pack, contact the fundraising team on 0151 331 5444 or email fundraising@hda.org.uk**

Recycling for Huntington's

You can help the environment and raise funds for the Huntington's Disease Association by taking part in our new recycling scheme! We have partnered with Recycling for Good Causes, who will recycle your unwanted items and turn them into valuable funds to support our work.

What can be recycled?

- Jewellery – gold, silver, costume jewellery, watches, broken and damaged items (like odd earrings, snapped chains or items with missing stones)
- Used postage stamps
- You can donate unwanted banknotes of any age from any country
- Old coins from any country and of any age
- Electronic items such as phones, MP3 players, cameras and games consoles

If you would like to recycle old jewellery and banknotes, simply pop them into the recycling envelope enclosed with this newsletter and send them in the post free of charge! If our recycling envelope is too small for your items, you can use a padded envelope or jiffy bag – no bigger than A5 in size and post them free of charge using the Freepost address below:

Freepost
RSXA-GJBY-ARRZ
Huntington's Disease
Association
Unit 14 Amber Business
Village
Amber Close
Tamworth
B77 4RP

 **For more information on recycling coins, postage stamps and larger items, including electronic items, please visit www.hda.org.uk/get-involved/fundraising/recycling-for-huntington-s**

'You've got a friend in me'



Top tips on supporting your friend with Huntington's disease

This section of the magazine has helpful tips that you can tear out and carry around with you anywhere or give to a friend! Here, we share with you the best ways to support your friend if they are affected by Huntington's disease.

Learn



Learn as much as you can about Huntington's. Look at the Huntington's Disease Association website for information on how to cope with changes in behaviour and how the disease affects the brain.

Allow space



Give your friend and yourself time and space to process information. Keep it simple and give information in small chunks, slowly and patiently. You will need to be flexible and learn to adapt.

Confide



Huntington's is a complex disease so there are many difficult conversations to be had. Your friendship may offer a huge opportunity to discuss what needs to be said.

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Top tips on supporting your friend with Huntington's disease

'You've got a friend in me'

Be patient



Try and stay calm and patient if things aren't going smoothly and be prepared to walk away. Give everyone a break and come back later.

Practical matters



Help with practical things; lifts to clinic, attending events, support groups and fundraising activities or simply spending regular time with your friend to give carers a break.

Practise self-care



Look after your own feelings. Try not to ignore them. You are very valuable and it's OK to feel sad, angry, guilty, resentful, fed up and exhausted. Try relaxation techniques and exercise to release tension.

It's the disease, not your friend



Your friend with Huntington's may not give you the responses you expect. You may not get the gratitude you would normally receive, you may feel isolated and exasperated at times. Try to find someone to talk to about how you are feeling.

Reminisce



Try to use humour and reminisce about fun times. Good memories are helpful and building more memories is important.

Ask for extra help



If you begin to think that the amount of support you can give to your friend isn't enough, ask for help!

The Huntington's Disease Association can provide further advice and support. Contact us at info@hda.org.uk or 0151 331 5444.



**Huntington's
Disease
Association**

New online community for carers 65+

We are delighted to announce that we have a new online community for carers who are 65+. Our virtual pop-in-café is run through the Huntington's Disease Association message board and is managed, moderated and read by staff from the Huntington's Disease Association. If you have access to the internet and an up to date email address you will be able to join! To access the virtual pop-in-café please contact Head Office who can either email or post you a booklet which will guide you through accessing the café for the first time.



Free Huntington's ID cards

Did you know that we offer a free Huntington's disease identity card that teaches those around you about the disease and explains what Huntington's is? You can also write important contact details on the back and wear the card on a lanyard if so desired! Take a look at our ID card and if you would like to order one please contact us on 0151 331 5444 or email info@hda.org.uk



Want to share your experience?

We are always looking for people to share their experiences of the Huntington's Disease Association with us! How do you feel about the services we provide? How has your Specialist Adviser helped you? Your story could be used to aid funding applications, shared on our website or social channels or used in our magazine! If you are willing to share your experiences with us, please email comms@hda.org.uk

Dates for the diary

Inbetweeners Day - an information day for people aged 35 - 45 who are affected by Huntington's disease. **14 March 2020 - YHA, London**

Understanding Huntington's certificated course - two in-depth courses each year (May in Liverpool and November location TBC) for professionals working with those affected by Huntington's. **19 - 21 May 2020 - Liverpool Science Park, Liverpool**

Awareness month - a whole month dedicated to raising awareness of Huntington's disease. The Huntington's Disease Association alongside the Huntington's community work together to light up buildings all over the country whilst holding fundraising events and sharing important information far and wide. **May 2020, Worldwide**

Juvenile Huntington's disease weekend - an activity weekend for families affected by the rare juvenile form of Huntington's. **29 - 31 May 2020 - Calvert Trust, Lake District**

Family Weekend and AGM - a three day information and social weekend for people affected by Huntington's or those involved in their care. Includes our annual business meeting. **23 - 25 October 2020 - Radisson Blu, East Midlands**



Family weekend 2019 success

We had a fantastic time at the Family weekend this year. There was a great turnout and an abundance of educational workshops and talks covering topics such as managing mental health, genetic testing, planning for end of life, tips on diet and nutrition and the importance of physical activity. Let's not forget our Disney themed party on Saturday evening!

Keep an eye on our website for any updates on our Family Weekend 2020.

Care Home Accreditation Scheme

The HDA Quality Assured Care Home Accreditation scheme is a way in which care homes can become accredited by the Huntington's Disease Association as facilities who invest significant time, resources and commitment in specialist care for people with Huntington's. This scheme aims to help the Huntington's community

when having to choose a care home. We are thrilled to announce that we currently have two fully accredited care homes on board. Fairburn Mews in West Yorkshire, the first care home to be accredited in England and Yr Ysgol, Swansea, the first of Wales' accredited care homes!

Visit www.hda.org.uk/professionals/hda-quality-assured for more information on the care home accreditation process.

Contact us

If you need advice, information or support about Huntington's disease please contact us on 0151 331 5444 or email info@hda.org.uk

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Website www.hda.org.uk

Facebook - @hdauk

Twitter - @HDA_tweeting

Instagram - @hdauk

LinkedIn - Huntington's Disease Association

We'll be there

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In the media

We have been working hard to expand our public relations to raise awareness of Huntington's disease. Our Chief Executive, Cath Stanley, appeared on two national BBC TV shows; BBC News speaking about gene silencing and The Victoria Derbyshire show discussing genetic testing. She also featured on BBC Three Counties radio talking about what Huntington's disease is and the Roche GENERATION HD trial.



A new Specialist Adviser

We have had a new Specialist Huntington's Disease Adviser join us to cover North Yorkshire, East Yorkshire, Leeds, Bradford and Calderdale. Justine is experienced in community liaison and has a wealth of experience with people with severe mental ill-health and long-term neurological conditions including Huntington's families.

If you live in Justine's area and would like to get in touch with her for support or advice, please contact 0151 331 5444 or email info@hda.org.uk