



Impact report 2019



Huntington's
Disease
Association

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**Huntington's
Disease
Association**

Our vision

A better life for anyone affected by
Huntington's disease.

Our mission

To enable everyone affected by
Huntington's to live life to their full
potential by:

- Improving care and support
- Educating families and the professionals
who work with them
- Championing the needs of the
Huntington's community and
influencing decision makers

Our values

We are:

- Tenacious
- Experienced
- Compassionate
- Inclusive



Welcome from the Chair and Chief Executive

As a little known rare disease, knowledge and understanding of Huntington's disease can be limited and symptoms are frequently misconstrued. When those that hold pivotal social, medical and financial decision-making powers know little about the complexities of the condition, it is easy to see how those affected by the disease can feel isolated, misunderstood and powerless to alter their situation. We work to change this.

Thanks to all our incredible supporters, from those that held bake sales, jumped out of planes and undertook gruelling endurance runs to those that provided us with grants, donations and pro bono support, we were able to make a difference in 2019.

Last year gave us so much to be proud of and this report is testament to what we've done and achieved together.

During the year, we were able to expand our support provision; growing our guidance publications, sharing useful content on our website and social media channels and streamlining our working practices to reach and support more people.

Through our awareness campaigns, increased presence in the media and specialist training programmes, we were able to bring knowledge and understanding of Huntington's disease to many people.

The launch of our new care home accreditation scheme meant we were able to take steps

forward in the fight to provide quality and consistent care for people with Huntington's disease.

Aligning ourselves with other rare disease organisations, gave Huntington's disease a louder voice when speaking with decision-makers, helping to impact positive change in policy to better meet the needs of the Huntington's community.

As research studies around the world bring us closer to potential treatments for Huntington's, we recognise the importance of building accurate data and information about the disease and its impact. Many important collaboration and partnership links were formed during 2019 with pharmaceutical companies, health and policy influencers and data analysis experts to help us gather information that will ensure fair access to potential future treatments.

There is still so much more we can do to ensure Huntington's remains on the agenda of those that have the authority to implement change. There are more resources we can provide and more people we can reach and help. With your support in 2020, we can make greater strides towards achieving our vision of a better life for anyone affected by Huntington's disease.

Cath Stanley
Chief Executive

Andrew Bickerdike
Chair



What is Huntington's?

Huntington's is a rare hereditary genetic disorder that is caused by a faulty gene passed down through families. The disease affects both men and women, it usually develops between the ages of 30 and 50 years old and is life-limiting. There is no cure, however, ongoing research programmes, such as those focusing on Huntington's gene-silencing, give hope for a potential treatment. Huntington's disease can affect children and young people, this is a very rare form of the disease called 'Juvenile Huntington's disease' and appears if a person under the age of 20 shows symptoms.

Huntington's disease changes the whole person – body, mind and behaviour. It is akin to being affected by Alzheimer's disease, Motor Neurone Disease, anxiety, depression, paranoia and Parkinson's disease all at the same time.



If a parent has the disease, their child has a 50% chance of inheriting it.

8,000

Around 8,000 people in the UK have Huntington's disease - that's 1 in 10,000 people.

32,000

Up to 32,000 people in the UK live at risk of developing the disease.

Who are the Huntington's Disease Association?

We are a charity that aims to facilitate a better life for anyone affected by Huntington's disease in England and Wales and enable them to live life to their full potential.

"We improve care and support services for people with Huntington's disease, educate families and professionals, and champion people's rights."

- Cath Stanley, Chief Executive

22

Specialist Huntington's Advisers across England and Wales



Collaborating with other organisations and hosting events to raise awareness, offer support and educate

2

Specialist Huntington's Youth Workers

36

Dedicated staff team of 36 people



The only dedicated Juvenile Huntington's Adviser in the world

50

Around 50 committed branches and support groups



Offering training to professionals to improve their understanding of Huntington's

700

Over 700 loyal volunteers who help raise awareness and funds



Comprehensive website, communicative social channels and message board that offer support, information and a place for interaction

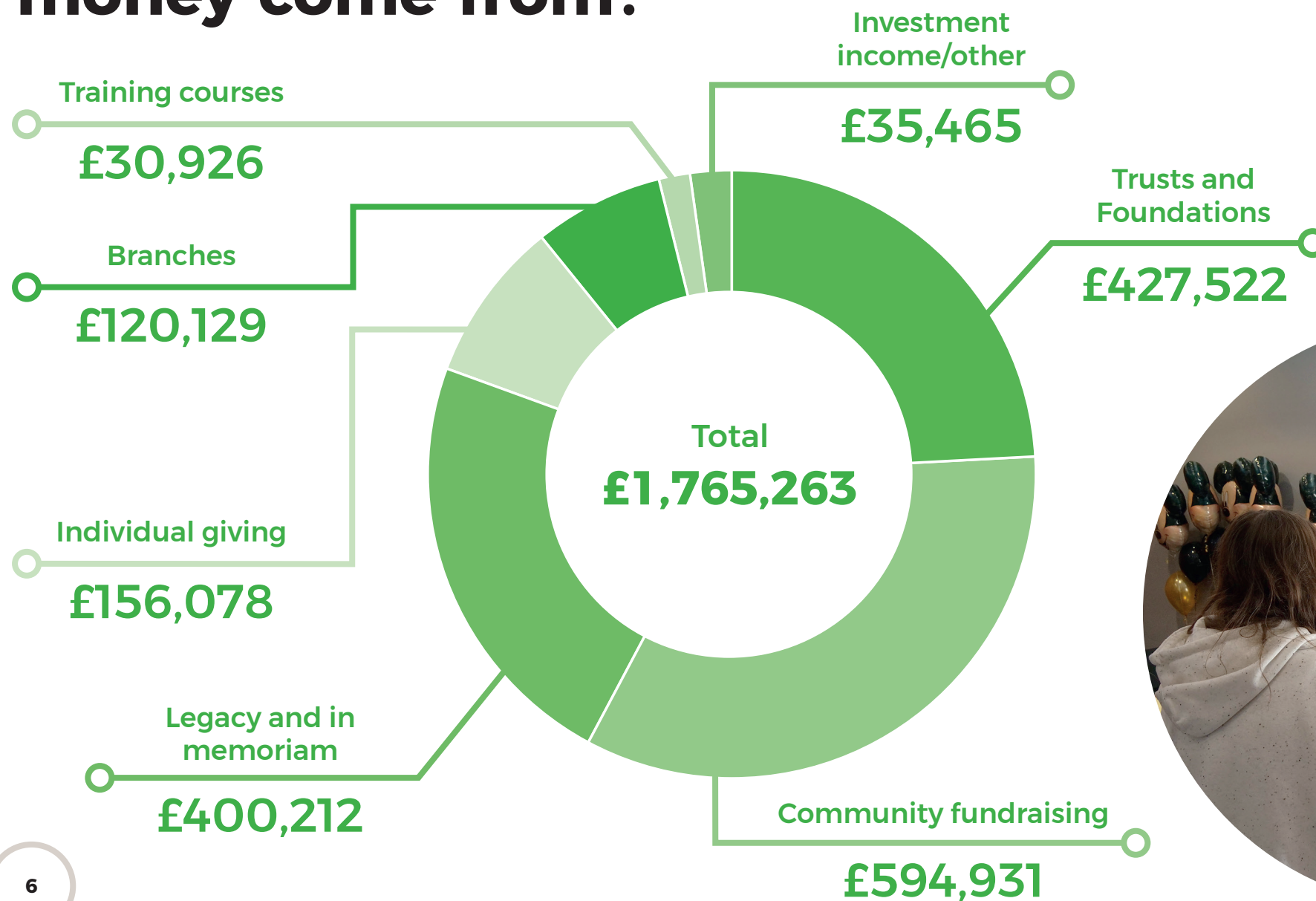
5,000

Membership of over 5,000 Huntington's families and professionals

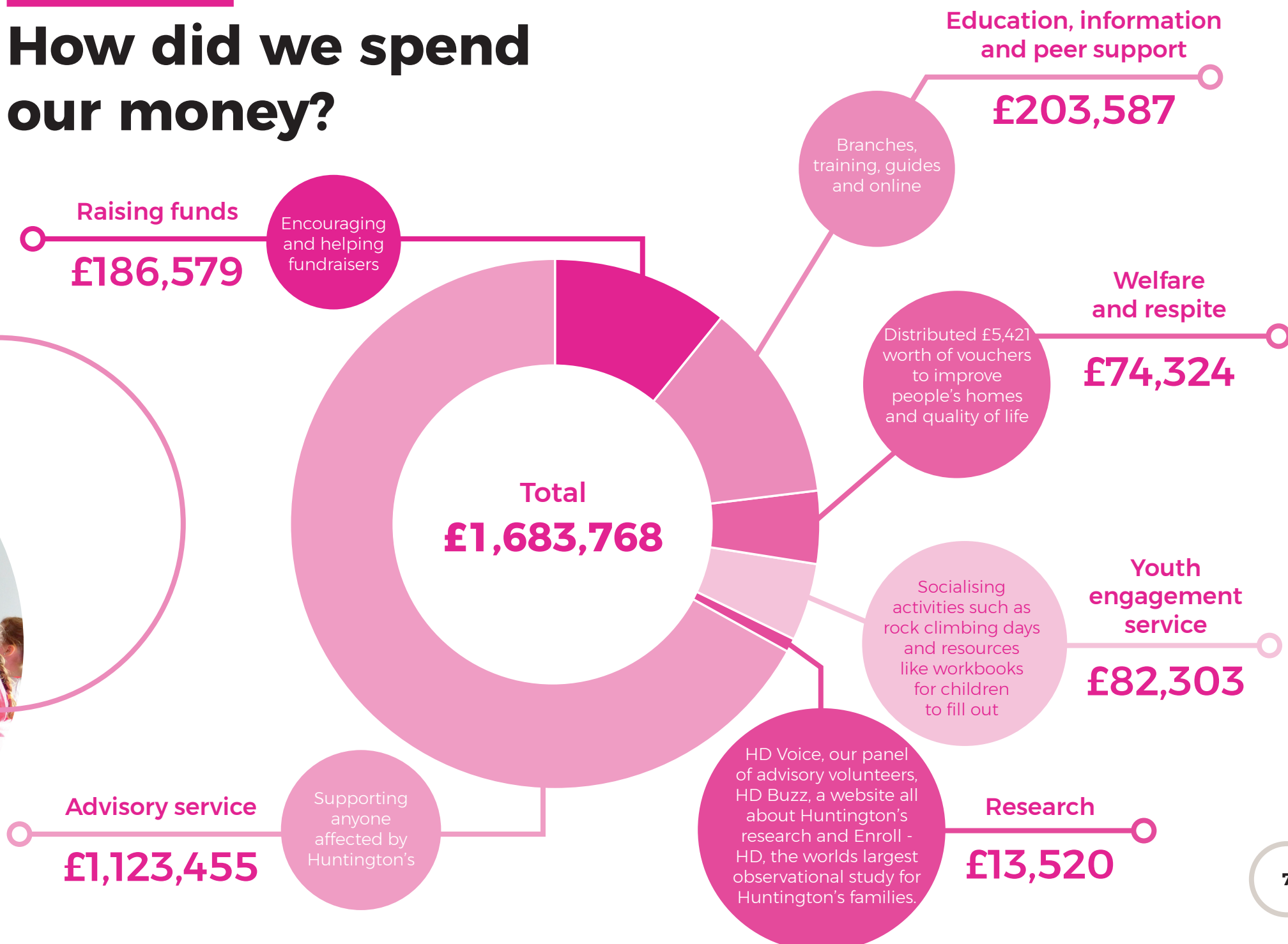


Funding of research studies that aid in the support and care of people affected by Huntington's disease now

Where did our money come from?



How did we spend our money?



Let's talk who we were there for in 2019...

55%

55% of those we supported were people with Huntington's disease. That is 2,692 people.



We offered advice and guidance to over 1,000 health professionals.

1,371

1,371 people we helped were carers, that is 28% of those we support.



We helped and advised over 1,700 fundraisers through their fundraising events and challenges.

5%

5% of young people and young carers were offered advice and support. That is 247 young people.

No matter what, we'll educate, support and care...

1046

In 2019, we delivered 154 training sessions to 1046 health professionals.



100% of those professionals said that they felt the quality of care they provide improved after training.

£5,421

We distributed £5,421 worth of vouchers to improve people's homes and quality of life.



Our website was viewed 480,051 times with our 'What is Huntington's disease' page being the most popular at 39,750 views.

17,500

By the end of 2019, our social channels were followed by over 17,500 people.

Lets talk events

The Volunteer Fundraiser Awards 2019

Our fourth volunteer fundraiser awards ceremony was one of the best yet! Nominees came from all over the country to join us for a meal and ceremony to celebrate the achievements of our fundraisers and to say thank you! In 2019, we had two categories from which winners were chosen. Our adult's category, Most Inspiring Volunteer, was won by Rosie Allen and Jo Hague, and our children's award, Young Volunteer of The Year, was snapped up by Eli and Isaac Greer.

"In 2019, we played the piano and sang during three one-hour slots over the summer outside John Lewis as part of 'Tickle the Ivories' at Liverpool ONE. It went really well and we were very thankful for everyone's generosity. Despite the wind and rain during two of our slots in 2019, we raised £577.59 and, with additional donations (including online), we raised a grand total of £766.59. The awards ceremony was a really special occasion - we stayed up really late and enjoyed the disco. We were really pleased to be nominated and couldn't believe it when we won! Learning about how Huntington's disease can affect families and the support offered by the Huntington's Disease Association to help them. We were really happy that we have been able to do a little bit to help." – Eli and Isaac Greer, Young Volunteer of The Year winners



Family weekend

We had a fantastic time at the Family Weekend this year. There was a wonderful turn out and an abundance of educational workshops, lectures and talks. Let's not forget our Disney themed party on Saturday evening! This event gave those affected by the disease a chance to meet others in a similar situation while discovering what's new in research, support and care. We also carried out our AGM where the floor was opened up to questions for our trustees.



Let's talk Specialist Huntington's Advisers

Our specialist advisers are located across England and Wales and support anyone who is affected by Huntington's disease at any stage of their Huntington's journey. This includes people living with the disease, people at risk of inheriting the disease, family members, carers, and young people. They can even advise friends, neighbours, employers and medical teams. Our advisers work to help those affected by Huntington's live their life to their full potential.

What they do

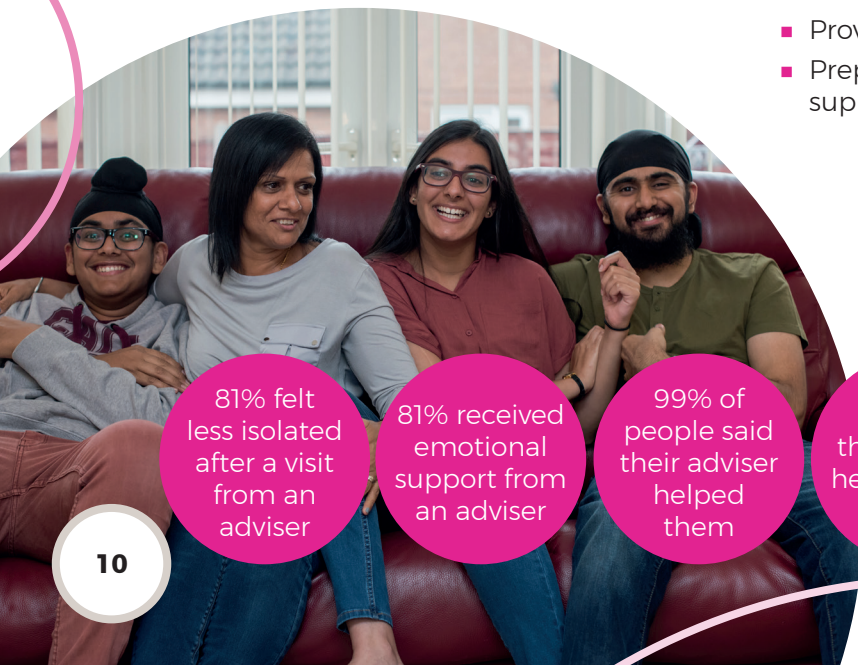
- Face to face visits
- Dedicated telephone helpline
- Training sessions for professionals
- Local support and advice events
- Attendance at specialist clinics and multidisciplinary team meetings

How they do it

- Guidance on life with Huntington's
- Emotional support
- Financial advice
- Pinpointing helpful resources and organisations
- Educating professionals on Huntington's
- Being an advocate for the person with Huntington's
- Coordinating support with medical, health and social care professionals
- Making referrals to specialist Huntington's disease clinics
- Provide a listening ear
- Preparing people for the future and giving support on sensitive end-of-life care

The support our Specialist Advisers carried out in 2019 impacted the Huntington's community in a variety of ways. From being that someone to turn to when in need, to offering comprehensive emotional and informational support, and helping to coordinate all the people involved in someone's care. Not to mention the training courses they carry out, educating professionals and improving the quality of care Huntington's patients receive in hospitals, care homes, schools and more.

"Our adviser has been such a source of help. I really think she is of so much benefit to my husband, who has the illness, in helping him understand his condition. And emotionally, for both of us, in dealing with the disease. She also advised on practical things, helping us realise the financial benefits we have been able to successfully claim."



81% felt less isolated after a visit from an adviser

81% received emotional support from an adviser

99% of people said their adviser helped them

43% said their adviser helped them in a crisis

"Our adviser was a shoulder to lean on and I was able to vent my frustrations with her at a very difficult time."

Who we supported in 2019

People with Huntington's – 2692 – 55%

People with Juvenile Huntington's – 56 – 1%

People who tested negative for Huntington's – 63 – 1%

People at risk – 491 – 10%

Carers – 1371 – 28%

Young people and young carers – 247 – 5%

Let's talk peer support

Branches and support groups

We have around 50 branches and support groups across England and Wales. Groups meet up and down the country for a mixture of social activities, information sessions, fundraising, awareness-raising and a good chat. Our branches and support groups are run by volunteers and offer the ability to meet others in a similar situation and to learn from first-hand experience.

In 2019, we developed the branch and support group pages on our website to improve the way information is communicated and to better reflect what each individual group offers. Including, meet up information, events, contact details and photos. This update also makes it easier for people to find out about peer support opportunities in their local area.

HD Voice

HD Voice is a panel of volunteers who help us learn about the needs of families living with Huntington's. They work together via two panels, the research panel and the reader panel, on different projects to help make sure information, literature and research have the biggest impact on people affected by Huntington's and best represents their plights.

In 2019, the group reviewed guides, commented on projects and online resources, gave feedback to researchers and made sure the voices of those affected by Huntington's were heard. HD Voice is vital to meeting the needs of those affected Huntington's in enlisting the Huntington's community themselves to advise. HD Voice is also a place for volunteers to meet others in a similar situation, join a proactive community of people and play an important role in influencing the work of researchers and the Huntington's Disease Association alike.

Online

- Message board
- Social channels
 - f @hdauk
 - t @hda_tweeting
 - i @hdauk
 - in Huntington's Disease Association
- Website

Our online resources offer access to instant information and support. Our website is available 24/7 and houses reams of information on Huntington's, it also signposts to other organisations who can help. Being able to access information and support at the click of a button can be a lifeline to those affected by Huntington's. It allows people to access information when they need it, connect with others who understand, reduce feelings of isolation and find support even if they are unable to leave the house.

Decisions, dilemmas and discussions –

Held in March, this event is for young adults aged 18 – 35 years who are affected by Huntington's. Throughout the day, attendees took part in workshops that covered topics such as genetic testing and options for having children.

Inbetweeners day –

Held in February, this event is for those who are considered to be in the 'Inbetween' stages of their Huntington's journey, ages 35 – 45 years. In 2019, the day covered topics such as mind, body and wellness, forward planning, question and answer with a neurologist and 'has anyone experienced...' sharing ideas and experiences.

JHD Weekend –

This June event is a staple for our summers. Aimed at people with Juvenile Huntington's and their families, the weekend is host to an array of exceptional activities like abseiling and canoeing! In 2019, the event was Held at the Calvert Trust where people of all abilities participated in exciting outdoor activities and enjoyed a themed party on the Saturday evening!

In 2019, our events offered those affected by Huntington's disease the possibility to meet others in a similar situation to them while learning must-have information about life with Huntington's. As our events are targeted at different age groups, topics are chosen accordingly. This means that people in earlier stages of the disease aren't given information that would be best shared at a later date.



Let's talk training

We work hard to not only support those affected by Huntington's disease but to educate professionals who work with them. Due to the rarity of Huntington's, medical professionals do not always recognise symptoms or know how to treat them and this can lead to misdiagnosis. There are also a mass of professionals, such as social workers, school teachers and physios, who will be involved in the care of one person affected by Huntington's, so we work to help each one understand the disease fully and offer advice on care, support and other organisations that supply information on the disease.

Key training topics –

- General Huntington's information
- Behaviour and cognitive changes
- Eating, swallowing and mobility
- Advances in research
- How to discuss the disease with loved ones



In 2019, we delivered 235 training and information sessions to 1754 professionals

The impact our training and information sessions had on professionals ranged from making them more aware of how people affected by Huntington's might feel and behave, to educating them on the important factors they should consider when caring for someone with the disease, such as dysphagia, diet and apathy. They were given the tools needed to improve the standard of care people with Huntington's receive and the knowledge to share with their colleagues.



"Today in the training session, I learnt that Huntington's disease patients can have a good quality of life when their needs and changes can be understood. Also, a better understanding of what people with Huntington's disease are going through and how they process information."

After our training session...

100%

100% said that they felt their quality of care will improve

100%

100% said that their knowledge and understanding of Huntington's had improved

100%

100% said they now know where to find out further information about Huntington's

EDUCATE

Let's talk resources for professionals

Our website -

Full of useful and accessible Huntington's information at the touch of a button. We also house our new suite of guides here which offer in-depth information and support on working with Huntington's patients. In 2019, several of our professional webpages were very successful, for example...



'Best practice in Huntington's disease' was viewed 5,108 times.



'Huntington's disease training courses' was viewed 1,838 times.



'Medication for Huntington's disease' was viewed 1,304 times.

Our professional guides -



'A Guide to Huntington's Disease for GPs and Primary Health Care Teams' was downloaded 218 times.



'Mental illness and mental capacity in Huntington's disease: A guide for mental health workers' was downloaded 154 times.



The information on our LinkedIn is tailored to professionals, why not check it out!

Social channels -

Our social channels are an excellent place for information sharing. In 2019, professionals came to learn about the latest events, information and research updates whilst using our posts to spark conversation and debate with other professionals in the field. We also allowed researchers and university students to promote studies which are recruiting those affected by Huntington's. This allowed those affected by the disease to be involved in developing research and helps those in education progress.

Huntington's disease certificated course

In 2019, we ran two in-depth certificated courses for professionals. The course allowed professionals working with those affected by Huntington's to meet, develop a deeper understanding of the illness, share ideas and discuss the management of complex situations. In 2019, professionals in the field presented on topics such as genetics, psychiatric problems, oral care, physiotherapy and end of life care.

"I have learnt so much from this training and feel confident that the understanding I now have will improve the support my team will give to Huntington's disease sufferers we support."



Let's talk ways we went digital in 2019

As we descend deeper into the information age, we are embracing digitised information that is readily and easily accessible to all who have access to the internet. In doing this, we are also aiming to reduce our carbon footprint and negative impact on the planet.

1

We made this specific document only available online unless a hard copy was requested. This cut down on printing and reduced our paper wastage. This is beneficial to the charity and its users as we were able to save money that could be reallocated to further supporting those affected by Huntington's.

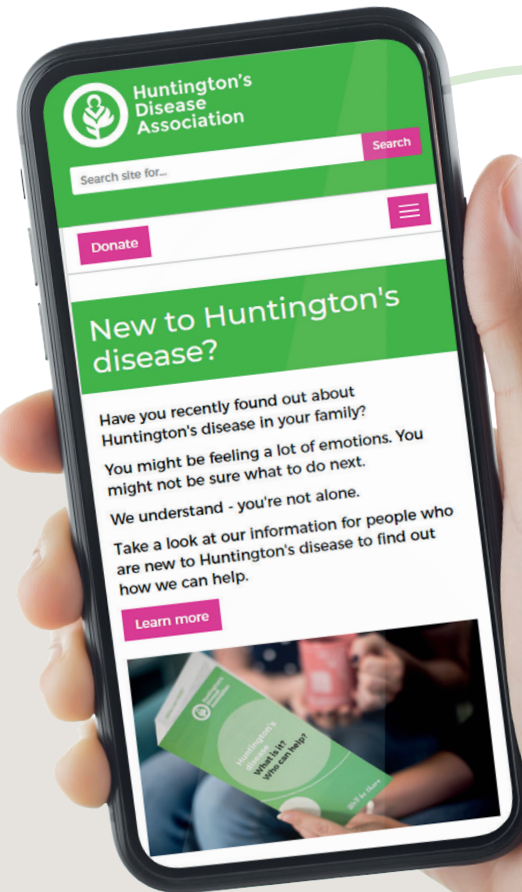
2

In 2019, our advisers used social media, texting and technology a lot more to communicate with those that use our services. This made communication easier as it opened a whole array of platforms in which our advisers could offer support and reduce feelings of isolation. It also allowed for those affected by Huntington's to communicate in the way they found most comfortable, whether over the phone, via text, email or using social media.

3

The launch of our new blog in 2019 brought targeted, easy to understand and enjoyable content to our users. Each blog was written with those affected by Huntington's in mind, they gave a concise, dynamic, visual and shareable

representation of helpful information and support. This type of information is more easily digestible and allows for guest authors to write about their experiences of Huntington's, enabling the community to learn from each other. Professionals also featured on the blog with in-depth, medically driven pieces, giving professional standard information that the community may otherwise not have been privy to.



Awareness month

In 2019, we changed our usual Huntington's disease awareness week to a whole month! This opened up new levels of opportunity, giving more time for the charity and the Huntington's community to work together to raise awareness of Huntington's disease. Our key focus in 2019 was raising awareness around being a Huntington's carer.

Together as a community

Once again in 2019, we collaborated with Huntington's charities all over the world to #LightItUpForHD. The Huntington's community were fantastic. They contacted buildings and landmarks all over England and Wales and asked them to light up in our brand colours during May 2019 to raise awareness of the disease. This enabled the Huntington's community to be active in our awareness campaign and made local communities more aware of Huntington's. We sent out awareness packs that gave helpful materials on how to approach buildings, publicise #LightItUp4HD and raise awareness. In 2019, over 20 buildings across England and Wales lit up in pink and green and we succeeded in getting several online news articles published relating to the #LightItUp4HD campaign.

The public were also able to light up their own homes or workplaces with our Light It Up packs, which included a coloured tea light and other useful materials. The pack was perfect for those



Weymouth Pavilion



Althorp Estate

who could not leave their homes or were not able to take part in requesting building or landmark light-ups. Inclusion is important to every endeavour we undertake and we are glad that we can work so closely with the community on campaigns such as this.

But the community didn't stop there, together we made our voices heard using social media. The community shared their Huntington's stories online using the hashtags #LetsTalkHuntingtons and #HDAwarenessMonth and they rose to the occasion. We also offered a frame for people's profile pictures to show support.

Solidarity as a charity

As a charity, we supported the communities amazing efforts by creating a suite of resources throughout awareness month that aimed to both educate and influence. We shared the personal stories of those affected by the disease to show the general public how hard the disease can

be and what it means to live with Huntington's. We also created infographics that gave simplified information on what Huntington's is and how the Huntington's Disease Association can help. This content not only raised awareness online but acted as a powerful tool that showed those affected by Huntington's that they are not alone while giving useful information on living with the disease.

Across the country our specialist advisers held multiple carers events to educate and raise awareness, our Carer's guide was launched and our volunteer fundraisers held fundraising events to raise money for our work. In 2019, awareness month offered up the potential for peer support via our social channels, helped urge people to break the secrecy and stigma surrounding the disease and brought people together to raise much-needed awareness.



Let's talk policy

National Institute for Health and Care Excellence

In 2019 we submitted Huntington's disease specific evidence to the National Institute for Health and Care Excellence (NICE). This was part of NICE's consultation and review of social care in complex illnesses. We submitted this evidence to help promote best practice care for people with Huntington's disease. This type of work helps to ensure Huntington's patients are supported and given the correct information from the very beginning of their care. Engaging with influential institutions such as NICE moves Huntington's into the light, impacting those affected throughout the whole of England and Wales.

Department of Work and Pensions

In 2019, we worked closely with the Department of Work and Pensions (DWP) to improve the journey people with Huntington's follow when applying for Personal Independence Payments (PIP).

Firstly, we provided an 'Insight into Huntington's' report as reference for the Independent Assessment service and Capita assessors when dealing with Huntington's specific applications. We hope that this provides a better understanding of the condition from the outset.

Secondly, we worked with the Independent Assessment Services (IAS) on a training programme that was rolled out to all of their assessors during the year and, with the support of Capita, developed a pack to help Huntington's families fill in PIP paperwork.

We hope that by working with the DWP in this way, we have increased understanding of Huntington's disease, made the process smoother for families applying for PIP and helped them to obtain the financial assistance they are entitled to.

UK Strategy for Rare Diseases

We worked alongside Rare Disease UK during the year to urge the Government to review and update the UK Strategy for Rare Diseases before the end of 2020 as the current strategy is based on out of date technologies, policies and systems.

Together with 125 other patient organisations, we signed an open letter to the government presented to the Minister in charge of rare diseases, Baroness Nicola Blackwood. This was coupled with a request to meet and discuss the review, to ensure patients and families affected by rare diseases play a key role in the development of future plans to ensure services, treatment and support are of the highest quality and adequately meet needs.

Working with the government and highlighting outdated information within their strategies impacts the Huntington's community in many ways. It urges the government to improve their practice and create overall better services. Every case of Huntington's disease is different and this is something that must be acknowledged and accommodated. Having the Huntington's Disease Association involved in the review of the UK Strategy for Rare Diseases ensures this is considered.



Let's talk research

At the Huntington's Disease Association, we are committed to supporting several different research studies that aid the support and care of people affected by Huntington's disease. The research we support looks at how we can help people affected by Huntington's disease now, with a focus on learning about the disease and treating symptoms.

Enroll - HD

Enroll - HD, the world's largest observational study for Huntington's disease families. This project helps scientists gain a better understanding of Huntington's directly from those affected and their families. We were delighted to continue supporting and promoting this project in 2019 as it aims to build a comprehensive and extremely valuable database of information and a body of evidence which will be available for use by Huntington's researchers worldwide. Enroll - HD is also used for identifying which volunteers may be suitable for forthcoming treatment trials. Enroll - HD is invaluable to those affected by Huntington's and impacts their futures by providing in-depth information about the disease itself. It also makes the process of finding people for studies easier, quicker and more reliable.



HD Voice

Our voluntary patient and public participation group, HD Voice, continued to advise on several important projects in 2019. This included market research with large pharmaceutical companies and a European health project. They also provided information for Cardiff University's 'DOMINO HD', a study looking at how digital technologies, like fitness trackers, can be used to support people with Huntington's, and University College London's 'Origin HD' study looking further at the genetic factors that impact people with Huntington's and future generations.

We continued to have HD Voice representation on the international Patient and Public Involvement group, 'HD Cope', providing a Huntington's family perspective to both national and international research trials. HD Voice is imperative to highlighting the perspective of someone who is living with Huntington's, therefore enabling better quality care and research studies.

HD Buzz

HD Buzz provides Huntington's disease research news, written by scientists in plain language for the global Huntington's community. We were pleased to continue our financial support of HD Buzz in 2019. HD Buzz is a website dedicated to providing up to date information about Huntington's research from around the globe and is a valuable resource for the Huntington's community.



"HD Voice is a fantastic initiative whereby the Huntington's Disease Association connects members of the Huntington's community with researchers working across the health and social care spectrum in true partnership. By listening to the experiences of those who live with the disease, we can better design and deliver truly impactful research. The members of HD Voice whom we speak to and involve in our research tell us that they appreciate being able to share their experiences knowing that it will make a difference to the future generations." -

Prof Monica Busse - Director of Mind, Brain and Neuroscience Trials, Cardiff University

Let's talk project work

Updated suite of guides

In 2019, we continued with a project to review and update our written advice and support resources to provide easy to read and informative guides for professionals and families affected by Huntington's disease. 2019 saw the relaunch of two guides for professionals – a guide for mental health teams and a guide on care in advanced Huntington's disease. Content was re-written in line with legal and professional practice and in a format that better explains the complexities of Huntington's in an easy to understand way. The guides will act as a go-to for Huntington's professionals. We hope the guides will promote best practice and provide healthcare professionals with all the information they need.

Huntington's animation

As part of Breaking Down Barriers, a project funded by the Sylvia Adams Trust, we produced an animated video about Huntington's, its impact on families and the support we can provide. From the perspective of one of our Specialist Huntington's Disease Advisers, you see how Huntington's can affect a whole family and what methods our advisers use to help and support families. The video helps viewers learn about other services who can also offer information, support and advice. This video is a fantastic resource for the Huntington's community as it describes our work in an accessible format that is easily understood. It answers any immediate questions newcomers to the charity may have, encouraging people to access further support and care. In 2019, the video was viewed 993 times from six different countries.

Care Home Accreditation scheme launch

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 that provide excellent care to those affected by Huntington's disease. This scheme aims to help the Huntington's community when having to choose a care facility. In 2019, we were thrilled to bring two fully accredited care homes on board. Fairburn Mews in Castleford, the first care home to be accredited in England and Yr Ysgol, Swansea, the first of Wales' accredited care homes!

Accreditation is a way for care homes who invest significant time, resources and commitment in care for people with Huntington's, to show this to the Huntington's community and benchmark the standards of care they offer. This makes it a lot easier for those affected by Huntington's when choosing a care home and gives families peace of mind that their loved one will be cared for well.





Susan Lewis-Ball, manager at Yr Ysgol, Swansea, said:

"Here at Yr Ysgol, we were delighted to be the first independent Care Provider in Wales to undertake the Huntington's Disease Association's accreditation process. The process was thorough, comprehensive and ultimately rewarding, giving us the opportunity to lead the way in providing an excellent service for those living with Huntington's disease. Our staff and service users played an integral part in our journey and enjoyed sharing their stories and contributing to a new and exciting project."

"Accreditation is vital for facilitating the quality of care provided and giving confidence to the service users and their families that their quality of life is paramount and at the heart of everything that we strive to achieve."

BUPA UK Foundation Older Carers Project

In 2019, we were awarded funding by BUPA UK Foundation to create an online area to support older carers aged 65+. The 'Older Carers Project' aims to improve the well-being of older carers while offering them peer support from the comfort of their own home and access to easy to understand resources. This project will include a whole section of our website dedicated to resources and support for older carers, including guides, videos, helpful audio clips and a dedicated message board area named the 'Pop-in-café'. There will even be helpful booklets that guide carers through using the website for the less tech-savvy among us.

In 2019, we launched the 'Pop-in-Café' section of the website. It is run through the Huntington's Disease Association message board and is managed, moderated and read by staff from the Huntington's Disease Association. It acts as an online place for people to access peer support, ask questions and take part in general chit chat. The café offers anonymity, so users can discuss any issue without judgement or divulging who they are.

Barry Mackintosh, former older carer and a project focus group member said:

"As an ex-older carer, and someone with another older carer in the family, I recognise many of the difficulties we discussed and welcome any initiative to provide more tailored information and support."

"It isn't possible to be alongside carers all the time so we have to take advantage of technology solutions wherever possible to provide this information and support. It won't answer everyone's needs immediately, but as the population of older carers become more tech-savvy over time, the benefits will grow too."



Let's talk Huntington's in the media

As part of our long term goal to raise awareness of Huntington's disease, we aim to feature information about the disease in the media. In 2019, the Huntington's Disease Association were approached by several members of the press to interview for news articles and television segments. We also worked hard to make sure members of the press were linked up with people affected by Huntington's so that the communities voices were heard. This ensured those eager to be advocates for the disease had the opportunity to tell their story and make a difference. We did frequent call-outs on social media, giving our followers the opportunity to be involved.

The Huntington's Disease Association in the media

BBC News – Gene silencing

In July 2019, our Chief Executive, Cath Stanley, appeared on BBC news to discuss gene silencing, a means of downregulating (or 'turning off') particular genes, in Huntington's disease. This was in the wake of the introduction of a new gene silencing drug to the NHS which is to be used to reverse a disease called amyloidosis.

Victoria Derbyshire Show – Genetic testing

In October 2019, we appeared on the BBC the Victoria Derbyshire Show. On the show, two sisters were interviewed about genetic testing in Huntington's and how one sister wanted to be tested and the other did not. Our Chief Executive sat on the panel as an expert in Huntington's to give non-biased information on testing.

BBC Three Counties Radio – Oxford becoming Roche site

Our Chief Executive spoke on BBC Three Counties Radio in November concerning the news that an Oxford hospital became one of the sites for the Roche gene silencing trial. She discussed Huntington's and the work of the charity while someone affected by the disease spoke about the opportunity of being on the trial. This helped the public learn about the difficulties of Huntington's and what it means to be part of a trial.

Huntington's disease in the media

Emmerdale

Character, Lydia Hart, was involved in a Huntington's disease storyline on Emmerdale in 2019. She discovered that she may develop the disease after coming face-to-face with her long-lost mother who explained that her father died from the disease. This type of true to life feature was brilliant for raising awareness of the disease in the UK.

Pointless

Comedy actress and impressionist, Jess Robinson, appeared on Celebrity Pointless in support of the Huntington's Disease Association alongside actor Mark Benton. All money won by Jess was donated to us. This was a fantastic way to raise both awareness and funds.



Huntington's Disease Association magazines and newsletters

In 2019, we released two Huntington's Disease Association specific publications. One was our yearly summer magazine that featured the love story of two jet-setters and discussed topics such as research, genetic testing and top tips on oral health. A few months later, we released our winter newsletter. This was a smaller publication that gave a summary and update of goings-on at the charity including, advice on supporting a Huntington's carer, fundraising ideas and tips on supporting friends with Huntington's.

These publications are imperative to keeping the Huntington's community abreast of charity and worldwide Huntington's updates, to give advice and to learn from others affected by the disease. They also act as a tool to show others that they are not alone and how to access support.



In 2019, we launched a new hashtag, #LetsTalkHuntingtons. This hashtag is used across all of our social channels to highlight content that is related to Huntington's disease. We urge all our supporters to use this on their social posts too! This helps raise awareness of the disease online and helps to connect people within the Huntington's community.

Let's talk community fundraising

We are extremely proud of all of the supporters who fundraise for the Huntington's Disease Association. Our community fundraisers worked tirelessly throughout 2019 to raise awareness and funds while taking on both physically challenging and extremely fun endeavours!

In 2019, our community fundraisers took on...

- Marathons
- Bike rides
- Bake sales
- Hikes
- Overseas challenges
- And more...
- Skydive

Do it for Dom

If you're looking for inspiration for your next fundraising venture, then look no further than Do it For Dom. Do it for Dom are a group of estate agents, agencies and landlords who have all come together in support of a fellow estate agent, Dominic Subbiani, who was diagnosed with Huntington's disease a few years ago. Upon finding out about the diagnosis they wanted to band together to help raise money to support our work.

In 2019, Do it for Dom took part in a two-day canoeing marathon along the River Wye which ended with an evening mini-festival in Ross-on-

Wye. The festival included a barbecue, stand-up comedy gig, a charity auction and games all of which helped to raise more funds. The event was a huge success with over £60,000 raised.

Do it for Dom is the perfect example of exciting and sociable ways to fundraise. The impact this kind of community fundraising has on the Huntington's community is exceptional. In 2019, Do It For Dom inspired others to fundraise and take part in fundraising activities. They have shown what dedication and love for a friend can achieve.

Incoming!

In 2019, we released a brand new fundraising e-newsletter entitled 'Incoming!'. Published four times in the year, the newsletter contained information on our fundraising work, shared fundraising stories to inspire readers along with different ways in which people can support us. We will continue to develop the newsletter for the coming year. Last year the fundraising newsletter helped keep our fundraisers up to date and inspired others to fundraise for us.



Let's talk company support

We were lucky to be supported by several companies in 2019, all of whom worked hard to host fundraising activities and raise funds for the Huntington's Disease Association. Without this dedicated sponsorship, we would not be able to provide the level of support we were able to offer to the Huntington's community last year.

FMP Global

"FMP Global chose to support the Huntington's Disease Association in 2019 because we as a company are passionate about the work that they do. An ex-employee, who has remained close to the business through colleagues and friends, has a personal link to the disease and we wanted to show our support to him and his family. We raised over £20,000 over the course of the year in a variety of ways, including bake offs, samosa sales, raffles, quiz nights, selling FMP-branded doggy bandanas, a Guinness World Record attempt day and an epic bike ride from Paris to Chichester, which finished at a

Summer party funfair hosted by our then-CEO, Justin Cottrell, at his house! Every single FMP employee threw themselves into fundraising during 2019, whether they hosted an event, took part in one or encouraged and cheered their colleagues on! We are thrilled with our grand total and are delighted to know how much our efforts will help those affected by Huntington's disease, their families and their friends"

– Jocelyn Levy, Senior Marketing Executive

Marks and Spencer, Edge Lane, Liverpool

We collaborated with Marks and Spencer, Edge Lane in 2019. By carrying out a book sale honesty stall and taking on individual staff fundraising, the Marks and Spencer store proved to be a fantastic addition to our supporters.

Let's talk Trusts and Foundations

Trust and Foundation support is imperative to our work. They provide much-needed funding to improve the information we provide and the support we can offer.

James Tudor Foundation

The Foundation has made three awards to the Huntington's Disease Association since 2016, the most recent being £10,000 awarded in 2019 to support the work of the local Specialist Advisory service in Bristol and South Gloucestershire.

"This post fulfils an important role in supporting those affected by Huntington's and their families. We have been very pleased to support this role and have received exceptional reporting and engagement from the Huntington's Disease Association, something that is much appreciated by The Foundation's trustees."

– James Tudor Foundation

The James Tudor Foundation's generous award meant that our Advisory Service was able to offer dedicated support to those living in the Bristol area in 2019.



50@50 – Helen's true celebration of life

In 2019, Helen Owen took on the fundraising venture of a lifetime all in the name of Huntington's disease. 50 challenges, in 50 weeks to celebrate turning 50. Helen's husband, Simon, was diagnosed with Huntington's disease in 2015 and since then Helen has become his primary carer and a fundraising fanatic! Below, you can discover why Helen decided to fundraise, what she's learnt on her journey and her reflections on what having a partner with Huntington's means to her.

What motivated you to start fundraising?

"I have been fundraising for more years than I care to remember, for lots of different organisations. I don't really know what drives me to fundraise, just that feeling sometimes of hopelessness in not being able to help a cause or someone who is suffering – fundraising sometimes feels like the only thing I can do."

What was 50@50?

"Well, I was originally going to 'Brave the Shave' for my 50th birthday and raise some funds that way but Simon said he wouldn't let me back in the house so I had to come up with an alternative. My niece-in-law recommended lots of mini-challenges and that's when I decided to do 50 challenges / activities in 50 weeks to celebrate my 50th birthday.

It took a while to decide on all the challenges and activities with some of them being much more demanding in time / cost and my own courage factor, but most of them I could do with family, friends and especially Simon. This meant that at the same time as fundraising, I could build loads of memories with Simon, making an album up at the end for me to keep and look back on. We tackled anything from...

- Completing a 3D jigsaw
- Soaring through the air doing the longest zip wire in Europe
- Baking cakes I had never made before and selling them on CakeThatHD! day
- Both of us holding a tarantula
- Trying falconry
- iFly the indoor skydiving experience
- Simon trusting me enough to be a passenger when I flew a plane
- Helicopter rides
- Driving a tank
- Getting lost in a maze plus so many more!"



How did this experience help you?

"Nothing makes it easy to watch someone we love decline cognitively and physically in front of you, nothing takes away the agony of seeing them change from the individual that you fell in love with. How would you feel if you were losing control of your body, mind and independence? I don't feel I would be handling it as calmly as my Simon is. Coming up with imaginative ways to spend days together doing normal and extraordinary activities helped us get through just a small part of the journey we are on, making memories for today, tomorrow and the future is an amazing way to survive. We felt exhilarated and scared but mainly enjoyed the world together. Suddenly we were husband and wife again and nothing else mattered for those few seconds, minutes or hours."



What did you learn from your fundraising experience?

"Subconsciously, I now realise, that I was looking for a way to feel normal again I had already consciously acknowledged that being a caregiver was challenging and life-altering. I didn't and still don't know what the do's and don'ts are when caring for someone with a life-changing illness but I was already feeling more of a carer than a wife. Having the complicated emotions, setbacks and trying moments, feelings of inadequacy to manage, this experience helped me escape that often exhausting feeling of treading water and sinking under the stress and pressure of day to day life living with a partner with Huntington's. Caring for a loved one strains even the most resilient of us."

What were the challenges of your adventure?

"Sometimes, I wished I hadn't started it as my stress levels went through the roof. I worried about Simon's capabilities and my capabilities, then on top of that the draining task of constantly needing to repeat to Simon again and again what we had planned. But with love, patience and letting the role of wife and life partner kick in, experiencing the adrenaline kicks post-challenge and seeing the smiles on our faces, made me so glad that my niece came up with an alternative to cutting off all my hair. Now we have those special moments, laughter, tears, memories, stories and photos to look back on."



What was the most positive thing to come out of your fundraising challenge?

"A couple of things, as always the generosity of family, friends and individuals I have never met and may never meet. Also, gaining the courage to overcome one of my biggest fears in life but most of all the special memories that we made with Simon."

Helen raised over £2,000 in 2019 through her 50@50 fundraiser. This is fantastic and helped the Huntington's Disease Association carry on supporting those with Huntington's disease. But something that we can also learn from Helen, is that fundraising is not just about making money. You can learn, grow and make incredible memories with friends and family, not to mention challenging yourself and realising your resilience as a carer or as someone affected by Huntington's disease.



Let's talk future plans

We have many ambitions for 2020 to continue our vision of creating a better life for anyone affected by Huntington's disease. Here are just a few of the things we are planning.

In 2020, we will see a greater focus on improving quality of care and our support resources. We will focus on educating people about Huntington's, creating more opportunities for community involvement and supporting research into Huntington's disease so that one day a cure can be achieved.

We plan to create our youth support provision further with plans to develop a guide to help adults talk to younger children about Huntington's and provide further peer support opportunities.

Work will continue on the creation of a new suite of guides for families affected by Huntington's disease. These guides will be providing families with in-depth information on several key areas including genetics, nutrition, symptoms of Huntington's disease and behaviour management strategies.

We will develop our digital and online technology over the next year. We want to improve the content and navigation on our website, further develop our social media channels to supply advice, support and interaction, use ENewsletters to communicate important information and utilise telephone and online tools to provide specialist Huntington's advice and improve our reach.

We want to increase understanding of Huntington's disease further and plan to explore ways to improve our training packages and guides for health and social care professionals and increase our media presence and visibility to raise awareness of Huntington's with the public.

With the HDA Quality Assured care home accreditation scheme pilot concluded, the scheme will be open for applications from care homes in England and Wales over the next year. We hope this scheme will go a long way towards improving the standard and quality of care people with Huntington's receive and provide them and their family members with reassurance when choosing a care home.

We want to grow our partnership working with the pharmaceutical companies, researchers, data analysts and policy influencers we forged links with in 2019. We hope to work together over the next few years to build evidence about Huntington's disease and its physical and monetary impact on people, services and public funds. This data collection is imperative to help smooth the rollout and access of any potential future treatments for Huntington's disease.



THANK YOUS

Thank you

- 29th May 1961 Charitable Trust
- Alice Ellen Cooper Dean Charitable Foundation
- Avast Foundation
- Baron Davenport Charity
- BBC Children in Need
- Birmingham City Council
- Blackburn with Darwen Clinical Commissioning Group
- Bruce Wake Charitable Trust
- Bupa UK Foundation
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- Chapman Charitable Trust
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- Friarsgate Trust
- Garfield Weston Foundation
- Gay & Peter Hartley's Hillards Charitable Trust
- Genetic Disorders UK
- Hedley Foundation Limited
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- John Martin's Charity
- Maud Elkington Charitable Trust
- Milles Charitable Foundation
- Milton Damerel Trust
- NHS Devon Clinical Commissioning Group
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- The Hospital Saturday Fund
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- The Sunrise (Sidmouth) Charitable Trust
- The Tanner Charitable Trust
- The Ursula Keyes Trust
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THANK YOUS

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- Cuthbert's Bakehouse
- Morrison's Belle Vale
- Ian Preedy
- Alex Reid
- Everyman and Playhouse Theatres

Our people

Patrons

- Tony Hadley
- Shane Richie

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- Mr Nicholas Heath (Treasurer)
- Dr Elizabeth Howard (Vice Chair)
- Prof Hugh Rickards
- Mr Matthew Ellison
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- Mrs Cathy Lyon
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Partnerships and affiliations

- Association of Medical Research Charities
- Genetic Alliance UK
- NCVO
- Institute of Fundraising
- Charity Comms
- HD Buzz
- HDYO
- International and European Huntington's Associations
- National Council for Palliative Care
- Neurological Alliance
- The United Kingdom and Ireland Huntington's Alliance





**Huntington's
Disease
Association**

Get in touch

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Get involved

Contact our fundraising team

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*"The Huntington's Disease Association
aim to improve care and support
services for people with Huntington's
disease, educate families and
professionals, and champion people's
rights. We work to support those
affected by Huntington's disease today,
whilst aiming to provide a better life
for future generations tomorrow"*