Huntington's
Disease
Association

Making a difference

Annual Review 2016-17

We'll be there

> "I rang for help when my father was very ill. The Specialist Huntington's Disease Adviser came with help and advice, and visited him at his care home. She supported us and our decision to get him into hospital, which saved his life. She was there to help and guide us, and the staff. She was invaluable. I am so glad I rang the HDA that day. Without her help I am not sure my father would still be with us."

Contents

You'll notice we look at bit different to our previous publications. We've started work to develop and modernise the look and feel of the Huntington's Disease Association. This has been made possible thanks to some generous pro bono support. By doing this we're aiming to connect better with the people we support and to reach new audiences. Keep a look out for more to come!

Introduction

Supporting families affected by Huntington's disease (HD) has and always will be the priority of the Huntington's Disease Association. We have achieved this in a variety of ways, including face to face support, email, video chat and our telephone helpline. We've helped to improve the standard and quality of care people with Huntington's and their families received by working hard to educate health and social care professionals.

In the face of a changing economic climate, health and social care resources are becoming even more stretched. It's more important now than ever that we work with families facing these challenges to ensure they get the services they need.

We've heard from many families about the difficulties faced when trying to find an appropriate care home for their loved ones. We've listened to their concerns and have secured funding to develop a project to increase the quality of care these homes provide, alongside improving their knowledge of Huntington's.

In an ever changing world with greater than ever reliance on technology, we've commissioned a digital agency to redesign our website. The new site will improve access and provide better information to empower people to cope with Huntington's.

It's an exciting time in Huntington's disease research. There are many research projects exploring different aspects of the disease and potential treatments, and lots of opportunities for people to get involved.

As the voluntary sector changes it is vital that the board of trustees keep up to date with current legislation and good practice, alongside having a clear plan for the strategic direction of the charity. Using an external facilitator, the board carried out a review of the charity and the direction it should take.

All our work wouldn't be possible without the amazing support of our volunteers. Whether it be our fundraising volunteers, those who run our branches and support groups, or those who help raise awareness of Huntington's in their local communities and beyond, their support is invaluable.

Andrew Bickerdike
Chair

Cath Stanley
Chief Executive

> "In the face of a changing economic climate, health and social care resources are becoming even more stretched. It's more important now than ever that we work with families facing these challenges to ensure they get the services they need."

Why we'll be there

Huntington's disease causes a variety of physical, mental and emotional symptoms which change how people think, feel, move, speak and swallow

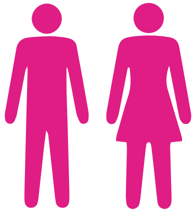
As the disease is rare, people can feel socially isolated

Huntington's disease is a genetic condition of the central nervous system - it affects the brain and spinal cord

7,120*

people in England and Wales are affected by Huntington's disease

* approx



Huntington's disease affects both men and women

It usually develops in adulthood between the ages of 30-50

There is a 50:50 chance a person will inherit the Huntington's gene if their parent has it

There is no cure but symptoms can be managed

28,480*

people in England and Wales live with a high genetic risk of developing the disease

* approx

Our year in numbers

14,237
people affected by Huntington's disease that we supported

2,433
face to face visits to support families living with Huntington's

265
young people supported by our youth engagement service

30,198
calls to our telephone helpline

56
regional branches and support groups offering peer support

397
training sessions delivered to 3,635 health and social care professionals

71,478
Huntington's disease fact sheets downloaded from our website

10,000
followers of our Facebook community

810
new members joined our online forum

We're there for families

Living with Huntington's disease is tough. It changes the whole person – body, mind and behaviour. Over time, people with Huntington's disease experience changes in their movements, behaviour and mental wellbeing.

People at risk of having the disease face difficult decisions around genetic testing. Carers and families can find themselves under huge stress.

People can feel lonely, isolated and afraid. With support and co-ordinated care, the person with Huntington's disease can keep their independence for as long as possible. Families can live a better life.

We're there so that people don't have to face Huntington's disease alone.

Specialist Huntington's Disease Advisory Service

We understand that whole families may need our support. Our Specialist Huntington's Disease Advisory Service remained our primary means of providing support during the year.

The service is delivered by our team of 23 Specialist Huntington's Disease Advisers, who are all experienced and compassionate care management professionals. Our advisers support people living with the disease, people at risk of inheriting the disease, their family members and carers.

Throughout the year, our advisers continued to:

- Deliver regular 1-1 visits at home or a safe space
- Co-ordinate support with medical, health and social care professionals
- Provide information resources on symptoms and how to manage the disease
- Make referrals to specialist Huntington's disease clinics
- Advocate for the person with Huntington's disease to get the best support
- Educate medical, health and social care professionals – meaning better diagnosis and ongoing care
- Organise and attend local support network and carers' group meetings
- Give support for sensitive end-of-life care

We're there for people when they first learn about Huntington's disease. We explain the disease and how it will progress to give families a better understanding of what's to come – and help them to cope with what's happening in the present.

We step in when families are in crisis. We help to get them through difficult times and to overcome challenges. We're there as little or as often as they need us.

> "Our adviser gives us a voice. She fights for us."

> *"I have had support from the Specialist HD Advisory Service over the last 14 years. They have been fantastic."*

Clare's story

"My dad was diagnosed with Huntington's disease just after my 25th birthday and died just after my 39th birthday. During those 14 years we watched our dad go from being the life and soul of any party to being bed ridden, needing to be fed blended food, incontinent…

"The worst for our family was how dad suffered from mental ill health. He had schizophrenia, depression, anxiety, obsessive compulsive disorder and extreme psychosis. He was extremely angry and frustrated by his situation. He even pulled a toilet out of the floor in his room in sheer rage.

"I live at risk and have a 50-50 chance of inheriting the disease.

"I have had support from the Specialist HD Advisory Service over the last 14 years. They have been fantastic. My adviser has always been there for me and has given me advice and support over the years. I cannot thank her enough.

"People need to know more about the impact that HD can have on families. I don't think there's a disease like it. I can't believe what it did to my dad.

"But every day I wake up and think, my dad wouldn't want me to be sad about the situation. I choose to be happy and positive – I stay strong every day just like my dad would have wanted me to."

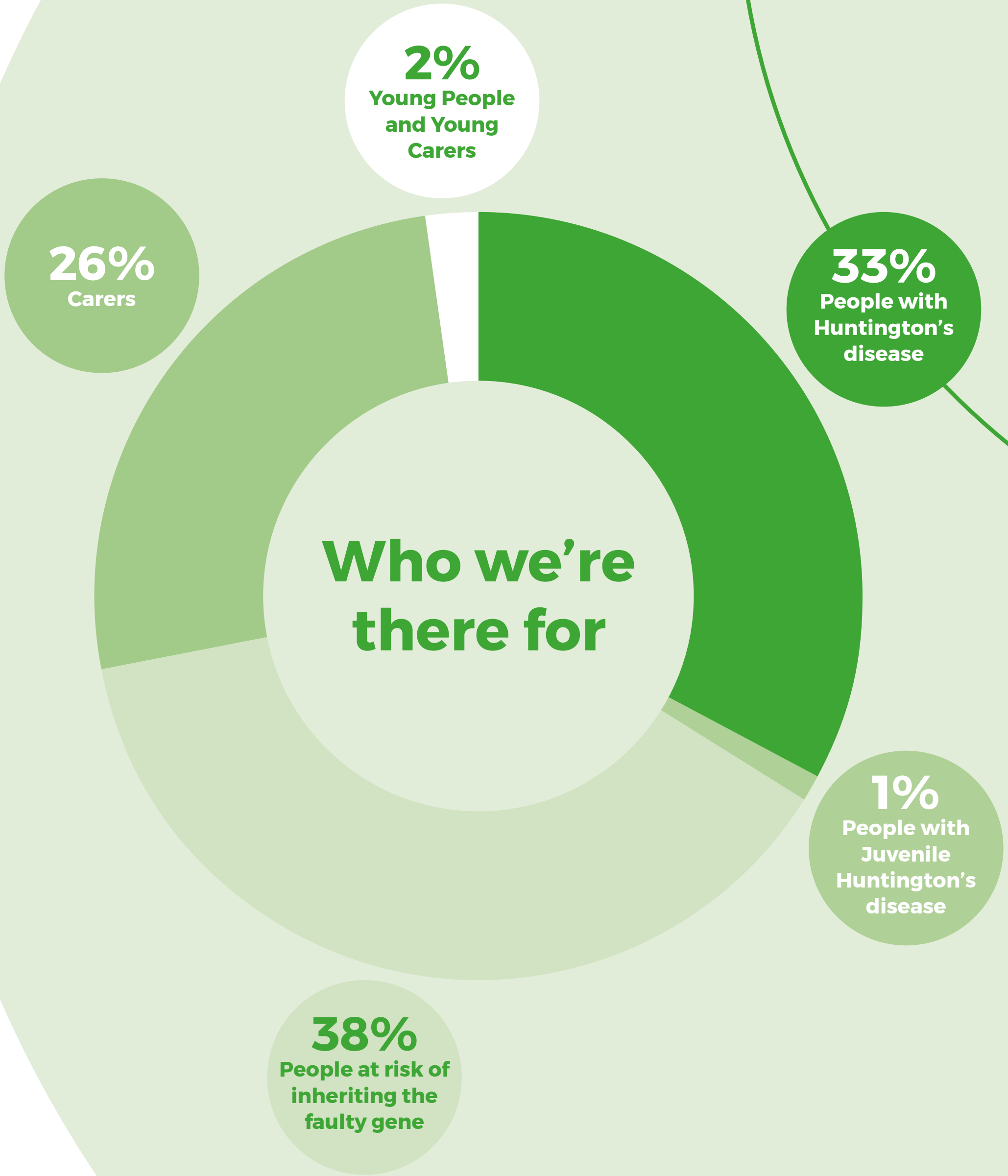
Telephone helpline

Our telephone helpline is available for anyone who needs help, support, advice or information about Huntington's disease.

Families have called us when they're in crisis, or when they've got to a dead end trying to access the services they need. Healthcare professionals have called us when they need an answer quickly to help their patient.

Sometimes all a caller needs is a listening ear from someone who knows what they're going through.

> *"We talked on the phone for two hours about worries, fears, feelings, coping, personal issues and support to deal with professionals. I call her when I have nowhere else to turn. She never says go away."*



We're working together

98%
of people said their visit from our adviser had helped

90%
of people said they had a better understanding of Huntington's

76%
said they felt more able to cope with their situation

> *"Our adviser managed to get a referral to a consultant when our GP couldn't, after waiting for nearly two years. She was a huge help completing all the forms and providing advice. We're so grateful for her help."*

Specialist Huntington's disease clinics

Our advisers support families to attend dedicated clinics with Huntington's disease clinicians. These appointments allow families to see a range of specialists in one place at one time, making it easier to get answers to their questions and get the right treatments and medication.

There are limited specialists in the field of Huntington's, so clinics are usually held in larger cities. This makes it hard for some patients and their families to attend regularly. By working closely with the clinicians, our advisers join up the medical aspects of the disease with care needed at home. This helps families to cope better in between appointments.

Multidisciplinary teamwork

Huntington's disease is complex and medical professionals often haven't even heard of it before – but they are key to families living a better life, and staying together for longer.

Our advisers bring together community nurses, mental health teams, social services, and other specialists, such as dietitians and speech and language therapists. Working in partnership means our advisers can wrap the best package of care around the person with Huntington's. Our advisers join together different healthcare specialists with expert knowledge to visit and help the people in their own homes.

Working this way means we've been able to help families live a better life, and stay together, in their own homes, for longer.

We’re there for young people

Children and young people growing up in families affected by HD can face challenges that others their age will never experience. Perhaps they’re at risk of inheriting the gene. Maybe they’re a carer for their parent who has the disease. They may have seen a loved one very poorly or die and have learned that may happen to them.

Youth Engagement Service

Children and young people are likely to have feelings and questions they don’t understand. They can find it hard to talk to their parents or carers – particularly if their parent has Huntington’s symptoms.

Throughout the year, we’ve provided ongoing support, either one to one or in groups, for children and young people from 8 - 22 years. Our youth worker helps children to understand the disease, and helps them create strategies to deal with the problems they’re facing. Sometimes they just need a listening ear and a voice of experience.

The demand for our youth service has grown year on year. It’s an area we intend to develop so we can reach more young people in need of support.

Young Adults’ Weekend

Families often find it hard to talk about Huntington’s with their children. Parents understandably want to protect their children, but by keeping important information from them, young people often grow up unaware of the cause of the illness or the fact it’s hereditary. This can have serious consequences when children grow up and begin to question things. They can become angry, confused, frightened and feel alone.

Our dedicated weekend for young people aged 18 – 35 has been running since 2009. It’s unique in the way it supports people at different stages: those who are at risk and not sure if they want to be tested for the Huntington’s gene, as well as those who have already tested either positive or negative, alongside their partners.

The weekend gives young people the chance to come together, listen to talks, get involved in workshops and meet others in the same situation – often for the first time.

Thank you to the Milton Damerel Trust and the Lord Cozens-Hardy Trust for funding this weekend.

Juvenile Huntington’s disease support

Children and young people under 20 years old who show symptoms early have Juvenile Huntington’s disease – an even rarer form of the disease. Of all cases, only 5 – 10% are Juvenile. This makes it even harder for families to get help. We continued to provide support, advice and information to these families, equipping them with the knowledge and motivation to face their daily challenges.

> “I was really worried about attending the weekend, but it was brilliant. The support from everyone is great and the information I’ve been given has helped massively. I now have hope.”

Juvenile Huntington's Disease Family Weekend

Our annual weekend for families living with Juvenile Huntington's disease (JHD) returned for its 12th year this summer. The weekend lets children take part in accessible outdoor adventure activities, alongside talks for parents, while giving respite for the whole family in a safe and friendly environment.

Thank you to Ian Preedy, Skelton Bounty and the Lord Cozens-Hardy Trust for funding this weekend.

We’re there for professionals

Huntington’s disease is rare and complex. One of the biggest problems families face is the lack of knowledge and understanding of the disease by their doctors, nurses and healthcare staff.

Many people tell us they feel like their roles are reversed – families have to explain Huntington’s to their medical teams. This means they don’t get the diagnosis, treatment and ongoing care they were looking for.

We’re there to educate professionals to improve the quality of care families receive.

Certificated course in Huntington’s disease

Our flagship certificated training course continues to be an essential development event for any healthcare professional working with Huntington’s families. It covers topics including genetics, neurology, communication and the impact of HD from a family perspective.

42 delegates learned from clinical experts, including some members of our Medical Advisory Panel, alongside our own experienced care management staff.

Training professionals up and down the country

We want every healthcare professional working with Huntington’s patients to have a full understanding of the disease. Throughout the year, our Specialist Huntington’s Disease Advisers have delivered training and information sessions to a range of health and social care professionals, including GPs, mental health teams, social services, and care home staff.

They’ve tailored their presentations to the needs of their attendees. They’ve given an overview of the disease for those who are new to Huntington’s. For those needing more help, they’ve covered topics in more depth, such as genetic implications, communication problems and managing difficult behaviour, and have given 1-1 training to care staff when needed.

Understanding behaviour with Jimmy Pollard

We hosted a series of seminars across North West England led by Jimmy Pollard, an acclaimed expert in Huntington’s care. The sessions covered informa tion to help people understand how and why people’s behaviour changes in HD and practical tips to help them manage these changes.

> *“I felt uplifted and more knowledgeable about how to deal with Huntington’s.”*

397
training sessions delivered to
3,635
health and social care professionals

99%
of delegates said they felt better equipped to carry out their work supporting people with Huntington's following our training

Our comprehensive teaching meant
94%
of delegates said their knowledge had increased 'considerably' or 'a lot' after attending.

Sara's story

"The training I received from the HDA was brilliant. It informed me greatly about how patients with Huntington's disease and their families cope with the illness. It means now I can work alongside patients with more knowledge and empathy.

"I used knowledge I learned from the training to fight for a specialist placement for one of my patients. The course gave me the knowledge to know what is required and how to achieve this.

"I had very little knowledge about Huntington's beforehand, but since going on the training, I have arranged to run a teaching session for my colleagues alongside our local Specialist HD Adviser."

Sara Ross
Team Manager, Avon and Wiltshire Mental Health Partnership NHS Trust

"The course has been insightful. I learned about the importance of building relationships and really getting to know the person with Huntington's and their family. I now have a better understanding about difficult behaviours, such as irritability and apathy. I found the information about symptom control for depression interesting and will feed that back to our pharmacy team. I now feel I have a better understanding of how Huntington's impacts the family."
Course delegate

Helping people be there for each other

Online support

Our online message board continues to be a valuable support network. For many people, the chance to post anonymously allows them to reach out to get information and help in a way they wouldn't otherwise be able to. This helps people feel they're not facing their problems alone, and gives them the knowledge they need to make decisions in their lives.

Our Facebook community continues to grow, reaching 10,000 followers during the year.

We also launched an Instagram channel to publicly celebrate our fantastic fundraisers, aiming to reach a younger audience.

Branches and support groups

Our 56 regional branches and support groups continued to be a huge support for families throughout the year. The groups, which meet all over the country, are run by volunteers.

As Huntington's is such a rare illness, many people find comfort and relief in meeting others who face similar challenges, because they can relate to each other's experiences. These groups bring people together to support each other, while also offering a chance to take a break from a chaotic time at home.

Thank you to everyone who generously gives up their time to organise the range of meetings, trips, activities and fundraisers that group members enjoy throughout the year.

Pop-up cafes and events

We've expanded our pilot of pop-up cafes. First launched in Cornwall, these informal pop-up events help to bring people together in rural areas and places that don't have a branch or support group nearby.

These get-togethers are hosted by our specialist advisers, offering respite for carers and a chance to chat with people who are going through the same experiences. They now also regularly take place in Kent, Sussex, Oxfordshire and the North East.

Jeremy's story

"After 15 years of being told my wife had paranoid schizophrenia and depression that caused her to resign from teaching, we were suddenly confronted with clear evidence she had Huntington's. The actual circumstances of that discovery were complicated and traumatic for many members of the family and I felt desperately guilty about allowing the situation to happen.

"I found our local specialist adviser and spent nearly two hours on the telephone. Being able to talk to someone who understood not only my distress but also the years of uncertainty and worry that we had all been living through was a HUGE relief.

"A short time later, she started a support group and I was one of the founding members. We have about four to six meetings and around 12 fundraising events a year. I try to attend them all. The thing that keeps me going is the relief I feel when I'm talking to people who understand the disease and the pressures it places on the whole family. It's that 'being understood' feeling that has been so crucial.

"Being involved helps me to understand all the ways Huntington's can affect people. Standing in supermarket foyers helps raise awareness and it feels as if we're giving something back in return for the support our family has received."

Jeremy, Cornwall

"It's that 'being understood' feeling that has been so crucial."

We're raising awareness

We're constantly inspired by the brave and inspirational people in the Huntington's community. They face the challenges of Huntington's disease with strength and courage. They motivate us to improve public awareness so they can lead a better life without fear or stigma.

Huntington's disease on the airwaves

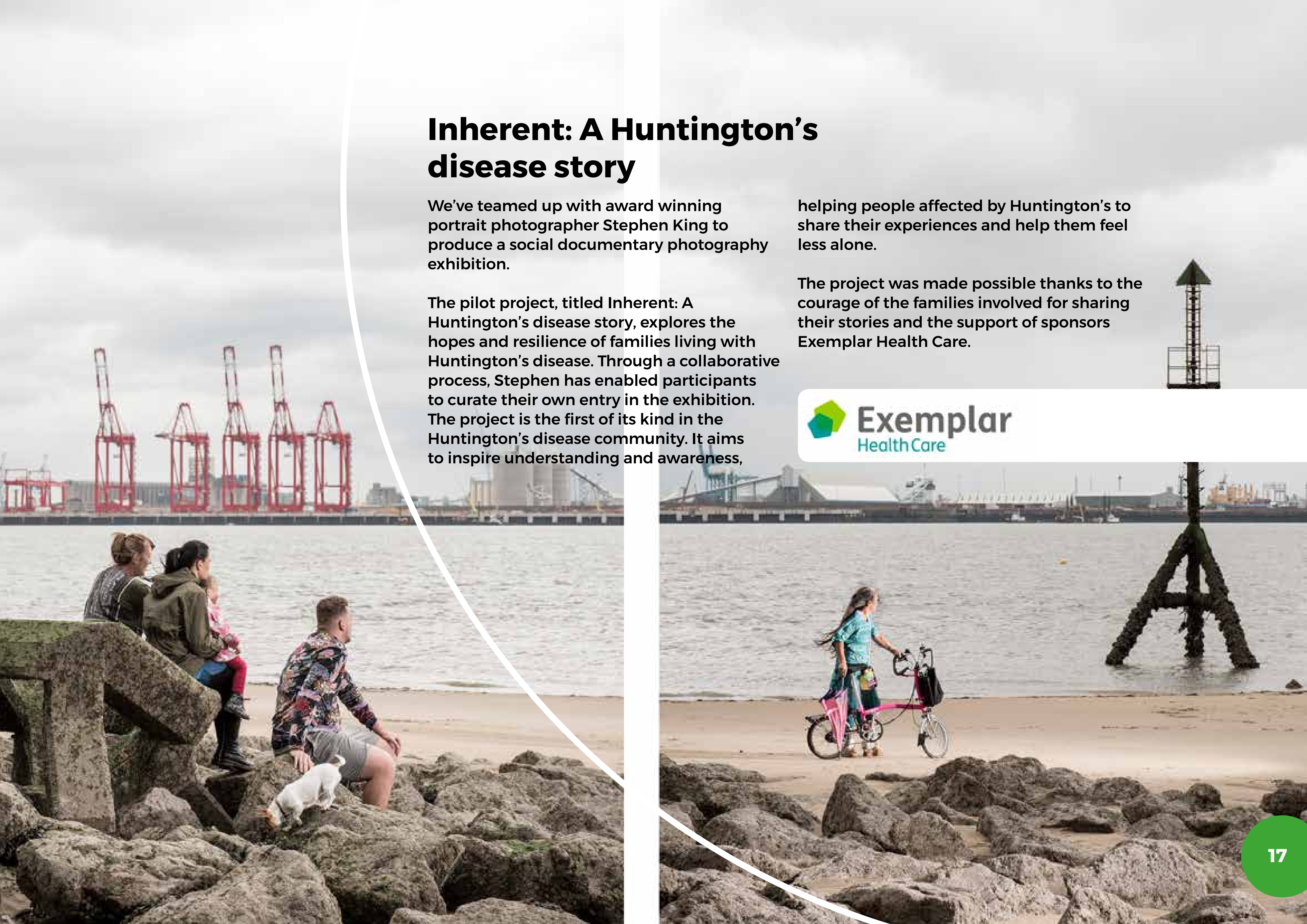
We contributed to a number of high profile radio programmes, including BBC Radio 4's Inside the Ethics Committee, Woman's Hour and the Jeremy Vine Show on BBC Radio 2. These discussions allowed us to reach new audiences who may never have heard of Huntington's before.

Shine a light for Huntington's Disease Awareness Week

To mark Huntington's Disease Awareness Week, we launched Shine a Light where buildings up and down the country lit up in the charity's colours of pink and green. Blackpool Tower, Liverpool Engineering Building and Spinnaker Tower in Portsmouth were the first landmarks to take part. We aim to grow this number in future years.

Furry awareness raisers

Dedicated volunteer Jackie Harrison masterminded the fundraising and awareness campaigns #Hounds4Huntington's and #Sybilontour, with help from fellow volunteers Lynne Burgess and Brenda Wylie. They made felt dogs in HDA colours, crafted in the likeness of Jackie's Border Terrier Sybil. The mini-Sybils have been on walkies across the world to raise awareness of Huntington's disease on social media using #Sybilontour, meeting some famous faces on the way.



Inherent: A Huntington's disease story

We've teamed up with award winning portrait photographer Stephen King to produce a social documentary photography exhibition.

The pilot project, titled Inherent: A Huntington's disease story, explores the hopes and resilience of families living with Huntington's disease. Through a collaborative process, Stephen has enabled participants to curate their own entry in the exhibition. The project is the first of its kind in the Huntington's disease community. It aims to inspire understanding and awareness, helping people affected by Huntington's to share their experiences and help them feel less alone.

The project was made possible thanks to the courage of the families involved for sharing their stories and the support of sponsors Exemplar Health Care.

Exemplar
Health Care

You’re there for us

Our dedicated supporters do so much to raise funds and awareness throughout the year. Thank you to each and every one of you!

Our volunteer fundraisers often know about the challenges of Huntington’s disease. Maybe someone they love has the disease. Maybe they’ve had a positive – or negative – test result for Huntington’s themselves. Maybe they’re caring for someone who is living with the disease.

Every penny they’ve raised this year has helped to make a better life for people affected by Huntington’s disease.

Our superstar fundraisers ran, skydived, cycled, climbed, trekked, walked, swam, crafted and baked to raise an incredible

£450,461

and raise much needed awareness of Huntington’s in the process. This is a fantastic 24% increase on fundraised income last year!

To celebrate their amazing support, we hosted our inaugural Fundraising Volunteer Awards Ceremony to honour our most inspirational fundraisers of the year.

Our 19 London Marathon runners raised a fabulous total of

£32,016

This the most popular event in the HDA fundraising calendar. Before the runners took to the streets, we hosted a pre-race motivational reception, bringing together #teamHDA runners, families and supporters.

The team shared inspirational stories of their Huntington’s journeys and why running the marathon was so important to them. It was a heart-warming evening full of positivity, with our patron Tony Hadley and actress Carol Royle from Casualty on hand to offer support and encouragement.

Charity of the year corporate partnership: Venatus Media

We joined forces with leading entertainment advertising agency Venatus Media as their charity of the year to raise awareness and funds to help people living with Huntington's.

With enthusiasm and relish they have led bucket collections in London Underground stations and lit up their offices in pink and green for Huntington's Disease Awareness Week. They also gifted us an advertising campaign on their online gaming platforms, helping us to reach a new, broader and younger audience.

> *"Venatus Media has thoroughly enjoyed working with the HDA to raise much needed funds and awareness of Huntington's disease. We have been supported through out by the fundraising team and we are keen to do more."*

Shaunagh Mulhern
Senior New Business Manager

venatus

Our finances

Donations from our generous supporters, raffles and direct mail appeals raised

£81,362

Losing a loved one to Huntington's is hard, but many families chose to honour their memory by making an in memoriam gift, collectively raising

£50,375

Funding from charitable trusts, foundations and corporates increased significantly to

£541,181

after a renewed focus on applications to these grant makers

For every £1 we spent on generating funds we raised an average of

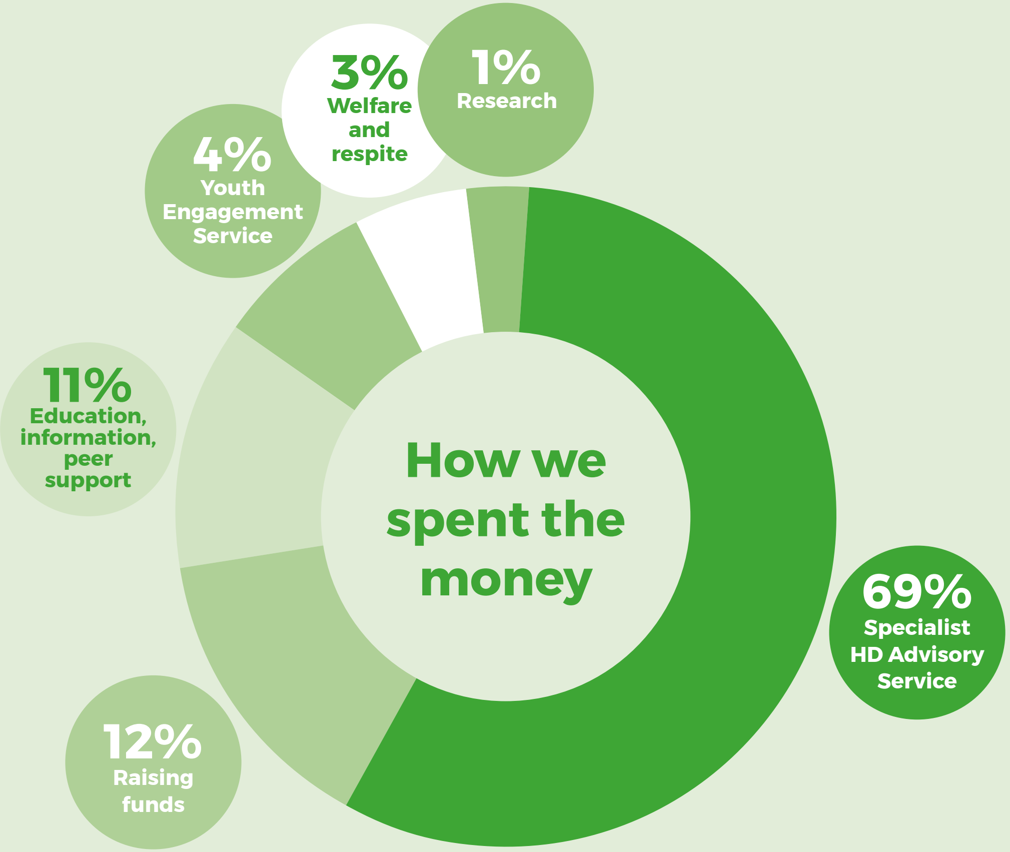
£8.29

> *"The support and advice our adviser provides us is invaluable. She keeps us moving forward to cope with Huntington's, which makes us feel better and positive. Without her I know we would feel isolated and be struggling with the illness. She is always very quick to help organise appointments with consultants and has the knack of getting things done without any fuss."*

Where our income came from

Corporate and trusts	35%	£541,181
Community fundraising	30%	£452,077
Legacies and in memoriam	14%	£219,796
Individual giving	10%	£151,377
Branches	6%	£85,978
Investment/Other	5%	£81,578
Total		**£1,531,987**

How we spent the money



Specialist HD Advisory Service	69%	£1,050,597
Raising funds	12%	£179,646
Education, information and peer support	11%	£174,089
Youth Engagement Service	4%	£53,481
Welfare and respite	3%	£48,177
Research	1%	£14,913
Total		**£1,520,903**

Our thanks

Thank you to the following grant funders, foundations, sponsors and corporate supporters who have helped make our work possible this year, including those who wish to remain anonymous.

Without your generosity, we couldn't be there for people with Huntington's disease.

The Adint Charitable Trust
The Alice Ellen Cooper-Dean Charitable Foundation
Anne Duchess of Westminster's Charity
The Barbour Foundation
Baron Davenport's Charity
Big Lottery Fund
Birmingham City Council
The Birmingham District Nursing Charitable Trust
Blackburn with Darwen CCG
The Bouttell Bequest
Bupa Colonia Court
The Cadbury Foundation
Cambridgeshire and Peterborough CCG
Charles S French Charitable Trust
Chrysalis Trust
The Clive and Sylvia Richards Charity
Cornwall County Council
Denman Charitable Trust
NHS Northern, Eastern and Western Devon CCG
Donald Forrester Trust
The Douglas Arter Foundation
The D'Oyly Carte Charitable Trust
Duchy of Lancaster Benevolent Fund
Dudley Metropolitan Borough Council
The Dyers' Company Charitable Trust
Eleanor Rathbone Charitable Trust
The Edith Murphy Foundation
Exemplar Health Care
Enroll-HD Clinic Leeds
The Ernest Kleinwort Charitable Trust
Eveson Charitable Trust
Fitton Trust
The Florence Turner Trust
The Frederick and Phyllis Cann Trust
Friarsgate Trust
Frognal Trust
The George A Moore Foundation
The Green Hall Foundation
The Hadrian Trust
The Hemby Charitable Trust
HMT Care Limited
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The Lord Cozens-Hardy Trust
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Milton Damerel Trust
Miss Jeanne Bisgood's Charitable Trust
The Miss Pannett Charitable Trust
NHS Arden and Greater East Midlands CCG
Nutricia Advanced Medical Nutrition
Dorset Healthcare University NHS Foundation
The Norman Family Charitable Trust
Normanby Charitable Trust
P F Charitable Trust
The Pennycress Trust
The Pharsalia Charitable Trust
Pilkington Charities' Fund
The Pixel Fund
The Purey Cust Trust CIO

The Rainford Trust
The Rayne Foundation
Richard Pollock Charitable Trust
The Roger and Douglas Turner Charitable Trust
Roger De Haan Charitable Trust
The Roger Raymond Charitable Trust
Royal Hospital for Neuro-disability
The Sandford Trust
Sandra Charitable Trust
Sheffield Town Trust
Sherburn House Charity
The Simon and Philip Cohen Charitable Trust
Sir George Martin Trust
The Sir James Knott Trust
The Sir James Reckitt Charity
The Sir James Roll Charitable Trust
The Sir Jules Thorn Charitable Trust
Skelton Bounty
The Sobell Foundation
Souter Charitable Trust
The Sovereign Health Care Charitable Trust
St Andrews Healthcare
The Steel Charitable Trust
The Strangward Trust
Stanley House Specialist Care Home
Suffolk Giving Fund, Suffolk Community Foundation
Sunderland City Council
The Sunrise (Sidmouth) Charitable Trust
The Sylvia Adams Charitable Trust
The Sylvia and Colin Shepherd Charitable Trust
Tanner Trust
Telford and Wrekin Council
The Lady Hind Trust
The Thomas Farr Charity
Virgin Care Services Limited
The Wixamtree Trust

Special thanks to those who have given their time and expertise in kind.
Cuthbert's Bakehouse
Roger Phillips
Ian Preedy
Alex Reid
Jonathan Saunders
Les Shan
Juan Pablo Yepez

Every donation helps families living with Huntington's disease

Our people

Patrons
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Shane Richie

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Partnerships and affiliations
Association of Medical Research Charities
Genetic Alliance UK
International Huntington Association
National Council for Palliative Care
Neurological Alliance
The United Kingdom and Ireland Huntington's Alliance

> *"As a young family, when my husband was diagnosed with HD we felt shocked, alone and scared of what was happening. Our specialist adviser sat and spoke to us, guided us and assisted with our financial worries. Our meetings have greatly lifted some pressure off us all. We are still trying to get our heads around the diagnosis but feel supported now by our adviser."*

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

Get involved

Become a fundraising volunteer

email **events@hda.org.uk**
phone **0151 331 5445**
for your fundraising pack

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