



**Huntington's
Disease
Association**

Magazine

Winter 2017

**Get involved
in research**

**63 marathons
in 63 days**

**10 top tips for
carers**

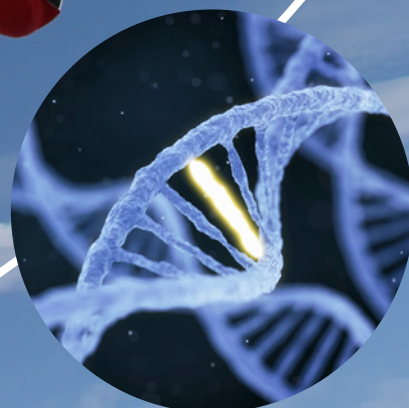
**Great grandma
has a head for
heights**



**TV, tattoos and
making every
day matter**



**Black days to
black belts**



**Blood test
breakthrough**

Elysium Neurological provides specialist care and rehabilitation for people with neurological conditions, acquired brain injuries and spinal cord injuries.



From our four specialist centres Elysium Neurological provides the specialised care and expert therapeutic interventions required for people affected by the majority of known neurological conditions including Huntington's Disease.

Located in Bosbury near Hereford, Stanley House is dedicated to providing a home from home for all its residents. Badby Park located in Daventry near Northampton is set within rolling parkland and like its sister service in Stoke on Trent, Adderley Green; offers a full inter disciplinary team to support and enable residents to undergo reviews of their specific and/or changing needs. The Bridge in Middlesbrough will open in late autumn 2017.

Our services provide long term complex care and respite for those adults who require specialist care to meet their complex physical and psychological impairments.



For more information about any of the services or care pathways Elysium Neurological can provide please contact:

Rachael Chamberlain on **07387 108625**
or rachael.chamberlain@elysiumhealthcare.co.uk

Confidential information should be emailed to:
rachael.chamberlain@nhs.net

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For advice or support from one of our Specialist HD Advisers visit:
www.hda.org.uk/supportnearyou

You'll notice we look a bit different to our previous publications. We've started work to develop and modernise the look and feel of the Huntington's Disease Association. 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!

The views expressed in this publication do not necessarily reflect those of the Huntington's Disease Association (HDA). The advertisement of third party products or services does not imply endorsement from the HDA.

Welcome



**From Andrew Bickerdike,
Chair of Trustees and
Cath Stanley, Chief Executive**

It's hard to believe that winter is upon us and another year has flown by. We've continued our focus on supporting people living with Huntington's and their families, through visiting people in their homes, providing information, and sharing advice online and over the phone. With an increasing emphasis on the digital world we're looking at how we can develop that side of our support. We launched our new website in October, which we hope will provide useful support and information. We'll be updating the site over the coming months and plan to add new resources and functionality.

We've made progress on a new scheme of accreditation for nursing homes – thank you to everyone who has participated in the consultation process. Read about the scheme on page 13.

New data protection laws come into effect in May 2018. This may change the way we keep in touch with you. You'll be hearing more from us in the next few months about how you can keep up to date with news from the Huntington's community when these changes happen.

We've packed this edition with updates on research into Huntington's, including how you can get involved. You can also read inspirational stories about people living well with Huntington's, raising awareness on TV and in the community, insights for carers and successes from some of our fantastic fundraisers.

We're incredibly privileged to have so many volunteers who tirelessly raise funds and awareness, run branches and support groups and offer a listening ear to others. Your help is invaluable – thank you for all you do.

Thank you

Blood test can predict onset and track progression of Huntington's disease

The first blood test that can predict the onset and progression of Huntington's disease has been identified in a study led by researchers at University College London.

The researchers say their findings should help test new treatments for the genetic brain disorder.

"This is the first time a potential blood biomarker has been identified to track Huntington's disease so strongly", said senior researcher Dr Edward Wild.

The test measures the neurofilament light chain (neurofilament), a protein released from damaged brain cells, which has been linked to other neurodegenerative diseases but hasn't been studied in the blood of Huntington's disease patients before.

The team, led by scientists at UCL Huntington's Disease Centre, working with colleagues in Sweden, the USA, Canada, France and the Netherlands, measured neurofilament levels in blood

samples from the TRACK-HD study, an international project that followed 366 volunteers for three years.

They found that levels of the brain protein were increased throughout the course of HD – even in carriers of the HD gene who were many years from showing symptoms of the disease. People with the HD gene had neurofilament concentrations that were 2.6 times more than the participants who didn't have the gene, and the level rose throughout the course of the disease.

In the group who had no symptoms at the start of the study, the level of neurofilament predicted the onset of the disease, as those with high neurofilament levels in the blood at the start were more likely to develop symptoms in the following three years. After taking into account factors already known to predict progression – age and a genetic marker – the blood level of neurofilament was still able to independently predict

onset, progression and the rate of brain shrinkage as measured by MRI scans.

Currently, the best biomarkers available are measured with neuroimaging or cerebrospinal fluid, which are more difficult and expensive than a blood test. The researchers say that predicting progression in people with the Huntington's gene who do not yet show symptoms has been particularly challenging.

"We have been trying to identify blood biomarkers to help track the progression of HD for well over a decade, and this is the best candidate that we have seen so far," said Dr Wild.

"Neurofilament has the potential to serve as a speedometer in Huntington's disease, since a single blood test reflects how quickly the brain is changing. That could be very helpful right now as we are testing a new generation of so-called 'gene silencing' drugs that we hope will put the brakes on the condition. Measuring neurofilament levels



Dr Edward Wild

could help us figure out whether those brakes are working."

However, the researchers caution that the test is not expected to be immediately helpful for individual patients. "This is the first time neurofilament has been measured in blood, so much more work is needed to understand the potential and limitations of this test," said Lauren Byrne, the study's first author. "In the future, if drugs to slow HD become available, it may well be used to guide treatment decisions. For now, this test is most promising as a much needed tool to help us design and run clinical trials of new drugs."

"We have been trying to identify blood biomarkers to help track the progression of HD for well over a decade, and this is the best candidate that we have seen so far."

Get involved with Huntington's research

Scientists around the world are researching ways to slow down or prevent Huntington's disease. There are also teams investigating new treatments to help with the symptoms. Getting involved in research is a great way to help people with Huntington's disease now and in the future - and you don't always need to have the Huntington's gene to contribute.

Here you can find out more about two important studies that are looking for participants right now.

HD
yours

A research team at University College London, led by Professor Sarah Tabrizi, have begun a new research project called the Huntington's Disease Young Adult Study (HD-YAS).

The study aims to identify the earliest point at which changes related to Huntington's can be found, and therefore the earliest

time when future therapeutic treatments can be given to prevent it. The study will include 120 young adults between the ages of 18-40. Half of this group will be people who carry the gene and the other half will be people who don't carry the gene.

The study opened in August 2017 and so far 22 young people from around the country have travelled to London to take part. The visit lasts up to a day and a half and involves having an MRI brain scan, playing computer based tasks and games to help understand the way



The research team at University College London

people remember and process information, having blood taken and answering questionnaires about symptoms such as anxiety and depression. There's also an option to donate cerebrospinal fluid (CSF). When the study is



Research participant Nick having an MRI scan. An MRI scanner contains a large magnet and can show detailed pictures of the brain. The researcher, Eli, explains the scan to Nick before he lies down flat on the bed and his head is placed inside the magnetic ring.



Enroll-HD is a clinical research platform that includes a worldwide observational study for Huntington's disease families.

The study is a global project designed to improve understanding of Huntington's and to enable faster, smarter and better clinical trials. Since the study started in 2012, over 15,000 people in 15 countries have signed up and the study continues to grow.

Enroll-HD has generated the world's largest database for Huntington's clinical research - a hugely important resource for researchers to learn more about the disease. The database includes information from a wide range of participants from around the world who are at different stages of the disease. This allows researchers to gain a better understanding of why and when certain signs and symptoms appear.

to develop new drugs, better ways to test whether the drugs will be effective, and helps drug companies set up trials more quickly.

In the UK, there are 28 study centres across England, Wales and Scotland actively recruiting new participants. Taking part in the study means visiting one of these centres once a year. The Huntington's disease specialist team at the centre will do some tests of movement, thinking and mood, and will ask for a small blood sample.

If you'd like to take part, you can find your nearest Enroll-HD study centre and more information about the study, at www.enroll-hd.org

While Enroll-HD doesn't involve testing any potential drugs or other therapies directly, it aims to speed up research into new effective treatments. It helps researchers identify new ideas

complete, the researchers will analyse the data and aim to publish the results of the study in spring 2020.

The researchers are still looking for people to take part until December 2018. The team arrange the visit to London and provide a hotel, travel and expenses. Participants are welcome to bring a friend, partner or family member for company.

If you're aged 18-40 and would like to know more about how you can take part, please email jessica.lowe@ucl.ac.uk or call 0203 108 7539.

5
years

15
countries

15,000+
participants

Investing in Huntington's research

Research into Huntington's is happening across the world, with scientists exploring all aspects of the disease to find effective treatments and the ultimate aim of a cure. While their inspiring effort continues to give hope for people in the future, it's important to consider ways to improve life for people with Huntington's in the here and now.

We're supporting projects that can help make a difference for people living with Huntington's. The projects have been reviewed by the HDA's medical advisory panel, a group of Huntington's disease scientific experts, and our HD Voice research panel, a group of people from our community who have direct experience of Huntington's disease.



Understanding financial decision making in Huntington's disease

University of Cambridge

The way we deal with money has changed in recent years, with internet banking, phone sales and pin numbers becoming the norm. This has left many people at risk of financial abuse, such as theft, fraud and exploitation. People with Huntington's disease are particularly vulnerable.

Huntington's is associated with a loss of connections in the brain that link critical areas deep within it to the thinking parts at the front. When these circuits breakdown it can lead to problems with thinking and changes in behaviours. These changes can often lead to

people with Huntington's acting impulsively and making quick, ill informed decisions. It can also mean they have difficulty working out the risks in situations and can struggle to handle multiple pieces of information, making it hard to solve complex problems.

Research has shown that problems at work are one of the first noticeable difficulties in Huntington's disease, closely followed by problems with managing their finances without support.

Professor Roger Barker and his research team at the University of Cambridge will investigate financial abuse by looking at the experiences of people with Huntington's disease, their families, carers and support workers, to see how much of a problem financial abuse is in Huntington's disease.

Through interviews and cognitive assessments, the scientists aim to



"We are very excited about working more closely with the Huntington's Disease Association on a project we feel very passionately about. The grant will allow us to look in great detail at the factors related to changes in financial decision making in Huntington's and also at how many Huntington's patients and families have been affected by financial abuse in the UK. This grant will allow us to do what motivates us the most - research aimed at improving the everyday lives of our patients."

Professor Roger Barker,
University of Cambridge

get an accurate understanding of how people manage their money, their perception of financial abuse and their experience of financial mismanagement.

By working with participants at different stages of the disease the team will identify the things that influence how people with Huntington's make decisions about their money. This will give the team an insight into the areas making Huntington's patients particularly vulnerable to financial abuse.

The team will also test a group of people with the Huntington's gene who are on the cusp of being diagnosed, and repeat it two years later. This may help to identify changes that could predict future financial vulnerability.



"The funding from the HDA means that we can work towards implementing the findings from large research studies in the real lives of people with Huntington's disease. We know that exercise is safe and beneficial - we now need to work out how people with Huntington's disease can integrate physical activity into their daily lives."

Dr Una Jones, Cardiff University



Encouraging people to get active through specialist Huntington's disease clinics

Cardiff University

Over the last ten years, more and more research studies have shown that exercise is safe and beneficial for people with Huntington's disease. But research also shows that physical activity levels of people with Huntington's remain low. So it would appear that there are challenges to this research being used within clinical practice. There's also evidence that healthcare professionals such as doctors and physiotherapists don't encourage people to get more active.

This research project, led by Dr Una Jones, aims to explore the challenges of applying the recommendations from the previous research in the clinics, and to help clinic staff to develop plans to promote physical activity with their Huntington's patients.

An important part of the project is to get the perspectives of healthcare staff, and importantly to hear from people with Huntington's and their carers. The researchers will bring both groups together, giving them the opportunity to discuss how physical activity could be promoted within specialist Huntington's clinics. The discussions will be summarised and sent to everyone who takes part, giving clinic staff the information they need to adapt their practice to promote physical activity with their patients.

The researchers will follow up with the clinics six and 12 months afterwards to find out what changes have taken place and any benefits there have been for their patients. The results will be shared with the Huntington's community so that as many people as possible can learn from their findings.

TV, tattoos and making every moment matter: how Huntington's has changed me



Twenty-two-year-old Harry-Jon Morgan is fit, healthy, self-assured and full of life, but he admits there have been 'dark, dark days'. Currently a student in sports coaching at Leeds Beckett University, Harry-Jon has a take on life that's mature beyond his years. As well as studying, he plays rugby at a highly-competitive level, has a part-time job helping children with disabilities and talks about the need to make every day count. This year he achieved his ambition to appear on national television. Much, if not all of this, he puts down to Huntington's disease - in particular, Juvenile Huntington's disease.

Harry-Jon's family knew nothing of Huntington's when his younger sister Ellie-Mae developed symptoms in 2011. She had always had difficulties and was thought to be on the ADHD and autistic spectrums, but then her mobility became affected. She was diagnosed with Juvenile Huntington's disease in 2012. "It took a long time to get to grips with what it was," says Harry-Jon. "Eventually we realised it was in our family and that our grandad had it."

Harry-Jon and Ellie-Mae were extremely close, part of a large family of six siblings with mum Samantha and stepdad Richard. Seeing his sister go through the disease was, at times, unbearable. "She really was amazing, though," he says, "She coped with so much. But my mum was the real hero in all this, because she was her full-time carer."

Ellie-Mae passed away later in 2014 aged just 16. "My biggest regret," says Harry-Jon, "is that I wasn't able to spend more time with her. It's hard for young people these days - you have academic pressures, decisions to make. But when something like this comes into your life, you change. There's a sort of collateral beauty that comes out of it - from something so terrible, you get something good. I had started letting myself go but I changed my lifestyle. I started playing rugby regularly again, I started smiling at people and I didn't even realise I was doing it. I knew my sister would want me to live every day, not to waste it."

Sometime later, he hit on an idea. Having seen an episode of the popular TV show Tattoo Fixers (where people get tattoos transformed or created), he got in touch and told them his story. "I knew exactly what I wanted,"

"The Huntington's Disease Association has not seen the last of me - there's so much more I want to do."



Harry-Jon's tribute tattoo was inked by celebrity tattoo artist Jay Hutton (top), based on his favourite photo with his sister (left)



he explains, "a tattoo of a photo of the two of us as toddlers on swings, me looking down on her. It said so much about our relationship." The programme makers agreed and soon he was travelling to London to record the programme.

The incredible life-like image was tattooed on his arm and Harry-Jon has nothing but admiration



Above: Harry-Jon and Ellie-Mae were very close

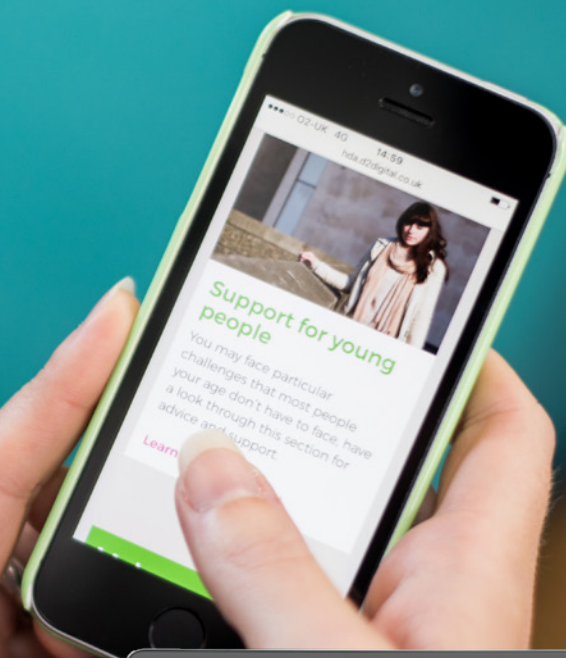
for the crew, who he says were very moved by what they heard, particularly the genetic nature of Huntington's and how it affects generations of families. Harry-Jon's grandad died from the disease eight months after Ellie-Mae, and his father has since been diagnosed with it.

The public reaction to the broadcast was huge. A segment from the episode featuring Harry-Jon shared on Facebook has attracted 7.6 million views to date, with over 90,000 likes and almost 30,000 shares. Harry-Jon's local paper covered the story and he was inundated with messages, not just from friends but from well-wishers, as well as others whose families were affected by Huntington's. The show was getting the message out about

Huntington's, to a new, younger audience.

"I love my tattoo but most of all I'm proud of the awareness I have been able to raise," says Harry-Jon. "I'm so happy I did it. I would say to anyone who is considering whether to go for something, just do it. Ellie-Mae is the reason and she keeps me going, even now. She fought with such dignity and grace and she inspired us all."

To watch the Tattoo Fixers episode featuring Harry-Jon, go to: bit.ly/2AQuyMg



Take a look
at our new
website at
www.hda.org.uk



Have you seen our new website?

We've added lots of useful information to help improve understanding of Huntington's disease and help you get better care. We've given it a fresh new look and made it easier to navigate.

We've got some exciting new features in the pipeline so keep checking back to see what's new!

HD Voice Reader Panel

A group of volunteers with lived experience of Huntington's disease reviewed the information throughout our new website, bringing their unique perspectives and offering useful suggestions.

Do you have experience of Huntington's disease? You could join our volunteer Reader Panel to help us learn more about the types of information that is useful for people living with Huntington's and their families.

To find out how you can get involved please get in touch with Ruth Abuzaid by email: ruth.abuzaid@hda.org.uk or phone: 0208 446 9879

HD
VOICE

Remember
someone
special this
Christmas



Dedicate a festive light on our online Christmas tree in memory of someone dear.

You can honour their life while helping others at the same time.

To dedicate a light to a loved one and leave a special message of remembrance visit:

www.hda.org.uk/remembersomeonespecial

Momentum building for new care home accreditation scheme

We understand that moving to residential care is one of the most difficult decisions a person with Huntington's and their family may make. We've heard from many people who have been through this, who would have found it helpful to know beforehand whether a care home can cater for their loved one's specific needs.

We've begun a project to improve standards at care homes that specialise in caring for residents with Huntington's. We're aiming to build an accreditation scheme to give families confidence when choosing a home.

Over the past few months, we've met people up and down the country who've shared their experiences to help develop the scheme, while others have shared their views in an online questionnaire and over the phone. Their feedback has given us unique insights into what is important to families, and will help form the care standards care homes will need to meet. These standards will be assessed through the scheme, and care homes will receive accreditation when they achieve the necessary criteria.

Importantly, we've also encouraged care home

providers to participate. In October we hosted a workshop for providers to learn more about the accreditation scheme and how it could benefit them to take part. Over 40 delegates from more than 20 care homes attended, and it was clear that they would like to seek formal recognition for providing specialist care. They also thought they would benefit from the chance to share good practice and learning. Cath Stanley, Chief Executive, commented: "It was encouraging to see so many providers at the event. Their enthusiasm for the project was exciting to hear."



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specialised neurological care

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- Huntington's Disease
- Motor Neurone Disease
- Parkinson's Disease
- Stroke Rehabilitation
- Acquired Brain Injury
- Multiple Sclerosis
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Our residents' care is at the heart of everything we do. We strive to nurture dignity, independence and privacy through our purpose-built facilities, our highly trained multi-disciplinary teams, the care models we offer and the therapies and activities we provide.

We have three specialist neurological care centres in Milton Keynes and Peterborough. To find out more, please call us on:

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or email us at: enquiries@pjcare.co.uk

www.pjcare.co.uk

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COMMITMENT
CARE**

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NEWS

BBC Children in Need awards grant to expand specialist youth service

A generous grant of £116,000 over three years from BBC Children in Need will extend our specialist youth service for children and young people growing up in families affected by Huntington's disease.

The grant will help fund a new Specialist Youth Worker, alongside new activities to bring children and young people affected by Huntington's together to share their experiences and support each other.

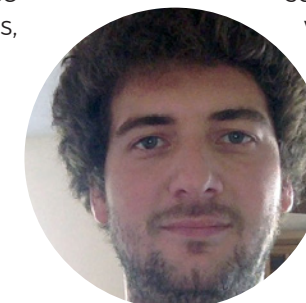
We're delighted that Neil Holman (top right) has joined us to develop the service in the south of England and South Wales, made possible by the Children in Need grant. He is joined by new Specialist Youth Worker James O'Connor (bottom right), who takes over from Adam Cho, who will work with children and young people in the north of England and North Wales.

Kate Davis, Head of Fundraising, said: "We're incredibly grateful to Children in Need. Their mission of improving the lives of children across the UK fits well with our plans to extend our youth services. Having Neil and James working



together will give more children and young people the opportunity to speak to someone who understands the difficulties they may be facing."

Ruth Abuzaid, Deputy Head of Advisory Service said: "We look forward to analysing and expanding the youth service by looking at the information we provide for young people and the opportunities we give them to get together, both virtually and physically."



James and Neil will continue to offer ongoing one-to-one support and will start working with children and families in January 2018. In the meantime, if you or a young person you know have any queries, or need help or advice, please call 0151 331 5444 or email info@hda.org.uk to be put in touch with your local Specialist Huntington's Disease Adviser.



Grand Prize Draw

Friday 2 February 2018

Tickets cost just £1 each and every ticket you buy will help us to support families affected by Huntington's disease.

To enter the draw, return your tickets to Head Office by 26 January 2018

All winners will be notified in writing. A full list of winners will be available on our website from Monday 5 February 2018.

For more information or to request more tickets please email info@hda.org.uk or call 0151 331 5444.

*You could
win £1000!
What a great way
to start 2018*

**1st prize
£1000
cash**

**2nd prize
£500
cash**

**3rd prize
£250
cash**

Inherent: a Huntington's disease story



Left to right: Shelagh Lucking, Helen McDermott, Amy Whittle and Ruth Lucking

The Lucking family's story



Shelagh: Our dad had Huntington's disease. He was one of 15. We sort of knew something was in the family but we didn't know anything about it until our dad was diagnosed in his sixties. I looked into it a bit more because I had three children, so I wanted to have the tests pretty quickly. I'm a need-to-know person.

Helen: Once I'd decided to have the blood test I just wanted to find out. You have to go through counselling. They have to do that and it's a benefit to some, to them as well, to find out whether you can cope with it. But at the time you just want to know. I wanted to set my life out and do different things if I was [gene] positive – which I was and I have.

Shelagh: I was [gene] positive too. I was really scared for the kids. Not really so for me. I was

We've teamed up with award winning social documentary photographer Stephen King to create an awareness exhibition, giving our contributors the chance to tell their own story and curate their own entry in the exhibition through words and pictures.

Sponsored by  **Exemplar**
HealthCare

petrified of passing it on to the kids, and that was my main concern with doing the test. I found that really traumatic. I felt really guilty. That was my focus for a long time before they went and had their own tests.

Amy: It was about six years between when I found out about mum, and having my own test. I didn't see the purpose in going and finding out before then. I'm not like mum, I don't see the point in dealing with that amount of detail. It was only when I was 22 and in a relationship and was going to be thinking about having children that it came into my life.

Ruth: When I had my test I was in shock. I had the test, and then they lost the results and I had to have it redone. The nurse didn't even wait for me to get in the room. She saw me pull my car up and she came running out. "I couldn't wait, I couldn't wait, I've been waiting for you to get here all morning. You're clear, I'm so

"You have a moment in your life which could last for 15 minutes, but could change everything."

happy for you." It's hard to know what to feel in that situation.

Amy: As you walk in to get the results, you have a moment in your life which could last for 15 minutes, but could entirely change everything. And that's when it hits – when you walk through the door to get the results.



Black days to black belts: How kickboxing helps Matt with Huntington's

Forty-three-year-old Matt Ward has a black belt in kickboxing. He also has Huntington's disease. Achieving this level in a martial art while battling the effects of the illness has not been easy, but Matt's pretty convinced he would not be as well as he has been, without it. "Huntington's takes so much away from you," he says, "and this not only has real neurological benefits, it's a way of me fighting back. Of me being me."

In 2002, Matt was married and living in London with a successful career in IT when his life changed forever. He didn't know the faulty Huntington's gene was

in his family and was hoping for a child of his own, when his father dropped the bombshell that his grandfather had died of the disease and they suspected his mum had inherited it. Any child, would be at risk. It was a devastating shock. By the time Matt met his second wife Marie, who had two children, he had taken the test and knew he had the Huntington's gene.

"I think because things were less hopeful when I was a child, and so much less was understood, my parents put their heads in the sand. It was sort of out of sight, out of mind," he says. Matt, however, took a different approach. He wanted to learn

everything he could about Huntington's, and he had a head start. He explains, "Coincidentally I'd studied HD whilst completing a molecular genetics degree. My first job after graduating was in a medical school lab, but I'd changed direction and got into IT." This knowledge, he explains, helped him to understand not just the mechanics of why he was getting ill, but also the emerging research. As a result, participating in clinical trials has always been important to Matt and Marie, and they began getting involved straight away.

Keen on all kinds of sports, in 2009 the couple took up kickboxing as something

fun to do as a family. Then, having progressed well, Marie sustained a bad injury and Matt's Huntington's symptoms started to develop. They took a break of around two to three years, during which Matt admits, "I'd become very unsure of myself. I was worried about falling over and suffering with insomnia. But I saw a sleep consultant, had some cognitive behaviour therapy and eventually realised that getting back into kickboxing could really help me."

Matt had read about clinical studies that suggested people with Huntington's, Parkinson's, brain injuries and other neurological problems may benefit from martial arts; that a mix of balance, strength, focus and co-ordinated moves can improve symptoms across mind and body. His kickboxing instructors noticed that while he entered the class using a walking stick, he was often able to leave without using it. "They also appreciated I needed to make progress, to get through the belts," says Matt. "So, they slowed things down for me and adapted the grading process. For example, I have problems with memory and getting fatigued, so they divided what should have been a whole day of testing into three chunks."

Last year, Matt won his club's 'most inspirational student' trophy and in March of this year, Matt and Marie both achieved their goal of attaining black belts.

Matt is now, health permitting, working towards his second Dan (the next grade above the first blackbelt) and he and Marie teach 'Little Dragons', a kickboxing class for children aged four to eight years.

Despite doing all they can to stay well, "Life is hard," admits Matt. "Getting out of bed each morning is a battle that needs to be won every day. But Marie tells me I'm the bravest, strongest man she knows, because I'm constantly fighting so many internal battles which HD throws at me." He explains that for him, it's all about trying to value himself, about reclaiming what Huntington's takes away. "I'm doing this as Matt Ward. Not HD Matt," he says.

"My kickboxing club were amazing. They really got how this could help me and what I needed to make it happen. They were supportive from the very beginning."



Matt's top 5 tips for living well

- 1 Every day I try to do some physical activity such as the gym or kickboxing as it has such positive effects on my mood and lifts my cognitive fog. I try to stay fit, physically, mentally, emotionally.
- 2 I prioritise my life differently, and spend more time with my family.
- 3 I try not to put things off. If you know you might not make retirement age, it makes sense to do things sooner rather than later.
- 4 Depression is very common - we all go through peaks and troughs. I try to do things that will help give me a more positive outlook.
- 5 Research has had a very meaningful impact on my life. By contributing and helping to find a cure - for me, that's fighting against it. I've felt in touch with the leading edge of the science. Huntington's is rare but the technologies being developed will help not just HD patients but people with many other neuro-degenerative conditions. Terrible as the disease is, it's uplifting to be a part of this.

Inspirational fundraising volunteers honoured with awards



Young Volunteer of the Year Henry Vervoorts with Cath Stanley, Chief Executive, and Charles Sabine



Most Inspiring Volunteers Margaret Cairney (above) and Mary Wormleighton (above right) with Cath Stanley, Chief Executive



Friend of the HDA Les Shan with Cath Stanley, Chief Executive

We were delighted to celebrate the fantastic achievements of our dedicated fundraising volunteers at our second Fundraising Volunteer Awards Ceremony.

Joining us at the Adelphi Hotel in Liverpool, as compère for the evening, was Huntington’s disease ambassador Charles Sabine, who congratulated each nominee for their wonderful contribution to the HDA and shared his own experiences of raising awareness.

There were a staggering 17 nominees for just two available awards in the Most Inspiring Volunteer category, and six nominees in the new category of Young Volunteer of the Year, with the winners chosen by public vote.

The Young Volunteer of the Year award was won by 14 year old Henry Vervoorts from

Nottingham. While Margaret Cairney from Nottingham and Mary Wormleighton from Northamptonshire were awarded the Most Inspiring Volunteers.

Winner Mary Wormleighton said: “I was thrilled to bits. There is no way I could have done it without the support of my friends and family. It was a really special night. The evening was a humbling experience as everyone in the room works so hard.”

Margaret Cairney said: “There are such great volunteers out there, I am just one of many. With or without an award, I enjoy every minute of raising awareness and fundraising.”

To complete the evening’s honours, a special discretionary award, Friend of the HDA, was presented to volunteer Les Shan for helping the HDA with his professional IT experience for many years.

Huge thanks to all the winners, nominees and each and every person who raises funds and awareness of Huntington’s disease. We couldn’t do what we do without you.

Thank you to headline sponsor Exemplar Healthcare, and award sponsors Nutricia and Diligence for making this event possible.



Great grandma’s head for heights helps the HDA

Daredevil Shirley McConnell showed you’re never too old for an adventure after taking on a tandem skydive to raise funds for the HDA.

The 82-year-old great grandma from Stockport, Greater Manchester, jumped out of a plane at 11,000 feet with her grandson Alex McConnell and his fiancée Tara Goldsmith. The trio chose to raise money for the Huntington’s Disease Association as Tara’s family is affected by Huntington’s.

Alex said: “Tara’s father Roy sadly passed away as a result of Huntington’s disease. Tara decided to take the genetic test several years ago and learned that she will also eventually develop Huntington’s.”

The thrill seeking trio took to the skies above Lancaster for the parachute jump and raised nearly £2000. Shirley said: “I’d



Shirley, Alex and Tara prepare for their jump



always wanted to have a go but not had the chance until now. I’ve always liked flying and I wanted to do it before I got too old.

“My friend did one and said it goes by so quickly you want to do it again, which sounded good. The thought that a nice young man was safely holding me was reassuring too. You are never too old.”

Has Shirley inspired you to take on your own challenge? Find ideas, inspiration and information for fundraising at www.hda.org.uk/fundraising

63 marathons in 63 days for inspirational fundraiser Nikki Love

An intrepid athlete from Leicester has completed her attempt to run 63 marathons in 63 days in aid of the HDA – and hopes to have her achievement recognised as a world record.

Nikki Love, a 50-year-old physical trainer, started her challenge at John O’ Groats on 27 August which took her across the UK, down to Land’s End, and back up to finish in Leicestershire’s Swithland Wood on 28 October. Over nine weeks, Nikki covered a staggering 1650 miles – the equivalent of running the length of Britain’s longest motorway, the M6, seven times!

Nikki is hoping her achievement will be recognised as a world record after having four tracking devices strapped to her on every run to measure her time and distance. She has sent the data to Guinness to be verified. Nikki said: “The world record for consecutive marathons by a woman is currently at 60, so I figured I’d simply round that up to nine weeks and go for 63.”



Nikki Love ran part of her challenge with friend Dirk Vervoorts

As well as attempting the world record, Nikki used the challenge to raise funds for the HDA, aiming for a target of £6300. Nikki’s motivation to support the HDA was close to home: “A good friend of mine, Dirk Vervoorts, was diagnosed with Huntington’s ten years ago. Around the time Dirk was diagnosed, I ran seven marathons in seven

days. I told him if I ever did anything crazy again it would be for the Huntington’s Disease Association, and I have kept my promise.

“I can see the changes he’s going through. By supporting the HDA I’ve been able to raise awareness and funds for the charity, as I know they are there to help him and his family.”

Rather than running in a straight line from John O’ Groats to Land’s End, Nikki zig-zagged across the UK to visit all the places she wanted to see, including Aviemore, St David’s, the Brecons, Brighton and London.

Nikki received fantastic support along the way, with friends and well-wishers joining her at different places to run part of the route alongside her. “Dirk joined me on the Nottingham marathon and I expected him to only do a small part, but he stuck with it till the end. That was inspiring.”

Photos courtesy of the Nottingham Post



Little Print Shop of Horrors reopens for Huntington’s disease awareness

A team of designers at Manchester-based branding agency Creative Spark have flexed their artistic muscles to raise funds for the Huntington’s Disease Association.

Little Print Shop of Horrors is an annual charity design challenge where the team pick a ghoulish theme and design unique posters which are sold to raise funds for charity. This year’s theme is ‘Netflix and Kill’, with illustrators choosing an iconic TV series to reinvent with a creepy Halloween twist.

Each year the team donates all proceeds to a charity close to their hearts. Business Development Director Claire Critcher explains why they chose the HDA: “20 years ago my wife, Nicola, found out that her mum, Lynne, had been diagnosed with Huntington’s disease – a condition that had been part of their family for generations but had skipped four other siblings and found to have been inherited only by Lynne. Because of this, Nicola faced the same decision as her mum all those years ago, and made the choice to take the predictive genetic test that has been likened to the ‘flip of a coin’.

“We are now almost two years on from receiving the news that Nicola does not carry the faulty gene and we are more involved in supporting the HDA than ever. It’s made us more determined to give time and energy back to those whose coin fell on the flip side.”

The exclusive series of 13 one-off designs are based on popular



Writer uses literary talent to raise funds

Author and poet Bruce Harris has published two books in aid of the Huntington’s Disease Association, after his long term partner was diagnosed with the illness in October 2016.

Odds Against, a book of 15 award-winning short stories, explores the theme of overcoming problems, with the characters tackling various problems in different ways. The book is supported by a group of writers including million-selling novelist Joanne Harris, who began her career writing short stories.

His second book, titled Kaleidoscope, includes 50 poems celebrating human diversity in a variety of patterns and verse forms.

Bruce said: “As I no longer have the youth and fitness to go in for marathons or swims, I have set out to contribute to the work the HDA does in the best way available to me, which is to dedicate to it the proceeds from my writing. The books are aimed at making a direct contribution to supporting the work of the HDA.”

To find out how you can order your copies of these special books visit harriscentral.org



shows, including Stranger Things, Peaky Blinders and Mad Men. One poster, featuring Royle Family star Ricky Tomlinson, (pictured above) made a big impression on the actor, who signed one of the limited edition prints to be auctioned online.



The new prints are on sale now, alongside classic favourites from previous years. You can browse and buy from the full selection of artwork at www.littleprintshopofhorrors.com

SPECIALIST CARE SERVICES: HUNTINGTON'S DISEASE

With over 200 care homes and 7 hospitals, Barchester Healthcare is one of the largest care providers in the UK and has over 20 years of experience. Barchester provides a wide range of specialist care services for those with complex needs and disorders, including Huntington's Disease (known as HD).

The teams at Barchester truly understand the unique challenges and presentation of Huntington's as a progressive disease. Should a time come when there is a wish, or need, to come into residential care for respite or longer-term care, we offer a range of care options to suit the needs of people with HD and their families.



ASSESSMENT

An assessment stay allows our staff to assess and monitor all aspects of well-being, while suggesting useful changes and strategies to help a person with HD maximise their independence – helping them to live their life, their way, for longer.

RESPITE

A respite break can give carers a well-earned rest whilst offering the person living with HD the opportunity to spend time with others experiencing similar challenges. Regular time away from caring responsibilities enhances the quality of time spent together, which can be invaluable in helping to maintain care given at home. We find many families benefit from regular, planned respite stays that enable the person with HD to become familiar with a specialist care team and environment, something they can rely on as their needs change.

LONG-TERM CARE

Longer-term care is offered to people who need on-going specialist support and services to help them get the most out of life. As the person with HD journeys towards the final stages of the disease we have the skills and expertise to help them through.

Millaton Court – part of Kernow House Care Centre in Launceston – is run by General Manager, Careen Harris (a HD Specialist and part of the HD Association) and her team of highly skilled nurses, carers and care practitioners. Their service meets the needs of individuals at different stages of the disease and understand that life with HD is very much a family affair. They work closely with the Regional HD Advisor whose role is to support people and their families in the community with HD.

To find your local Barchester care service, or for more information on specialist care services, visit:

www.barchester.com/huntingtons



Upcoming events

Our events give people the chance to come together with others facing similar experiences to learn and share. Find out about our upcoming events and how to book your place at www.hda.org.uk/events or call 0151 331 5444.



Juvenile Huntington's Disease Family Weekend
Friday 1 June to Sunday 3 June 2018
Calvert Trust, Keswick, Lake District

Our weekend for families living with Juvenile Huntington's disease (JHD) welcomes all the family – the young person with JHD, parents, carers, brothers and sisters. The weekend gives families the chance to meet others in a similar situation, while also enjoying a great weekend full of exciting activities.

Children can take part in a range of activities suitable for all ability levels, including horse riding, archery, canoeing, rock-climbing, sailing and swimming. It's also a chance for parents and carers to find out more about JHD from specialists in Huntington's disease care and share experiences with other parents. There's also a themed fancy dress party on Saturday night to give everyone the chance to relax and enjoy themselves with new friends.



Young Adults Weekend
Saturday 24 to Sunday 25 March 2018
Holiday Inn, Telford

Our dedicated weekend for young people gives those aged 18 – 35 the chance to come together to hear talks from Huntington's experts, get involved in workshops and meet others with similar experiences. The weekend welcomes people 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. Partners are welcome to come along too.



Certificated Course in Huntington's Disease for Healthcare Professionals
Courses in London and Liverpool, dates TBC

Our unique training course is an essential development event for healthcare professionals involved in supporting patients with Huntington's disease. It's your chance to meet fellow professionals, develop a deeper understanding of the illness, share ideas and discuss the management of complex situations. You'll learn from Huntington's disease experts and gain valuable insight to enhance your practice.

A date for your diary
Huntington's Disease Awareness Week
14 – 18 May 2018

Keep an eye on our website in the spring to find out how you can get involved to raise awareness of Huntington's disease.

Family Weekend 2017



Family weekend highlight

Feeling isolated is one of the biggest challenges people with Huntington's tell us about regularly, so each year we bring people from across the country together at our Family Weekend and AGM.

The gathering gives people the chance to let their hair down in an environment where everyone understands and meet others facing similar experiences. It's packed full of information sessions, workshops and presentations, with a chance to hear from Huntington's disease experts and plenty of time to chat with new friends.

For those who couldn't make it to the weekend this year, our keynote speaker, Paula Meir, shares advice from her inspirational presentation about taking control of your story.

Thank you to our event sponsors Exemplar Health Care, Elysium Neurological, St Andrews Healthcare, PJ Care, Healthcare Matters and Repose.

Redefining your story: your life, your way

Executive coach, therapist and author Paula Meir has a passion for helping people to be the best they can possibly be. She has over 20 years' experience in a global corporate environment as an HR Director and now consults independently. She is also a master practitioner in Neuro Linguistic Programming, qualified executive coach and wrote a book earlier this year called *Your Life, Your Way: a practical guide to getting your s**t together*. Paula is no stranger to Huntington's – her mother and brother both died from the disease.

Paula is passionate about improving people's lives – especially in the Huntington's community. "I understand what

it's like to live with Huntington's. Until I was 40, for most of my life I had been either dealing with the symptoms of the disease or visiting nursing homes. It's so easy to allow yourself to be defined by this terrible disease."

Despite her family history, Paula has never been tested for Huntington's and has no plans to do so. She now runs a private therapy practice in Norwich and London and insists that whatever the circumstance, people have the power to shift their thinking and live a more fulfilling and happy life.

She explained: "The biggest inhibitor of us creating and living the life we want to is the story we tell ourselves." She told the audience how Huntington's had defined her story for the first 40 years of her life. "I had lived life fast, convinced that my life would be, to all intents and purposes, over by my mid-forties." An incident at work led her to completely re-evaluate her life. She left her job and decided to go it alone. She read, trained, and

Reflections from Cath Stanley, Chief Executive

"This year's family weekend saw a change in venue to the Radisson Blu, East Midlands. The general agreement from families was that it was a good move, with much better facilities and space. Friday night offered the opportunity to meet old friends and also new, with lots of new families attending. Great hilarity was had with a play dough quiz, and a very touching poem,

read and written by 15-year-old Lauren Tuhill. On Saturday we heard from a variety of speakers on topics including an update on the work of the charity, some practical advice about claiming benefits, a motivational speech about how to help deal

with situations and a research update. Saturday night gave the opportunity to walk the red carpet to our 'night at the movies' themed evening. With a wide variety of workshops on Sunday, it was all too soon time to go home."



A date for your diary
Family Weekend and AGM 2018

12 - 14 October,
Radisson Blu Hotel,
East Midlands Airport,
Derby



Paula's 5 top tips for changing your story

love pattern and habit and sometimes they can be over protective.

4 Really think about what brings you joy and happiness and do more of it. Practicing gratitude for what we have rather than being sad about what we don't naturally moves us into a more positive frame of mind. Think of one thing every day you are grateful for!

5 If you 'let go' of what isn't helping you or serving you, you can make room for more positive thoughts and actions. We can be limited by thoughts, most of which don't turn out to be true or accurate.

1 It's easy to focus on your limitations and be defined by them – focus on what you can do and start opening up possibilities.

2 Don't assume you can't do something until you try – even small steps of trying something new or different move you in a more positive direction.

3 Watch out for the 'little voice inside your head' that might try to dissuade you from thinking or doing something differently. Our brains

set up her own consultancy – and eventually wrote her first book, *Your Life, Your Way*.

"And if I can do it anyone can," Paula told the conference. "I left school with virtually no qualifications, never had a degree, and felt like an imposter for most of my career. Who was I to write a book?"

Paula lives by her favourite quote by writer Joseph Campbell - *You have to be willing to let go of the life you have planned, in order to receive the life that is waiting for you*.

She combines this mantra with a technique based on storytelling to help people improve their lives. She said: "Many people are governed by a model of thinking in which life experiences lead to choices, which then lead to our life's story." Paula encouraged the conference to think differently. "Define what you want your story to be. This leads to a much greater number of choices, and that then leads to more positive experience, regardless of the cards you have been dealt in life."



Get your copy of Paula's book, *Your Life, Your Way: a practical guide to getting your s**t together*, from www.hda.org.uk/shop

50% of the proceeds will go to the HDA

Spotlight
on....

Newcastle

Up and down the country, local Huntington's Disease Association branches and support groups bring people together - a cup of tea, a chat, a collection in a supermarket. Each of the 57 groups, all run by volunteers, make a huge difference for people affected by Huntington's in their local community. They offer the chance to meet others facing similar experiences and provide comfort and companionship to those who need a listening ear and a shoulder to lean on.

Each edition we'll be learning more about one of these groups - first up is the Newcastle branch.

*"I feel part
of a family
where everyone
understands."*



The Newcastle Huntington's Disease Association branch began in 1993 after founder Christine Baines lost her mother to Huntington's. She reached out to see if there were others who were going through a similar experience and was amazed that over 100 people turned up. The group is now run by a volunteer committee led by Christina Bage, Joanne Somerville and Alan Bright. They offer support for families and help to organise information days, children's activities and social events.

Joanne and Christina tell us how they became involved and what the group gets up to.

How did you become involved with your local HDA branch?

Christina: I got involved about eight or nine years ago. Christine re-stood as chairperson and she asked if I could help as secretary. Christine's sister Dianne, who passed away, was my sister-in-law. She had the Huntington's gene, which was passed onto my two nephews who I now help.

Joanne: I've been involved with the HDA for many years. When I moved to the North East five years ago I contacted the branch. Everyone was so lovely and made me feel so welcome.

How often do you meet and what kind of things do you do when you get together?

C & J: We meet once a month at Walkergate hospital, usually for about two hours. In the first hour we have a chat over coffee. Our local Specialist HD Adviser John Gregor usually arranges speakers to come along. Recently we've had workshops on mindfulness, first aid, financial advice, and the new scheme of accreditation for care homes. The second hour is our formal business meeting discussing fundraising, upcoming events and information from head office. We have a summer social where we all go out for a meal together.

For awareness week, we lit up the Gateshead Millennium Bridge in HDA colours. We stood by the



Members of the branch lit up the Gateshead Millennium Bridge in pink and green for Huntington's Disease Awareness Week



The Newcastle branch committee Christina Bage (back), Joanne Somerville and Alan Bright



Newcastle branch members get together once a month

bridge with banners, balloons, buckets and leaflets to talk to the public about Huntington's. We had an information stand at the local library and volunteers in Newcastle town centre with buckets and leaflets talking to passers-by. Lighting up the bridge gained lots of attention and many people asked us questions. The Light it up for HD campaign was a huge success - everyone from the branch got involved and there was a great feeling of community spirit.

How has being involved with the branch helped you and your branch members?

J: It's allowed me to stay connected with the HD community. I enjoy getting together with my HD friends and keeping up to date with information, events and research. I feel part of a family where everyone understands. It's given me support and a place to go to talk and share experiences. It helps people who attend by reducing feelings of isolation

and helping them to access local support. They can meet others who understand and make lifelong friendships.

C: Our committee are all brilliant and very supportive. Our members know that we are there for them, whatever the problem. We are like a close knit family.

I'm training to be a counsellor so my role as chair helps with this. Some members like to talk. Some people are seeking counselling but want to talk to someone who knows about Huntington's and understands. Now my two nephews have Huntington's, I can use my experiences and knowledge to help them and others.

What does the branch mean to you?

J: It gives me a sense of belonging and giving back to the Huntington's community. It's a big part of my life and who I am as a person. It's my family.

HDA branches and support groups meet up and down the country. To find your nearest group visit

 www.hda.org.uk/branches

C: The group means a lot to me. We help each other, which means I get comfort from others too. I feel very privileged to be able to do this. Our Specialist HD Adviser John helps us enormously and we couldn't do it without his help and advice. The group can only go from strength to strength.

Top 10 tips: Caring for someone with Huntington's disease

Are you caring for someone with Huntington's disease?

Huntington's affects the network of nerve tissues in the brain and spinal cord that co-ordinates our bodies. It changes the whole person – body, mind and behaviour.

But a person with Huntington's disease doesn't always realise that they're changing. They can find it difficult to express their thoughts – and speech can be a challenge. The person may not tell you how they feel.

If you're caring for someone with Huntington's disease, this checklist could help you.

Tip 1 Check hunger



A person with Huntington's disease needs a nourishing diet and increased calories in a way that is manageable. The person with Huntington's disease may have lost any feelings of hunger. They may have lost their sense of taste.

A better diet has a big impact on overall wellbeing.

If the person is hungry, this can have a negative impact on their movements and mood. Making sure that the person is not hungry can have a positive impact on movements – and reduce their frustration and fatigue.

Tip 2 Check pain



Pain can affect mood and emotional wellbeing. The person may not tell you how they feel. Changes caused by the disease may mean that the person can't feel pain anymore. This is dangerous, especially if the person cuts or burns themselves. So, if you think that the person could be in pain, always ask.

Tip 3 Check temperature



Check if the person is too hot or too cold. A person with Huntington's disease may not tell you how they feel, so always ask. Check the person's clothing and room temperature to make things better.

Tip 4 Check communication challenges



Communication challenges can make the person feel frustrated and anxious. This can have a negative impact on their movements. Hunger, pain, mood and room temperature can all have an impact on the person's ability to communicate. A speech therapist can make an assessment, give useful advice and introduce exercises to help with speech. This can also help the person to swallow more safely.

Tip 5 Check if something has changed



Depression is very common for people with Huntington's disease. The person can also become frustrated, angry, irritable and more impulsive. If you're concerned about the person's mood, check if something has changed. Also check if the person is hungry, too hot or too cold, tired because they're not sleeping, feeling lonely or frightened, or has another health condition.

Tip 6 Check falls



If the person is falling more frequently, check that they are getting a nourishing diet. Also check their mood, if the person is too hot or too cold, tired because they're not sleeping, or has another health condition. Also check the person's environment and make any necessary changes to prevent falls. An occupational therapist can help with this.

For more information
about caring for
someone with
Huntington's disease
please visit:
[www.hda.org.uk/
carers](http://www.hda.org.uk/carers)

Tip 7 Check sleep



Huntington's disease can make the person really fatigued. Poor sleep is common – and can be the reason for changes in mood and overall wellbeing. Short power naps during the day can be really helpful. Read Professor Jenny Morton's simple rules for a great night's sleep on the HDBuzz website: hdbuzz.net/120

Tip 8 Check medication



Check if the person is under or over-medicated because this can have an impact on diet, mood, communication and overall wellbeing.

Tip 9 Check emotional wellbeing



The person with Huntington's disease can feel lonely and frightened. They can think about the same things over and over. This can have a negative impact on overall wellbeing. Help to improve the person's self-esteem and emotional wellbeing through exercise, activities and family support.

Tip 10 Check other health conditions



If you've checked whether the person is hungry, too hot or too cold, tired because they're not sleeping, or feeling lonely or frightened and you're still concerned about a particular issue, then this could be related to another health condition. Remind the person's GP that people with Huntington's disease can also have other health conditions.

You can cut out and keep these pages to refer back to or give a copy to support workers, carers and healthcare professionals helping you look after your loved one.

Visit our online shop

Browse and buy from our brand new range of awareness raising merchandise and support the Huntington's Disease Association.

Visit our online shop
www.hda.org.uk/shop

Be part of the team! Our stylish t-shirts are on sale now



New to the shop!
Be one of the first to buy a HDA drinks bottle



Support the HDA and raise awareness with a wrist band



Get in touch

For advice and support or to speak to a Specialist HD Adviser

Email: **info@hda.org.uk**

Phone: **0151 331 5444**

Web: **www.hda.org.uk/supportnearyou**

Get involved

Become a fundraising volunteer

Email: **fundraising@hda.org.uk**

Phone: **0151 441 5445**

Web: **www.hda.org.uk/fundraising**

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We'll be there