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# Magazine

Autumn 2021



Huntington's  
Disease  
Association

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Cath Stanley

## News from the Chief Executive, Cath Stanley

It is hard to believe that the nights are drawing in and the leaves on the trees are changing. I hope with the mass vaccination and testing programme we are beginning to emerge back into some sort of normality but I know many of you emerge with battle scars of loved ones lost.

As a charity, we have continued to support and advise in a number of different ways. Our online offering of training, carers meetings, branch leader meetings, support groups, webinars.....the list goes on... has enabled us to reach families throughout the pandemic and continue with this vital aspect of our care. As we begin to reintroduce in-person visits, the virtual support will continue as it means we can offer more support than ever before.

Writing this just after the London Marathon, we continue to be thankful and amazed by the incredible efforts the Huntington's community make on our behalf, whether it is running the marathon, organising a race day, taking part in our #HD8000 series of events, selling jam.....whatever it is, your contribution is so appreciated and helps us to be there to support those affected by Huntington's disease.

I recently attended the virtual European Huntington's Disease Network conference. The thing that struck me most about the event was the amount of research happening in the field of Huntington's disease. This is also reflected in the number of pharmaceutical companies who are taking an interest Huntington's. Working with these companies to give them a better understanding of the disease has become a big part of our role.

We really enjoyed virtually seeing many of you at our 50th anniversary conference and AGM, we had a great lineup of speakers and it was a fantastic event. Read on in this magazine to find an update of the event and a recording which you can watch at your own leisure.

Finally, if you haven't already, please sign up to our mailing list so we can keep in touch and tell you more about upcoming events and our work. You can sign up by visiting our website and navigating to 'Get involved' and clicking '[Join our mailing list](#)'.

*Cath Stanley*

Chief Executive



# A note from the Chair, Professor Hugh Rickards

The Huntington's disease community has experienced a year of loss. Some of us have lost friends, relatives and patients in relation to COVID-19 and have witnessed how devastating that illness can be, especially to people who are otherwise physically vulnerable. As the virus tsunami starts to recede, we are starting to rebuild slowly. For many of us, it's about re-awakening old habits and attachments, but also considering the new patterns that have emerged. There are those people whose illness has been worsened by isolation and lack of structure and who have found it difficult to get help and advice during periods of lockdown. I recognise what a huge strain this can place on families.

The Huntington's Disease Association has been active throughout the pandemic on a work from home basis but is now moving towards reinstating most of our usual functions. Some staff members retired or moved on to other work opportunities over the past 18 months, so we are actively recruiting and training replacements including new Specialist Huntington's Disease Adviser posts. We are also incorporating virtual meetings into

everyday work to allow us to provide support and advice more efficiently. We've managed to keep in a healthy financial state through the pandemic, thanks to the whole team, and we now have the opportunity to strengthen some of our office functions.

We've also been hit by the stopping of two promising clinical trials from Roche and Wave Life Sciences. It's important to realise that we're not "back to square one" though. We are still able to reduce mutant huntingtin levels in the brain consistently, something that we could only dream about five years ago. I'm keenly anticipating the data from the Roche trial, to better understand what the problems with this treatment were and to think about solutions. One of the roles of the Huntington's Disease Association is to evaluate clinical trial information and provide updates to the Huntington's community. In both the Roche and Wave Life Sciences cases, it is clear that both trials were stopped for good reasons. As Cath has mentioned, there are a number of other pharmaceutical companies reaching out to our organisation for advice and joint-working. Of course, this is very encouraging

for the whole community. As a charity, we have a huge job on our hands to understand how pharmaceutical companies work, as well as regulatory and licencing bodies and biotech companies. All these pharmaceutical companies are involved in Huntington's disease because they believe they can develop products that will benefit our community. This is immensely encouraging but the Huntington's Disease Association is on a pretty steep learning curve.

Alongside this work, we'll be developing a new charity strategy for the next five years. Central to that process is understanding what you, our members, really want from the organisation and trying our best to respond to that. In the meantime, a huge thanks to all of you who have walked, cycled, ran, sold things (and too many other things to mention) to raise money for us. You're amazing! Thanks to all our members and staff for your patience, resilience and adaptability in the face of huge challenges.

*"She stood in the storm and when the wind did not blow her way, she adjusted her sails."*

-Elizabeth Edwards.

*Professor Hugh Rickards,*  
Chair of the Board of Trustees.



Professor Hugh Rickards

# Through my eyes - A journey into Huntington's disease

**Everyone's Huntington's story is different. Some know about the disease affecting their families from a young age, to others, it comes as a surprise. In this honest and open piece, Geraldine shares the rollercoaster ride that is her family's Huntington's journey and how her determination to raise awareness of the disease led her to speak on BBC Radio 4.**

## Chapter 1 - Geraldine and Huntington's disease

I'm Geraldine (Gez), I'm 38 and live in South Wales. I'm a mother of two to Ewan and Lacey. I've been married to Robin (Rob) for 16 years and I am a primary school teacher.

I first found out that Huntington's disease was in my family when I was 17. I don't think I really understood back then how much impact it would have on my life. At that time I was still in school, focused on completing my A-levels and going to university. My mum and dad sat me down and told me how my aunt, Ann, had tested positive and was showing symptoms of Huntington's disease, but up until that point, they didn't know whether my mum would get the disease. My mum's dad, Bill, had died when my mum was 16 and at that time they didn't know if he had Huntington's or not. So finding out Ann was positive, meant that my mum then had a 50% chance of inheriting the disease.

## Chapter 2 - To test or not to test?

The next few years were a blur, Huntington's was always there but I didn't really pay much attention to it. Over those years, we found out that all of my mum's five siblings, bar one, Aidan, had inherited the disease. Unfortunately, we will never know whether Aidan had Huntington's, as he was killed over 30 years ago.

In 2005, I had finished university and was due to get married to Rob. This is when I went for my first appointment at the genetic clinic, I took Rob with me as I wanted him to know exactly what he was getting into and give him the opportunity to leave if he so wished. At the appointment, we discussed having the genetic test but as my mum didn't know her outcome, I felt I wasn't in a position to have the test, because if I was negative then brilliant, but what if I was positive? That it would mean my mum would definitely have the disease.

## Chapter 3 - Life is looking up

In 2005, Rob and I got married, everything was fine. My mum had always said if she reached 50 she was going to have a massive party to celebrate, as Huntington's onset is usually between the ages of 30-50. Mum turned 50 and in May 2008 she had a massive party! We thought we were in the clear. I was pregnant at the time and in August 2008 our beautiful son, Ewan was born. Life was good, we were happy and Huntington's disease wasn't an issue for us. Yes, I was still surrounded by it as it was ravaging the lives of my aunties and uncle but still, we carried on. Both my brothers were happy, off to university and having a great time.



Geraldine (right) with  
mum, Bern (left)



## Chapter 4 - A Christmas to remember

Fast forward to Christmas 2009, the Christmas I will never forget. Christmas Day itself was lovely, Ewan was 16 months old and into everything! Mum, Dad and my two brothers came to our house for Christmas Day, Mum seemed a bit vacant at times but ok. On Boxing Day we went to Rob's parents to celebrate with them. In the afternoon, I had a phone call from my dad to say he was going to take my mum to the out of hours at St. Woolos Hospital. He was very concerned, she was acting extremely strange and seemed to be having a psychotic episode.

I met my dad and one of my brothers at the hospital. To say Mum was acting odd was the understatement of the year. The Doctor came out and called my mum, "Bernadette Basley" my mum refused to move, saying "That's not my name" (everyone calls her 'Bern', and has done for years) As you can imagine, the doctor was getting frustrated, he just put my mum down to being drunk and said that he "hadn't got time for this". At this point my usually calm and quiet dad shouted "wait, hang on!" and made my mum get up. That's when me and my brother went outside and cried.

After the hospital visit, my mum had been in bed since Boxing Day, only getting up to use the toilet. She was refusing to eat and drink, so needless to say she didn't need to go often! I'd go and talk to her in bed, trying to persuade her to get out - nothing worked. I remember standing in the kitchen, my brothers, dad and I, discussing the need for a genetic test for Mum. This is when Dad told us that Mum had been tested back in December 2007 and was positive for the Huntington gene. They had decided not to tell us. They thought it was the best thing and that it would become obvious as time went on. As it turns out, the week Mum got her test results in 2007 was the week we told them I was pregnant.

We eventually got Mum downstairs and sitting at the dining table, she still wouldn't eat. At this point, I completely lost it. I told her she was being "f\*\*king selfish" - I never swear in front of my parents. I then told her that yes, she had Huntington's, and yes it's s\*\*t, but we love her and would be there for her. I then burst into tears. Neither of my brothers knew what to do, they both tried to hug me and in my angry state I shrugged them off. My mum then reached out and ate a mince pie! Life went back to normal then, well as normal as it can be, but things needed to change.

## Chapter 5 - Life will always go on

We got ourselves into a routine and life carried on, in February 2011 our beautiful daughter, Lacey, came to join us - our family was complete. Things were hard but we were getting through it. My dad took early retirement so he could spend quality time with Mum before it all became impossible. Things got difficult around May 2014, Dad was coming to the realisation that things were changing and it was hard. I remember him getting upset the day after his birthday when he realised that my mum would never bake him a birthday cake again - I had made one for him, after discussing it with Mum.

May 2017, Mum was in a wheelchair, but we all flew out to America for my brother's wedding. She even managed to stand up with support for some photos. She looked so happy. It was so nice to all be together for a happy occasion. I remember really relaxing and having a great time, it was good.

Huntington's carries on, Mum has got progressively worse, she has carers in, struggles to eat, can't walk, struggles to talk, can't do anything independently. I find it hard. Hard to see. Hard to be around. Hard to understand her. In her eyes, nothing has changed but in mine, everything has. My mum is not my mum anymore. I miss her, I miss the carefree times we had, the times we went shopping together, the things that a mother and a daughter should do.



Geraldine and family

## Chapter 6 - Opening up

I have struggled with my own mental health and find I am constantly questioning myself. I do not know whether I have the gene or not, I cannot bear the thought that I may have given it to Ewan and Lacey, I do not want them to ever feel like I am now.

I am trying to do everything I can with regards to Huntington's without knowing my "status". I am taking part in medical research, I am a number! Somewhere in Italy, that number states whether I have the gene or not. Around 20 months ago, I started the medical research journey and I have an amazing team supporting me and Rob. I know if the time comes they will do the same for Ewan and Lacey. We limit how much information we tell Ewan and Lacey as I genuinely believe that there will be a cure. Let them be children. Let them live.

Around two years ago my brother came over from America, we were talking about Huntington's, he told me he had the test and it was negative! This was amazing news! I was so pleased for him, and still am. However, how could I have a test? What would this mean for Ewan and Lacey? I needed to do something, something to remind me that life is too short. A tattoo - no, I would never decide what to have! A piercing, yes, so off I went and had my nipple done! It didn't hurt, I think I was just running on adrenaline. I see it every day as I get dressed and it reminds me that life is in fact too short, and I can do this!

It's really hard at times to remember Mum without Huntington's, yet we have glimmers of her. We had just come out of lockdown when Mum and Dad came over, we have skateboard ramps in the garden, so Dad said shall we take Mum on the ramps, Ewan and Lacey said yes, so Mum went on, giggling away - she loved it! It was like she was her again! She loved roller coasters and it reminded me of that - little things that you forget! I've decided to get a virtual reality headset so she can really pretend she's on a roller coaster - I hope she enjoys it!

## Chapter 7 - Fighting Huntington's disease

That night Ewan started asking questions, we have never kept the words 'Huntington's disease' a secret, we'd just not told the children the implications. I couldn't lie to him, we explained that I was at risk, but we have to live in hope, we can not fear it, we have to live life to the full. I explained that medical research was taking place and I was doing everything I could to help. He then said, "look how quickly they found a vaccination for COVID-19, could they find a cure?" I explained that a lot of money went into the research for COVID and unfortunately that isn't necessarily the case for Huntington's, at which point Ewan, who has previously fundraised, said "I'm going to do everything I can to raise awareness and fundraise for it so that more people know about it, there is more money for different kinds of research, and then a cure can be found sooner." I am determined to follow my son's example to raise awareness and to fundraise, as every little thing helps, you never know who is listening, and what they can do. I try really hard to not let the disease affect me, but it is always there. I question everything, I've struggled with depression - work-related, but then think is it real or is it the start of something? I have to live in hope, I have to live for my children!

I recently took part in BBC Radio 4's The Listening Project - a radio show that shares intimate conversations between friends or relatives, to build a unique picture of British lives today. We recorded for over two hours, which was hard, but amazing at the same time. The person I was on the show with to is so inspiring, I am still in touch with her, she has become a good friend, we have weekly catch-ups, despite living over 400 miles apart. I would love to meet her face-to-face one day! For anyone who is thinking of doing something similar - do it! You never know who you may meet, who may hear what you have to say and what will become of it!

**You can listen to Geraldine's BBC Radio 4 interview, ['The Listening Project, Anything Is Possible'](#), on the BBC website.**

**A huge thank you to Geraldine for sharing her story. If you are affected by Huntington's disease and need support or advice, please contact us on 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk).**



# Integrating back into society after COVID-19 and the impact on mental well-being

**COVID-19 has been extremely tough for most of society including those affected by neurological illnesses. Lack of social interaction, not seeing loved ones and being isolated with the same people for a long period of time has been extremely hard for those with Huntington's disease, carers and family members alike. In this article, Clinical Psychologist Dr Maria Dale talks about ways in which COVID-19 has impacted mental well-being for people affected by Huntington's disease and makes suggestions on how to integrate back into society now lockdowns are lifted.**

## About Maria

Maria is a Clinical Psychologist for a specialist Huntington's disease service in Leicestershire. She is also co-chair of the Psychological Interventions and Approaches Working Group for the European Huntington's Disease Network. Maria was recently involved in the British Psychological Society's guidance

on psychological interventions for people with Huntington's disease.

## How has COVID-19 impacted Huntington's disease families?

It has been over 18 months since the COVID-19 pandemic started to change all our lives. According to Public Health England's [COVID-19: mental health and well-being surveillance report](#), during periods of national lockdown and high COVID-19 cases, there was an increase in psychological distress among the general population. For people affected by Huntington's, whether it is those who live with the disease or loved ones who care for those with Huntington's, COVID-19 has had multiple impacts. Visit the [gov.uk](#) website for further information on the COVID-19 mental health and well-being surveillance report.

In terms of healthcare, the pandemic resulted in people with Huntington's not having face-to-face visits by professionals and being frightened to visit their GP or hospital if they were ill. They also experienced increased waiting times for appointments. The closure of daycare, shops, hotels, restaurants and leisure facilities has meant that rewarding activities, such as going for a coffee with friends or having a weekend away, have been less available.

Much has been spoken about the isolation that the pandemic has brought upon people. Many people with Huntington's were deemed clinically extremely vulnerable and were asked to shield. Moreover, for Huntington's patients in hospitals or care homes, the lack of visits from loved ones has been a particularly cruel aspect of how the COVID-19 pandemic has affected families. Aside from the loneliness this has caused, some consider that such isolation has been detrimental to

people with Huntington's social skills, and cognitive, physical and functional capacities. Caring for someone with Huntington's can be challenging at the best of times. During the pandemic, these pressures have been exacerbated, with many carers having been alone with their loved ones, carrying out caring roles within isolation for a very long time. Or they have been unable to see or touch their loved one who is in a care facility. For those with children, periods of homeschooling, with children frequently isolating at home, has also added to the stress.

## Reintegrating after covid

### Establishing new routines

After such a drastic change to our habits and routines during the pandemic, it might not be easy for many people to return to pre-pandemic "normality". This is the case for people more generally, let alone someone living with Huntington's. We know that people affected by the cognitive aspects of Huntington's will find change to routine difficult. New habits and patterns are likely to have been established during the COVID-19 pandemic after having isolated and socially distanced for so long. Therefore, reconnecting after this time might cause distress to some people with Huntington's who struggle with change. People



Dr Maria Dale



## ADVICE

with Huntington's who have been shielding and have spent little time out and about during the pandemic might find it difficult to adjust to being back in society with changes that have occurred during that time, such as following advice about "hands, face, space and ventilation".

Using general tips for building a routine and dealing with the cognitive symptoms of Huntington's will help in this transition - see pages 7-9 of our [Behaviour and Communication guide](#) which you will find on our website. If you do not have access to a computer, you can contact us for a hard copy. Establishing a new routine involving reconnecting and socialising again is likely to take time, discipline and support. It might be that returning to daily life post-COVID will be easier if routines that have built up during lockdowns are worked around rather than changed. People with Huntington's can experience "cognitive overload" from too much stimulation therefore it is important to pace any such changes and not place too many demands on the person with the disease. Family members might find themselves having to adjust expectations of the person affected by Huntington's as changes in the person's abilities or behaviours might well have occurred over the pandemic period.

### Loneliness and reconnecting

After the loneliness and isolation that the pandemic brought, the ability to rebuild our lives is important. Reconnecting is crucial as we know that loneliness is bad for our health. However, while we might be keen to jump back into social activities, there might be some fear and uncertainty.

We will all need to exercise patience, compassion and understanding, as there will be a variety of responses to the return to daily life in a post-pandemic society. While we had to learn how to try to stay connected during the pandemic with the use of online meetings and the like, it will be challenging to know how to reconnect again in our more traditional ways. People have varying degrees of fear about contact with others, and there will be a range of responses as to how people reconnect. Differing opinions, on issues such as wearing a mask, could create tensions within families and between friends. Living within the shadow of

Huntington's can be stressful for all members of the family so understanding the impact of Huntington's on others is important. It might be that some people who are at-risk themselves might find it hard to meet up again with someone with more advanced Huntington's disease, even if they are a loved one. Understanding and giving each other opportunities to talk about Huntington's and the impact of the pandemic can be beneficial, but not forcing the issue is important, and people vary widely in how easy they find opening up about this. In addition to allowing space to talk, the importance of laughter and fun when reconnecting is not to be underestimated!

### Managing psychological distress

Attempts to return to old routines might be fraught with anxiety and stress. This is to be expected given the number of changes we have undergone. In terms of tackling anxiety in the return to a more regular daily life, this might mean needing to take things slowly. Avoidance is something that can keep anxiety going, and being able to face one's fears is a crucial part of evidence-based psychological approaches such as [cognitive-behaviour therapy](#) (CBT) - visit [nhs.co.uk](https://www.nhs.co.uk) for further resources on CBT. However, jumping into an anxiety-provoking situation is rarely something that people who experience anxiety will wish to do. Building up gradually is usually the best way to help people overcome anxiety. So perhaps if you have a fear of returning to a restaurant or café, try simply leaving your home first to build confidence. This could then be followed by choosing a café where you might initially get a takeaway rather than eating inside, or possibly eat outdoors or in a more ventilated area to begin with. Once anxiety about this comes down, then you could proceed to the next stage more confidently - and make sure you praise yourself (or the person you care for) - as facing anxiety is not easy.



Many people who struggled with their mental well-being during the lockdowns have recovered without the need for professional help. It has been a tremendously stressful time and this context is important to acknowledge. Nevertheless, it is important to seek professional support for anxiety and low mood if these issues persist or become too distressing. In addition to professional support, there are a number of ways to help our mental well-being: connection with nature has numerous benefits, while meditation/mindfulness, taking exercise, eating well and good sleep hygiene are all important. For some, unplugging from the news and social media can help. A number of [mental health apps and tools](#) are available on the [nhs.co.uk](https://www.nhs.co.uk) website.

### Re-evaluating our lives and values

The pandemic might also have been a period of reflection for some. It has been a chance for us all to think about our values and what gives life meaning and purpose. Returning to “normal” might involve some re-evaluation and this could potentially bring about positive changes. Ask yourself, what are the things that give my life, and/or the person that I am caring for, meaning? Maybe there are things from pre-pandemic days that we don’t need anymore?

Recently, in a research paper, a group of people in the UK described their experiences of living in the

premanifest stage of Huntington’s. A number of themes were mentioned related to psychological well-being. Despite the very real difficulties which Huntington’s presented to individuals and their families, hope prevented them from being paralysed by the fear of the disease and allowed them to live their lives. Participants talked about ‘making the most of time’, staying positive, and choosing valued connections. You can view this paper by Googling [‘The experience of a sample of individuals in the United Kingdom living in the pre-manifest stage of Huntington’s disease: An interpretative phenomenological analysis’](#).

Unfortunately, though we are focussing on re-integrating into society, we don’t yet have a clear sight of the end of the pandemic, the future remains uncertain, and so developing a plan now that will enable you and your loved ones to reconnect may be beneficial.

Compassion for ourselves, as well as empathy for others, is important and it is vital to take care of ourselves to enable the reintegration and social connectedness that we all need.

Thank you to Dr Maria Dale for her useful advice and tips on integrating back into society without COVID-19 restrictions.

If you are struggling with reintegration back into society after

COVID-19 and would like some additional support, please contact us on **0151 331 5444** or email [info@hda.org.uk](mailto:info@hda.org.uk).

**If you are a carer who needs a break, please take a look at the [carer well-being section](#) of our website [hda.org.uk](https://www.hda.org.uk). There you will find guided meditations, nutritional advice and instructional yoga videos to help you look after your own health and well-being as well as the person you care for.**



# Huntington's disease and using the toilet

**Huntington's disease affects the body's nervous system, the network of nerve tissues in the brain and spinal cord that coordinate the body's activities such as the bladder and the bowel. These changes can result in bladder overactivity and uncomfortable bowel symptoms. In this piece, Occupational Therapist, Kirsty Page, discusses common problems such as going to the toilet with Huntington's and gives advice on helping those affected.**

## Issues with using the toilet through the stages

Due to the neurological changes that someone with Huntington's disease may be experiencing, different symptoms relating to going to the toilet may occur. These can include an increased urgency and frequency to urinate, waking at night to urinate and urinary incontinence. Bowel symptoms may include constipation, stool retention, faecal incontinence and impairment of the sensory perception of the need to defecate.

Gradual changes in a person's ability to carry out and manage going to the toilet appear as Huntington's disease progresses, these changes can impact an individual's quality of life. It is helpful to understand these changes at the different stages of the disease to identify strategies and equipment to maintain independence and safety for as long as possible.

## Early stages - Forward planning

In the early stages of Huntington's disease, changes in the frequency or urgency to urinate will result in more frequent toilet trips. Anxiety of being away from home, finding a toilet and possible urinary incontinence can impact normal activities that a person is used to and enjoys. Some people may benefit from planning ahead to where toilets are available when going out. Consider using incontinence products when out of the home to prevent accidents and packing a spare change of clothing. An individual may begin to find the activity of using the toilet becomes slower due to movement difficulties and difficulty in concentrating and planning the task.

## Middle stages - Introduction of support equipment

In the middle stages of Huntington's disease, physical changes in mobility, balance, coordination and involuntary movements will make it increasingly difficult to perform tasks such as standing, getting on and off the toilet, maintaining balance in sitting, undoing buttons/zips, managing clothes and the ability to wipe and clean one's self. As the physical ability to perform the task of going to the toilet becomes more difficult, cognitive and behaviour changes can also impact function. Impulsivity, reduced awareness and self-monitoring, reduced concentration, poor planning and sequencing will all impact on performance to complete the task thoroughly and safely. An individual may not recognise the support they require to maintain their hygiene or gradually stop initiating basic self-care routines such as managing incontinence and resulting in self-neglect.

An Occupational Therapist can assess the person affected by Huntington's physical environment and provide advice on equipment. Handrails - fixed or drop-down - can help with sitting and standing from the toilet. If using a toilet frame, this should be fixed to the floor to prevent it from moving.



Kirsty Page



Toilet seats, wash and dry toilets and commodes can be considered, however equipment must be sturdy and padding considered due to involuntary movements. This reduces the risk of harm whilst still promoting independence for as long as possible. Do expect toilet seats to become loose and need regular tightening or replacing because of involuntary movements and heavy transfers.

Regular toilet routines and consistent approaches from caregivers may assist in slowing down a person who is impulsive when using the toilet. Setting up the toilet and prompting the same sequence of tasks can compensate for cognitive changes enabling the individual to perform the task with support. If an individual is requesting support to go to the toilet, respond immediately as they may not be able to 'wait'.

## Late stages - Medical options implemented

In the later stages of Huntington's disease, people usually become incontinent of both urine and faeces. Good management with appropriate continence products is essential to maintain an individual's comfort, dignity and skin integrity. A continence advisor will be able to offer guidance on the different types of incontinence pads. Regular pads may be ineffective, for example, if a person has involuntary movements. Advice can also be sought on catheterisation, such as a suprapubic catheter. A medical review is important as Antimuscarinic drugs may be considered to medically treat an overactive bladder. Caregivers must observe for urinary tract infections and constipation which can both be common in advanced Huntington's due to poor fluid and nutrition intake, immobility and the side effects of medications.

**Further information on using the toilet with Huntington's disease can be found in our guide ['Care in advanced Huntington's disease'](#) which you will find in the professional section of our website, [hda.org.uk](http://hda.org.uk).**





# Celebrate our 50th anniversary with a Flamenco Queen Amaryllis

**We are delighted to announce the sale of our popular amaryllis for a second year running! This year we're proud to present the stunning Flamenco Queen Amaryllis in partnership with Marshalls Garden who will be selling the flamenco bulb in a beautiful gold pot in honour of our golden 50th anniversary. Bloom into the new year with this stunning flower. All proceeds will go to the Huntington's Disease Association!**

## Why the Flamenco Queen Amaryllis?

The amaryllis has represented Huntington's disease for many years with most charities using the flower as their logo. We chose the Flamenco Queen Amaryllis to represent the passion and drive the Huntington's community exudes every day - from carers who do their utmost to support their loved ones, to young people living in a Huntington's family, people who are presymptomatic or at risk and all those with the disease who demonstrate resilience, love and care. This amaryllis was chosen to celebrate our 50th anniversary with the community in mind and to commemorate the 50 years in which the Huntington's Disease Association has offered support, advice and guidance to those affected by Huntington's disease in England and Wales.

**Buy yours on the Marshall's website today!**

## About the amaryllis

An indoor bulb, this vibrant red and mottled white amaryllis has elegant large blooms atop single flowering stems. Flamenco Queen will often produce up to three separate stems from just one bulb which, when in bloom, complement the beautiful golden pot in which it sits. The bulbs will be dispatched in early December 2021 making them the perfect Christmas present! Flamenco Queen will begin to bloom in January/February 2022, welcoming you into the new year and adding a splash of colour to your home during those winter months.

## Where can you buy one?

You can visit [Marshalls Garden's website](#) to purchase an amaryllis bulb for £16 or save £5 per amaryllis when you buy two or more bulbs! Enter **Flam20** at checkout. You will receive your amaryllis bulb (approx. 26-28cm in size) with compost and a decorative gold plastic pot to give you everything you need to immediately plant and allow it to start growing! The bulbs will be dispatched 9 December 2021 just in time for Christmas.





## Why buy a bulb?

Displaying this beautiful flower in your home shows solidarity with the Huntington's community, representing their strength in the face of Huntington's disease. The bulb also makes for a wonderful and sentimental Christmas gift for your loved ones while raising much-needed funds for the charity and celebrating our 50 years of being there.

You can find further information on our partnership with [Marshalls Garden](#) by visiting [their website](#). For any questions regarding the product please contact Marshalls Garden via their customer service team.





# Interview with the Huntington's Disease Association's founder - Mauveen Jones

**To continue the celebrations of our 50th year supporting those affected by Huntington's disease, we reached out to the charity's founder, Mauveen Jones, for an interview on how the Huntington's Disease Association came to be.**

**Tell us a little about your background and where you are from?**

My name is Mauveen Jones, previously Hart. I was born 1939 and lived in Whitton, Twickenham with my parents and younger brother, born four years later. I attended local schools and later married at the age of 23.

**What's your connection to Huntington's?**

My grandfather, Philip John Wysom, died of Huntington's in 1939. My father, also Philip John Wysom, was the last out of his siblings to develop

Huntington's disease at around the age of 40. His younger brother, Ronald was the first, then his sister Violet was next. The fourth sibling, Stanley, did not get the disease.

When I was about 13, I gradually became aware that there was something wrong with my father, and also that the uncle and aunt above were not talked about. My brother later developed the disease.

**What urged you to seek out others affected by Huntington's?**

In 1965, my husband and I were referred to a consultant, Prof. McArdle, at the National Hospital for Nervous Diseases (now The National Hospital for Neurology and Neurosurgery) in Queen Square, London – this was for 'genetic counselling'. For a start, it was a grim rainy November day. Prior to the 'counselling', nurses twice demanded urine samples from me,



Mauveen Hart

pushing me into the toilets although I protested that I was there because of my father's illness. I thought they had decided I had the disease too and was going to be taken in as a patient. It was very frightening. When we did see Prof. McArdle, it was in a tiered lecture theatre with students in the audience. He told us that because three of my father's family had inherited Huntington's, I had a 75% chance of developing the disease, which is incorrect. He strongly advised us not to have children. He also said that there were only about a dozen or so families with the disease in the UK. I walked out into the rain into Queen Square in great despair. I have avoided the square ever since, even though it is near the British Museum which I visit frequently.

**What was the journey to becoming a charity like?**

In 1970, I read an article in a newspaper about Arlo Guthrie, a US

singer, whose father, Woody Guthrie, had recently died of Huntington's in New York. Woody Guthrie wrote amongst many others, "This Land is Your Land". I wrote and eventually heard from Woody's widow, Marjorie Guthrie, a former dancer with the Martha Graham Dance Company. She had set up the 'Committee to Combat Huntington's Disease' in the US to improve awareness and research into the disease. After Woody's death, other US Huntington's families had contacted Marjorie and she realised that the disease was more prevalent than first thought. Marjorie sent me leaflets with information on the disease – previously I only had the information from Prof. McArdle or a short but frightening description in a medical book.

While I was pondering how to set up something similar in this country, still thinking that our numbers would be small, the Sunday People newspaper ran a story about a family in Hayes with Huntington's. I contacted the reporter and he suggested a letter from me to appear the following Sunday asking other Huntington's families to contact me. I then received a number of letters from families and it was wonderful to read of others who were facing the same problems. I was very frustrated,



having got going, that things then came to a long halt with the postal strike in 1971. In those days, letters were the only way to communicate.

We called ourselves the 'UK Committee to Combat Huntington's Chorea', but most members referred to it as 'Combat', and I remember a social worker years later telling me she had been startled to hear a family constantly referring to 'Combat'.

### **What did starting the charity mean to you?**

It was heart-warming to hear from other families and to not feel so alone. Some gave me names of doctors, consultants etc. who had been helpful to them locally and had an interest in the disease, so I wrote to them with information on our charity. This led to Dr David Stevens of the Gloucester Royal Hospital helping us, and also Dr Adrian Caro in Norfolk and Dr Harper in Cardiff. Dr Stevens wrote the first explanatory booklet on Huntington's disease for us.

Combat grew in membership with a branch network in London and Sheffield being formed and a National Committee taking shape. This was just a matter of following suggestions or ideas from families or professionals. We got a number of

small grants and then came under the aegis of the King's Fund, an independent charitable organisation interested in improving health and care in England. This was very beneficial to us. With grants, we were able to employ our first Social Worker, then a Development Officer and a part-time Admin Assistant.

### **Do you have any advice for others who would like to set up their own charity?**

Someone told me early on to never be put off by asking for help, all it cost was a letter and a stamp. I'll always remember in the early days the joy of receiving our first donation of £5 from a pharmaceutical company. Dogged determination also helps, and applying logic and letting the charity develop itself.

### **Do you have anything else you'd like to share with the Huntington's Disease Association community of today?**

I made a decision not to have children when my father was diagnosed but in common with others from Huntington's families, I've spent the last 60 years dodging the question that inevitably comes up when meeting someone new – it is always 'where do you live' and 'how many children/grandchildren do you have?'. You have to make an instant

decision whether to just say 'None' and leave it at that, or whether to go on to explain Huntington's disease.

Recently, I have remade my Will, which for 'normal' people is pretty simple – they leave their estate to be divided between their children and that's that. I've left mine to be divided amongst 30 younger beneficiaries and charities.

But the real problem recently has been making out a Lasting Power of Attorney, which retired people are strongly encouraged to do by the Government. Again, other people usually use their children to act as their Attorneys. Not having any, and no younger close relatives, I have spent the last six months trying to find an alternative. I contacted 16 agencies from Age Concern to the Office of the Public Guardian, but each could only suggest using 'a trusted family member, younger friend, or a solicitor'. In the end, I had to ask the son of a friend to act for me. I feel awkward putting this on him, but there is no alternative. Mostly I have always shrugged my shoulders over Huntington's but this problem has made me resentful of the far-reaching effect of the disease – from birth to death.

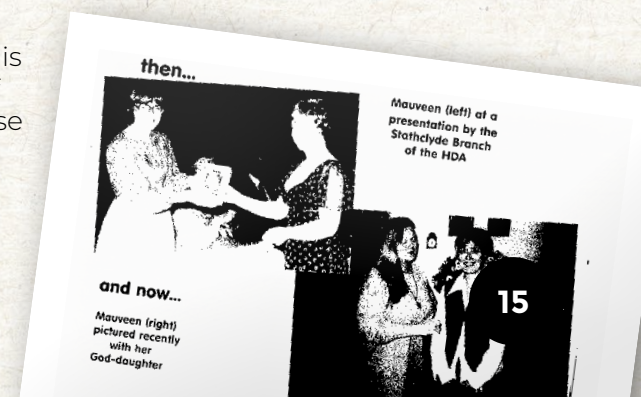
And I can't be the only one who has or had this problem – apart

from other Huntington's families, an elderly person could have two children living abroad and the third nearby but not able to deal with complex paperwork etc.

Additionally, I understand that some younger professionals are choosing not to have children and will in later life, come up against the same problem. I feel this should be discussed on a wider basis.

A massive thank you to Mauveen for enlightening us on the beginnings of the Huntington's Disease Association. We have been offering support to those affected by Huntington's for 50 years and still do to this day. Visit our website, [hda.org.uk](http://hda.org.uk), for more information.

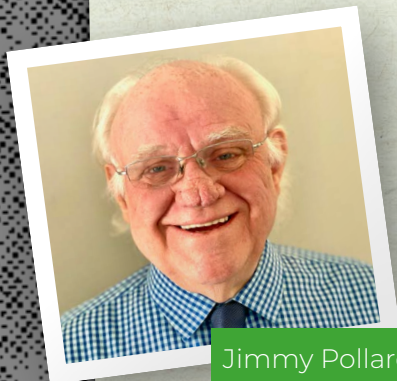
**If you would like to make a donation to thank Mauveen for setting up the charity over 50 years ago and to help the thousands of people with Huntington's disease who still need support today, please visit our website and click [donate](#).**







Alice Wexler



Jimmy Pollard



Professor Ed Wild

## 50th anniversary conference and AGM update

**On 16 October 2021, we held our 50th anniversary conference and Annual General Meeting (AGM). This year, instead of our usual family weekend away, it all took place online. The conference featured world-renowned speakers in the Huntington's community as well as the Huntington's Disease Association's annual general meeting.**

### During the event we heard from...

- » **Professor Hugh Rickards, Neuropsychiatrist and Chair of the Huntington's Disease Association** with an overview of the charity's work in 2020/2021 and our formal business meeting which included the appointment of trustees, auditors and a financial update by our Treasurer, Nick Heath.
- » **Cath Stanley, Chief Executive of the Huntington's Disease Association** who discussed 50 years of the Huntington's Disease Association in celebration of our [50th anniversary](#).
- » **Alice Wexler, Huntington's disease author and historian**

shared the history of Huntington's disease over the last 50 years.

- » **Jimmy Pollard, world-renowned Huntington's expert** explored the practical management of Huntington's disease.
- » **Professor Ed Wild, Professor of Neurology** with a research update.

Below is a brief lowdown of all the charity updates from the event.

### Charity update - The highlights

Our Chair began by discussing our [Specialist Huntington's Disease Advisory Service](#). As one of our key support networks, the advisers provide experienced and compassionate care management, they understand that whole families may need support at all stages of the Huntington's journey. In 2020/21, we had 759 new referrals to the advisory service who provided information and support to 4,148 people.

Due to COVID-19, the way we communicated with those who support us and use our services had to be adapted in 2020/21. We moved to a virtual world in which video support calls, virtual adviser

surgeries and Multi-Disciplinary Team (MDT) meetings alongside the introduction of regular information webinars and online support groups became commonplace. Visit the [events section](#) of our website to see all upcoming webinars and support groups.

Our helpline was very busy at this time with 9,849 phone calls and 26,812 emails being received. 95% of people reported that they found their contact with us helpful, 86% said they obtained relevant information and advice, and 74% came away with improved knowledge and understanding of Huntington's disease. You can utilise this service for support and advice by calling **0151 331 5444** or emailing [info@hda.org.uk](mailto:info@hda.org.uk).

Our [Huntington's Disease Youth Engagement Service](#) (HDYES) supported 212 young people between the ages of 8-25 years. In 2020/21, we had 56 new referrals and a dedicated [HDYES Facebook page](#) was created for additional support for young people. Search @HDAYouthService on Facebook to join the page and get involved today.

**If you would like to watch Hugh's full charity update, we have a recording of the [50th anniversary conference](#) and AGM on our YouTube channel.**



## 50 years of being there - The Huntington's Disease Association through the ages

**Our Chief Executive provided a whistle-stop tour of the Huntington's Disease Association over the last 50 years to commemorate the charity's 50th anniversary, covering 1971 to today.**

1970

Starting with the 1970s when the charity's founder, Mauveen Jones, put a letter in a newspaper called The Sunday People calling for Huntington's families to contact her to the first-ever Huntington's support group in Sheffield and the naming of the charity as the United Kingdom Committee to Combat Huntington's Disease (UKCCHD).

1980-90

Moving onto the 1980s, UKCCHD was officially registered as a charity, the Scottish Huntington's Disease Association was formed and we got our first ever computer.

The 1990s was a time of significant development for the charity. UKCCHD was renamed as the Huntington's Disease Association, the Huntington's gene was discovered and Princess Diana became one of our patrons.

2000

In the 2000s, we launched our first ever website, hired a Juvenile Huntington's disease adviser role and held the first Juvenile Huntington's disease (JHD) Weekend. Tony Hadley and Shane Richie both joined us as patrons and we won an NHS Health and Social Care award.

2010-20

The 2010s saw the launch of our Facebook and Twitter pages, our first young adults event and an audience with Pope Francis at the Vatican. HD Voice, our panel of volunteers who review research and project proposals on behalf of the charity and provide a voice for the Huntington's community, was established and we carried out a prevalence study of Huntington's disease in the UK.

In the 2020s, we have adapted to working in a global pandemic, carried out the ever-popular Family Matters campaign, launched our HD Quality Assured Accreditation scheme for care homes in England and Wales and released our older carers project.

**To catch up on the rest of our 50th anniversary conference and AGM and hear from Alice Wexler with the history of Huntington's disease over the last 50 years, Jimmy Pollard discussing the practical management of Huntington's disease and Ed Wild's research update, visit our [YouTube channel](#).**





## FUNDRAISING

# 2021 Virgin Money London Marathon

**34 runners took part in the 2021 Virgin Money London Marathon on Sunday 03 October 2021 for the Huntington's Disease Association. Runners could take part virtually by running in their local area or by attending the event at the River Thames.**

**Our amazing #TeamHDA runners together raised over £100,000. A huge round of applause for #TeamHDA!**

**Our fastest runner was Antony Beamish, completing the 26.2 miles in a brilliant time of 3 hours 16 minutes and 2 seconds. What an achievement!**



Antony Beamish

18

David Baker, one of our Gold Bond place runners, said -

"Well, what a day. It was so emotional, amazing and genuinely the toughest thing I've ever done, but TOTALLY worth it running for the Huntington's Disease Association. I hope everyone got round ok. We saw fellow #TeamHDA members on our way around, it was so lovely to see fellow Huntington's Disease Association participants and to meet them in person, as fleeting as it was!

I was so proud to be running for the Huntington's Disease Association and to raise lots of cash and to raise awareness of the disease and for the amazing charity that the Huntington's Disease Association is.

Once again, Hannah Longworth, thank you and the charity for everything you've done - accepting my application (twice!), organising all the get-togethers, sending out our kit and pasta packs and supporting us along the way. You're amazing!

And of course, thank you again to Helen for agreeing to run with me and keeping me going at times throughout the race. For someone not directly impacted by Huntington's disease, your selflessness to spend months in training and put yourself through what you have done, is incredible. Love ya.

Helen raised £5,926 doing the marathon but also her amazing employer, Brit, are double matching Helen's sponsorship money and giving another £11,852 on top! They also donated £10,000 earlier this year to the Huntington's Disease Association, so in total, they've donated over £20k on top of what Helen and I raised.

Lots of love, hugs and congratulations to everyone who ran for this amazing cause.

*Dave xxx"*



David Baker & Helen Gemmell



Philip Napleton



Tim Lunnan



Josh Beasley



Katie Johnstone



Charlotte Whetnall



Sabienne North



Lauren Hj

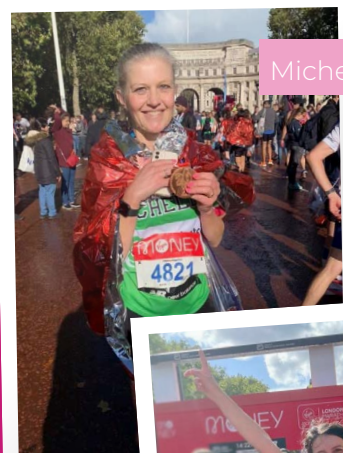




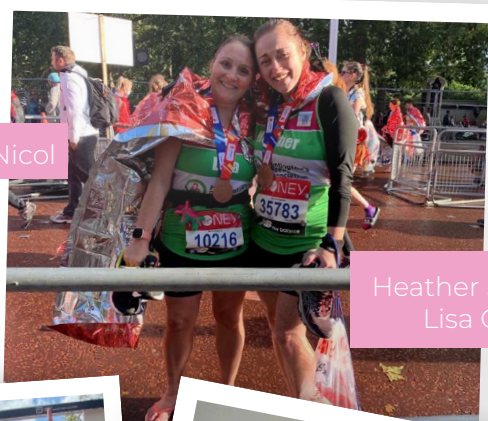
# #HDHike and #HDBike

In May, we called on supporters to step forward for the 8000 people living with Huntington's disease in the UK and join us for our challenge, #HDHike. The Huntington's community rose to the occasion, raising an incredible £28,000 and collectively walking 11,271km - which is the distance from London to New York and back again!

In August, #HDBike took place. Throughout the month we asked our supporters to get on their bikes for Huntington's disease and help us cover a total of 8000km by bike for the 8000 people living with Huntington's disease in the UK. The team raised an amazing £5,000 and cycled 5,234km.



Michelle Nicol

Heather Solan &  
Lisa Guy

Denisa Dumitrascu



John Thompson



Kevin Barrett



Richard Ingle



Hannah Elliot





# The Cuckoo of Awareness - Grief, loss and humour

We're extremely excited to bring you an interview with the author of a brand new novel, *The Cuckoo of Awareness*. Written by father, husband, Huntington's carer and entrepreneur, Andrew Brush, all proceeds for the novel are coming to the Huntington's Disease Association.

**The Cuckoo of Awareness is written in poetic prose with short chapters. The novel deals with delicate subjects surrounding grief, the loss of a child and attempted suicide. Humour and farce occupy nearly every page, with humour acting as a form of relief and something that the author employs in his everyday life as a coping mechanism.**

**Following hard on the heels of tragedy and a botched suicide attempt, *The Cuckoo of Awareness* has flown into the Cotswolds to rescue the life of Tom Atkins - whether he likes it or not. And if that wasn't bad enough, at the same time a 'Black Swan' event - the 'Battle of Wellington Square'**

**the most uplifting peacetime civilian massacres in history - was coming to the doorstep of his home in 'Cheltenhamshire'.**

**'Creative, lyrical, whacky, witty and sad all at once. A great read'. - Eleanore Kelly, Daily Telegraph**

**Andrew was kind enough to share an interview with us on his life with Huntington's disease and why he decided to write '[The Cuckoo of Awareness](#)'.**

**Tell us a little about yourself and your background?**

I am a writer trapped in the body of an entrepreneur with an MSc in Applied Behavioural Sciences - I love the crackle of excitement working in enterprise and helping people get to where they want to go. I've been a carer for my beautiful wife Sophie for the last ten years until she went into a wonderful care home in April 2021. It took me a long time to realise that being a carer is a full-time job - I missed my identity as a businessman and the pride and creativity it gave me. Losing that was difficult for me. I could always fix business problems and find solutions. I couldn't fix Huntington's. Now Sophie is safe and loved, I've sort of lost my job! It was the greatest honour of my life caring for my wife but in all honesty, in the end, my son and I were so exhausted, it was a blessing to lose this occupation. I am now a husband again. You could say

I'm currently unemployed, but the fire for business still burns and I'm now returning my attention to work.

**What is the plot of your book?**

The main protagonist is Tommy Atkins - he's an English teacher which gives the book a literary bent. Tragedy strikes when he loses his cherished son - the grief and pain this causes leads to a botched suicide attempt and the appearance of a voice in his head - 'The Cuckoo of Awareness' who flies in to rescue him and help him carry on with life whether he likes it or not. You're probably thinking 'Blimey, this sounds like a laugh a minute and book to turn to in your hour of need!' Don't be put off; as Mark Twain, the famous American writer said: "Humour is the great thing - the saving thing." There is a lot of absurd crazy humour in the novel to counterbalance the sadness. I needed the same humour to help me cope with Huntington's disease. Without humour as a crutch, I would have fallen over a long time ago.

**Did the experience of caring for your wife with Huntington's disease find its way into the book?**

Inevitably I think it did yes. Like the main protagonist in my book, I've had a rather sad relationship with time. I found it difficult to live in the here and now - the dark worrying gravity of the illness was hard to escape and it felt like I was living in

stale time. The Greeks went to the Oracle at the temple of Delphi for Apollo to tell them their future but with Huntington's disease we don't need to travel that far as so much is revealed in the genetic test. Knowing the future can be a curse.

I have also been struck by the kindness and compassion of strangers in relation to Huntington's and this finds its way into the novel as does the opposite side of ignorance and people thinking Sophie was drunk. The experience of Huntington's disease helped me see more in relation to people's behaviour. Emotions will betray us and leak out of us, but so will illnesses and I am more perceptive now to this.

During the 17th century, women with Huntington's disease were burnt at the stake for being witches! I never felt like burning my wife but I have to say there were times when I felt like a gentle barbecuing was in order.

**Are you raising money for the Huntington's Disease Association via the sale of your book?**

Yes. All the proceeds from the book are going to the Huntington's Disease Association, and deservedly so. Living with Huntington's, there are people that hold your hand, keep you above water and eventually rescue you when you are going down for the last time. You realise what a fragile place

society is without these people, these human atoms of kindness. Our local pharmacy, our wonderful GP practice, the district nurses, but most of all the incredible work and support of the Huntington's Disease Association. Without their support, I couldn't have managed. Sophie, I and my son, Noah, have the three simple words that describe our guardian angel "We Have Carol". Thank God. This is of course Carol Dutton who is a [Specialist Huntington's Disease Adviser](#) at the charity.

Visit our website, [hda.org.uk](http://hda.org.uk), to find an adviser in your local area.

### What do you hope to achieve by writing and selling your book?

I wrote the book because I wanted to entertain people, to make them laugh and cry. Like a chef that wants you to enjoy his food, I wanted people to enjoy the taste of my words. The novel is the original self-help book, it takes us out of our minds. Writing was the same for me, it took me out of my mind and hopefully, it will do the same for others.

### Do you have any advice for people affected by Huntington's disease who may be having similar experiences to you?

Yes. Everybody's experience of Huntington's disease is different. I can only own my own experiences

and share them in the hope there is some universality and comfort in doing so and that you're not alone. Hopefully, I am not a unique screw up!

I can tell you that bombardments of anger won't make a cure. I tried and failed. I got angry with the illness, not the person. At the heart of anger is fear. I was frightened. I hated the sound, the symphony of illnesses truth – the sound of crockery falling and breaking was almost a metaphor for what was happening to my family. Sophie was the percussionist of crash and fall. I hated seeing the bruises bloom on her skin, bearing tender witness, knowing I was not there to protect her when she had fallen. I wanted to cast a gravity spell to watch over her and protect her, drop her gently down to earth. I remember thinking – I wish I was a robot, with a cybernetic love. Robots don't get tired, or resentful or angry. It was easier for me at first to be angry than face the truth, to be in denial is less painful. But it isn't. Don't be hard on yourself - anger, fear, shame, guilt, even feelings of giving up and walking away are all normal, it's very very hard living with Huntington's disease. The clinical diagnosis is different from the reality. The disease will try and steal your identity, your income, your intimacy and your health as a carer. Let's face it, Huntington's disease is a son of a b\*\*ch. In my case, it is also stealing away Sophie the wife, Sophie

the mum, Sophie the daughter, Sophie the auntie and friend, and Sophie the beautiful person we all love. Don't fight it. Surrender to it, accept it. Chromosome 4 might be defective but all the other 22 chromosomes are just perfect - the person I fell in love with will always be there, the illness will try and hide it, extinguish it. Don't let it. Find it.

**Thank you to Andrew for such a touching insight into his life with Huntington's. Putting the emotions felt as a carer into words can be hard for many and we hope that some have found solace in Andrew's words.**

**You can purchase his book 'The Cuckoo of Awareness' as a paperback at [Waterstones](#) for £10.99 and a Kindle edition at [Amazon](#) for £5.99. All proceeds go to supporting people affected by Huntington's disease.**



Andrew Brush



# Welcome new Huntington's Disease Association staff

## Three new advisers you say?

We are so happy to welcome three brand new Specialist Huntington's Disease Advisers to our charity. These new additions to our team will help to bridge the gaps in care across England and Wales whilst bringing new experience and knowledge to the advisory team. Say hello below!

### **Dawn Stilwell - Cambridgeshire, Norfolk, Suffolk and Essex**

"For many years I have worked for disability charities, one of which was around neurological conditions. From time to time I'd see articles or programmes on Huntington's disease and it is a condition that I was drawn to. I have always enjoyed support and advisory work so when I saw the advert for the Specialist Adviser role I knew I had to apply or be forever kicking myself that I hadn't! Fast forward a few months and I'm now four months into the role. I have learned a lot about the condition and have worked with lots of lovely people.



Dawn Stilwell

I continue to learn so much more about Huntington's and its impact on the person affected and their families. It's great to be part of a lovely team who are always happy to help and share their wisdom."

### **Tiffany Stevenson - Cornwall, Devon, Guernsey, Isles of Scilly, Jersey, Somerset**

"I first became aware of the Huntington's Disease Association when I was working with homeless women at a shelter in Birmingham. One of the women I supported showed signs of Huntington's disease but had not yet been formally diagnosed. Whilst supporting her and her family, I became increasingly aware of how little many of the professionals I was working with knew of the condition. It was during this time that I reached out to a Huntington's Disease Association Specialist Adviser to help guide me in this process. I shared the resources available on the website with others to make sure I got the right help for the family. I thought at the time what an important and valuable role this was and how I would love such a role in the future.

Fast forward six years after finishing my social work masters degree, I was seeking a role in a charity that aligned with my values and voila! Here I am. It is all I hoped for and more. I have learnt a lot so far, got to know the great team here, other professionals and the fantastic families that we work with that I am continually in awe of because of their strength and determination. There is still a lot more for me to learn and every day I learn something new from the experts - the families we support."

### **Rachel Boothman - Bedfordshire, Buckinghamshire and Hertfordshire**

"I've received such a warm welcome since starting with the Huntington's Disease Association almost four months ago and I'm delighted to be here. I trained as an occupational therapist over 20 years ago and have worked in the NHS and charity sector throughout my career. I enjoy meeting people, listening to their stories and ensuring they receive the best possible care and support. Sometimes the smallest things can make the biggest difference and it's a privilege to be able to walk alongside families affected by Huntington's. Every day is different and I have learnt so much since starting. Now restrictions have



Tiffany Stevenson

eased and we can see people face to face, I'm looking forward to meeting more families and professionals in my area."

**All our specialist advisers are experienced and compassionate care management professionals. They support anyone who needs help at any stage of the Huntington's journey and can help people living with the disease, people at risk of inheriting the disease, family members and carers, children and young people. They can even advise friends, neighbours, employers and medical teams.**

**We are slowly starting to integrate in-person visits by our specialist advisers back into our support system after COVID-19. If you are affected by Huntington's disease and need support from a specialist adviser, please visit the '[Support near you](#)' section of our website or contact us on [0151 331 5444](tel:01513315444) or email [info@hda.org.uk](mailto:info@hda.org.uk).**



Rachel Boothman



Natalie Parker-Jones

## Two new faces at central office

Our behind the scenes team is also growing with the recruitment of two brand new posts, Senior Individual Giving Co-ordinator and Data Manager. These roles will help streamline our fundraising and the way we manage and use data to show the charity's impact.

### Natalie Parker-Jones - Senior Individual Giving Co-ordinator

"I've always loved working for charities, and I knew I wanted to stay local to my home town of Chester. The Huntington's Disease Association seemed like the perfect opportunity to continue doing what I love, for an amazing cause. I'm only a few weeks in, but there seems so much scope in my role, and everyone I've met (in real life or virtually) has been fantastic."

### John Gandy - Data Manager

"I was delighted to join the Huntington's Disease Association this year as their new Data Manager. My background is in data and information in the charity and social care sectors. Working at the Huntington's Disease Association is a fantastic opportunity to use my skills and experience to have a positive impact on the work of the charity."



## The NHS survey

In August, we worked in partnership with Kent Surrey Sussex Academic Health Science Network, Guildford and Waverley ICP / Surrey Heartlands ICS and Roche to launch a survey that will inform the development of a new service model for Huntington's disease in Surrey.

### About the survey

Standards of care for people affected by Huntington's can vary across the country. This project aims to build on existing services to develop a model that is fit for purpose and provides equitable care for Huntington's disease patients. Initially, the model will service Surrey with the hope of rolling it out across the whole of England and Wales in the future.

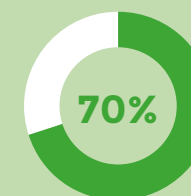
The survey has now taken place with 167 people completing it. Results are being analysed and working groups arranged to

discuss what these findings mean and how they can inform the new service model.

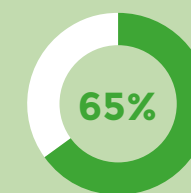
*"This survey offers the unique opportunity for the Huntington's community to have their say into what a service model for Huntington's disease should look like. The NHS currently does not have a service model for Huntington's disease which leads to a huge variation of support received. This survey offers the opportunity to create one. This will promote better care, understanding and support for those affected by Huntington's disease."*

- Cath Stanley, Chief Executive of the Huntington's Disease Association

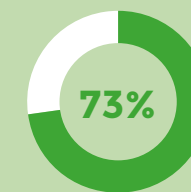
## The results



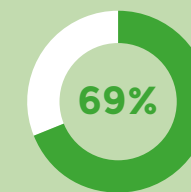
70% of people completed the survey for themselves and 30% on behalf of someone else.



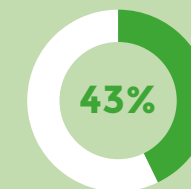
65% said that they have a named Huntington's disease specialist through the NHS or social services.



73% said they have support from the Huntington's Disease Association.



69% were able to contact a named Huntington's disease specialist and get support with difficulties associated with Huntington's disease.



43% know who to contact for advice and support for mental health and well-being services.



John Gandy

These results are mostly great to see with a large percentage of people getting the care they need, however, the survey did unveil areas in need of improvement where the co-ordination of care falls short, for example, when elaborating, people said that their first point of call would be the Huntington's Disease Association rather than the NHS, which is positive for the charity but not for the NHS. People should feel that they can approach the NHS for the care they need.

62 people out of the 167 who completed the survey said that the primary carer of someone affected by Huntington's disease had not received a carer's assessment and 57 said that their local council did not assess their care or needs. 50 people felt their care and treatment plans were not personalised to them and that they didn't have the opportunity to fully discuss their plans with 61 people saying they weren't given information and the opportunity to discuss future care needs.

The survey also showed us that the Huntington's community felt that there were several services that they do not receive that would impact positively on the care and quality of life of someone affected by Huntington's.

These include -

- » Mental health support
- » Psychological support
- » Counselling
- » Respite care
- » Day services
- » Support groups
- » Huntington's disease nurse specialist
- » Support from social services
- » Annual mental health assessment
- » Neurological nurse specialist
- » Emotional support for carers
- » End of life care support
- » Palliative care support
- » A holistic approach

These results show that there is a gap in care and support for those affected by Huntington's disease in England and Wales. The main issue lies with co-ordinating the care for those affected by the disease as there are many people involved in the care and support of one person with Huntington's. These results will be used to create a new service model for the Surrey area that will be used by the NHS to inform and properly synchronise care.

# Save the date

## London Marathon 2022

**When** - Sunday 2 October 2022

**Where** - London

**Cost** - £50 registration fee

The TCS London Marathon (previously Virgin Money, London Marathon have recently changed sponsorship to TSC) is the largest annual fundraising event on the planet - runners have raised over £1 billion for good causes since the race began in 1981. We're looking for 50 people to join #TeamHDA for our 50th year and run the 2022 London Marathon! Take on one of the world's greatest challenges to help support families living with Huntington's. Register for one of our charity places and learn more about the event by visiting the [events section](#) of our website.

## Understanding Huntington's disease - a certificated course for professionals

**When** - Monday 22 November 2021 - Wednesday 24 November 2021

**Where** - Online via Zoom

**Cost** - £110

This three-day course provides a unique opportunity to learn from leading Huntington's experts and virtually meet with fellow professionals working with people affected by Huntington's. We will help you develop a greater understanding of the disease, give you opportunity to share your experiences and ideas and discuss the management of complex situations. Leading Huntington's disease professionals will present online over three days on topics such as genetics, neuro-psychology, psychiatry, physiotherapy, occupational therapy, speech therapy and palliative care. Learn more and book on by visiting the [events section](#) of our website.



# Support groups and upcoming webinars

## Online carers groups

**When** - Various dates throughout the year

**Where** - Online

**Cost** - Free

We are hosting regular online carers groups which offer a safe space for Huntington's disease family carers to speak with others in a similar situation to them. This is a relaxed and informal group giving carers a chance to chat and share experiences. The groups are facilitated by our Specialist Huntington's Disease Advisers and are open to all carers no matter what part of the Huntington's journey they are on or their caring role.

This is an ongoing event. Please email [info@hda.org.uk](mailto:info@hda.org.uk) or call **0151 331 5444** to find out the next available dates, to book on and for further information and instructions on how to join a session.

## Continuing health care webinar

**When** - Friday 19 November 2021

**Where** - Online

**Cost** - Free

Visit the [events section of our website](#) to learn more about our webinars.

## Personal Independence Payments (PIP) webinar

**When** - Tuesday 07 December 2021

**Where** - Online

**Cost** - Free



# Carer resources

Funded by BUPA UK Foundation, we created a [section of our website](#) that is specifically for older carers (65+). The idea of the web pages is to provide carers with resources to aid with their well-being. Although these resources were created with older carers in mind, the information is suitable for carers of all ages.

When visiting the pages you will find an array of useful resources such as our yoga, relaxation and nutrition videos, guides and information sheets, webinars, carers stories, different places to find advice and our online community, the Pop-In-Café. The Pop-In-Café is a great place to find peer support, it allows you to speak to others in a similar situation, ask questions and have a general, helpful chat.

Visit the [Older carers section](#) of our website to locate the resources and learn more.



# Why join our online carers groups?

**We host regular online carers groups which offer a safe space for Huntington's disease family carers to speak with others in a similar situation. This is a relaxed and informal group giving carers a chance to chat and share experiences. The groups are facilitated by our Specialist Huntington's Disease Advisers and are open to all carers no matter what part of the Huntington's journey they are on or their caring role. But why should you join our groups? Below, Susan Fletcher provides an in-depth look at how our carers groups have helped her and her family.**

My husband Tracy has Huntington's. He was diagnosed in 2016 but was showing symptoms before then. We only learned about Huntington's disease when I took his mum for a routine check-up at the doctors. She cried and then I was told the enormity of it all. We'd already had our own daughter, Marie who was two years old at the time.

I swore I wouldn't let her grow up not knowing about it. My husband's

brother Russell died last year from Huntington's, he'd had to be in a secure home as he became violent and struggled with alcoholism.

I joined the Huntington's Disease Association's online carers group during COVID-19 as we had originally met a small group of people affected by Huntington's in our area face to face. One person had Juvenile Huntington's disease and one was affected by severe chorea, each displaying very different symptoms as is common with Huntington's.

The online group, however, meant I could meet people from all over the country and get a bigger sense of us as a community. I learnt about how to obtain respite, that I need to start sorting out Power of Attorney and also realised I could help others who had only just been given a diagnosis of a loved one.

We have laughed, cried, swore, got angry, shared many memories and it's been such a support for me and for my husband.

I can't thank the Huntington's Disease Association enough for getting us all together.

It's been the hardest thing I've ever done, caring for Tracy. It took me a long while to stop feeling guilty, to stop having hysterical sobs sometimes at the enormity of it. But since my daughter bravely had the test at 30, to find she did

not inherit the gene, there's hope on the horizon. It means my little granddaughter will also not have it but she's very clear about what Huntington's is and why grandad has a "funny mouth" and doesn't talk very well. She is five and often chatters away to him, telling him to be careful if he gets wobbly which makes us all laugh, including Tracy.

I've always been a cup half full person so I try to look at the positives, finding ways to have a bit of fun when we can, buying Tracy a cappuccino when we are out, his favourite thing. And continuing to cuddle him even though he shows no love back anymore, that's the hardest bit.

At least I can now share the ups and downs of this crazy part of my life with fellow carers. We have to be tough but like all carers, it's hard work and means we often sacrifice our needs for them. But I will be there for him, until he no longer needs me and then, who knows? That's another chapter in my life.

**You can learn more about our carers groups by visiting the events section of our website, [hda.org.uk/events](https://hda.org.uk/events). You can also email [info@hda.org.uk](mailto:info@hda.org.uk) or call 0151 331 5444 to find out the next available dates and to book on to a session.**



Susan Fletcher

# Research that you can sink your teeth into



Claudia Metzler-Baddeley

## HD-DRUM - Beating mental and motor problems in Huntington's disease with drumming by Claudia Metzler-Baddeley, Reader and Research Fellow, Cardiff University

There are currently no NHS services that can help with movement and thinking changes in Huntington's disease. HD-DRUM is a project funded by Health and Care Research Wales which plans to develop and test a new movement and rhythm training tool that people with Huntington's can use at home. This involves learning drumming sequences that gradually increase in difficulty. Drumming requires key abilities of concentration, planning and making movements, and multi-tasking. The drumming tool will train these key abilities.

Claudia plans to work with people affected by Huntington's disease, their families and carers, and

Kinneir Dufort, a digital software company, to develop a new digital drumming tool, HD-DRUM. In the future, HD-DRUM may be able to provide an enjoyable and remotely accessible training tool to help improve movement and thinking in Huntington's without the risk of harmful side effects.

The project will start at the beginning of 2022. Claudia is looking for people with Huntington's disease to help with the development as well as with the testing of HD-DRUM. Taking part does not require any specific skills but a willingness to meet up with the team in Bristol/Cardiff a few times starting from December 2021 - time/travel compensation is available. If you are interested and would like to find out more, please get in touch with Claudia by emailing [Metzler-BaddeleyC@cardiff.ac.uk](mailto:Metzler-BaddeleyC@cardiff.ac.uk) or calling **029 208 70705**.

## HD VOICE - Have your say

HD Voice is a panel of volunteers who help the Huntington's Disease Association learn about the needs of families living with Huntington's. They work on different projects to help us make sure our information, literature and the research we're involved in has the biggest impact for the people we work with.

Members of HD Voice have a say by helping to select the types of research we get involved with. They also help scientists to plan and develop their research ideas and review the information we share as a charity.

We believe that by encouraging involvement from people with direct experience of Huntington's, our information and the research we are involved in will be more relevant to the needs of the people who need it.

You can learn more about [HD Voice](#) on our website, [hda.org.uk](http://hda.org.uk).

To get involved please contact Ruth Abuzaid at [hdvoice@hda.org.uk](mailto:hdvoice@hda.org.uk) to request an application form or call **0151 331 5444**.





## RightMarket - Get creative

RightMarket is a new design platform that allows you to create on-brand posters, social media posts, leaflets and flyers. Simply register for RightMarket and start designing. All designs are in line with Huntington's Disease Association branding and offer space for your own text and images. To celebrate our 50th anniversary, we've added special 50th banding to all our RightMarket designs. When creating your design, navigate to 'Design options', 'Design' and select '50th Golden Jubilee' to use this feature. This is a free tool for you to use and is great for people who are hosting fundraising events, taking on fundraising challenges or holding Huntington's disease awareness events that they need to promote.

Once you have completed your design, it is sent to us for approval. When approved, you are free to download your design as a pdf and use it online or to print. Please note, all printing costs are the responsibility of the user.

You will find a user guide once logged into RightMarket that explains how to utilise the platform properly.

**Take a look and register  
to use RightMarket here!**

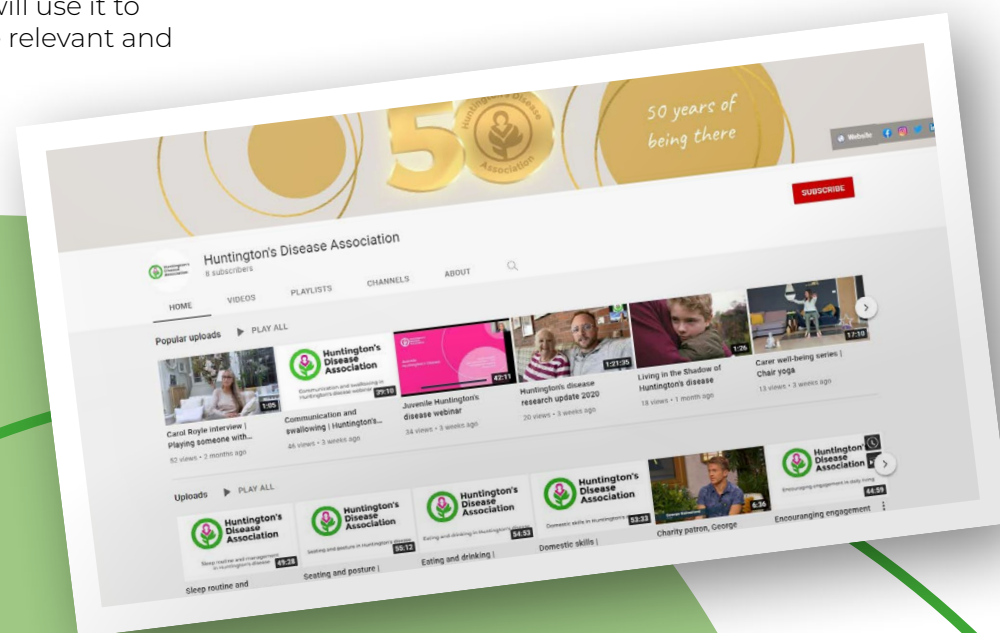
## Our brand new YouTube channel

We are extremely excited to announce that the [Huntington's Disease Association](#) has launched a YouTube channel. All of our charity videos including webinar recordings, Huntington's family interviews and well-being videos will be located here. Just search 'Huntington's Disease Association' on [YouTube](#) and filter the results by channel to find us.

We hope that our channel will be a place for people to not only be educated but also engage with one another in the comments. It is an interactive platform that allows you to have your say on any video. We have made sure that the channel is easy to use by sorting all our videos into playlists. YouTube is also the second biggest social media platform in the world, which means we will use it to raise awareness as well as share relevant and informative information.

Once a video you are watching on YouTube ends, YouTube will auto-play another video related to the current topic you are watching. If you are not comfortable with this and are worried that YouTube will suggest a video you don't want to see, use the scroll bar at the bottom left of the video (desktop) or top right of the video (mobile) to switch auto-play off. This means that you won't be surprised by any content you don't want to see.

**Please [subscribe to our channel today](#), the more subscribers we have the more awareness we can raise!**





## Kim's Friends

[Kim's Friends](#) is an online peer support group formed to support anyone who has undergone a predictive test for Huntington's disease and received a negative test result.

The group is a Facebook group that got its name from a young woman who had experienced predictive testing but sought more support following a negative result. She touched our hearts which urged us to reach out to others and offer support. Search '[Kim's Friends](#)' on Facebook to find the group and join today.

## Useful resources

There are many groups out there made to support people with life-limiting illnesses. Below we have listed a few of our favourites.

[Unforgettable Experiences](#) provide creative, interactive and practical support to help older people with dementia, those with neurological conditions and their carers to access arts, culture and heritage-based activities as an alternative model of care. Visit their website to learn more about the session they hold and how to sign up.

[Golf In Society](#) aims to improve people's lives, whether affected by a chronic illness, a carer seeking a break or someone who is trying to get their life

back on track. They introduce people to the health and well-being benefits of golf by creating opportunities to discover how local golf clubs can become an integral part of a happier, healthier life. Visit their website to learn how you can get involved.

[Willow Foundation](#) is the only national charity working with seriously ill young adults aged 16 to 40 to fulfil uplifting and unforgettable experiences. They provide unique and unforgettable moments and experiences tailored to each individual. Every effort is made to ensure a stress-free, seamless experience, not only meeting but exceeding expectations. Check out their website to see how the Willow Foundation could benefit you.





# Shop

Our shop has a fantastic range of Huntington's Disease Association merchandise for all the family. You can support our work by purchasing anything from a water bottle for your run, informative Huntington's disease books or our 50th anniversary pin badge. These make perfect stocking fillers and all proceeds go to people affected by Huntington's disease. Visit our [website](https://www.hda.org.uk) to make a purchase today and don't forget to stock up on Christmas cards at the same time!



## Contact us

**If you need advice, information or support about Huntington's disease please contact us on 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk)**

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

Website - [www.hda.org.uk](https://www.hda.org.uk)

Facebook - [@hdauk](https://www.facebook.com/hdauk)

Twitter - [@HDA\\_tweeting](https://twitter.com/HDA_tweeting)

Instagram - [@hdauk](https://www.instagram.com/hdauk)

LinkedIn - [Huntington's Disease Association](https://www.linkedin.com/company/huntingtons-disease-association)

YouTube - [Huntington's Disease Association](https://www.youtube.com/channel/UCqK8j8j8j8j8j8j8j8j8j8j)

## We'll be there

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



## Why your donation is so important

Our Specialist Advisory Service provide advice and support to anyone affected by Huntington's disease across England and Wales. 2020 showed us new ways of working, now our advisors are able to provide a mix of in-person and virtual help. This means we can reach more people, offer more advice and make even more of a difference.

Your donation today can ensure that our Specialist Advisers are there when they're needed, directly supporting people living with Huntington's disease and their families. You can donate by using the button below, by visiting the homepage of our website or by calling us on

**0151 331 5444** or email [info@hda.org.uk](mailto:info@hda.org.uk).

## Donate

When you're at a crisis point, the right support can mean everything and the Huntington's Disease Association is there to help. We know we can't stop Huntington's from happening. But we can make sure those affected by the disease receive the knowledge and support they need.

**Together, we can make a big difference. [Please donate today.](https://www.hda.org.uk)**