Huntington's
Disease
Association

Impact Report

2022 - 2023

Inspired by our community

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WELCOME

The Huntington’s Disease Association was founded in 1971 by 76 Huntington’s families. For over 50 years we have supported and helped anyone affected by Huntington's disease across England and Wales.

Everything we do is to ensure we can continue to be there for people affected by Huntington’s disease. Every year brings new challenges, like the disease itself the challenges can be complex.

Our community is anyone affected by Huntington's this could be someone who is gene positive. gene negative, a carer, a family member, or even a neighbour. We aim to educate everyone about the disease. A key audience for us is professionals we work with them to educate and empower them.
We listen to what our community wants and offer events that reflect their needs.
Our fundraising community are the best. They constantly inspire with the things they want to do!
We can not thank them enough for the efforts they create to enable us to continue our support for the people who need it most.

As our fundraising efforts continue so do our investments in the charity. This year we created new roles designed to support people where it makes a difference this includes a helpline advisor, more youth team workers, and a Volunteer Manager so we could support all of our amazing volunteers. This year we created a new post of Policy and Public Affairs Manager - because we want to make a difference and create change where it will make a lasting difference.

This year we reflected on what we had achieved in our last strategy so we could move forward with our new strategy, all Inspired by our community.

We were delighted to have won two awards this year for the Huntington’s Disease Awareness Month campaign, My Family Matters. All four Huntington’s disease charities across the UK and Ireland came together to raise awareness of the impact of Huntington’s disease, not just on individuals but on families too.

Best Campaign
Gene People Awards
2022

Charitable Campaign of the Year
Communiqué Awards
2022

2022 - 2023

Who we are?

Our Vision

A better life for anyone affected by Hutington’s disease.

Our Values

- Tenacious
- Experienced
- Compassionate
- Inclusive

Our mission

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

- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the community and influencing policymakers

Goal 1: Improved Quality Care and Support

Goal 2: Better Knowledge and Understanding of Huntington’s disease

Goal 3: Greater Opportunity for Peer Support and Community Involvement

Goal 4: Improved Understanding of Huntington’s and the Association's Role with the General Public

Goal 5: A Strong Charity to Better Champion the Needs of Our Community

Goal 6: Supporting Huntington’s Research

What difference do we make?

90%
understand more about Huntington's disease after accessing our services

72%
strongly agree or somewhat agree they feel more connected to others

60% strongly agree or somewhat agree they have improved emotional wellbeing

63% of service users strongly agree or somewhat agree they were able to give/receive better quality care

48%
of our users have been using the charities services for more than 7 years

What’s happened at a glance

1

Support - who and how many?

Individuals supported: Over 4600
Family sessons: 989
Children and young people supported : over 350

2

Huntington’s Disease Youth Engagement Service

Support by the youth service: over 350
Family visits: 429
New contacts: 84

3

Working with professionals

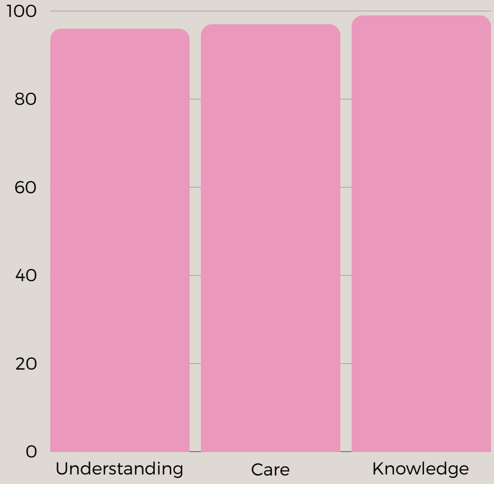
Interactions - email and phone: 16720
Training sessions: 135 sessions with 1368 attendees
Attending professional meetings: 656
Attending HDYES professional meetings: 60
HDYES information sessions for professionals: 19 sessions delivered

4

#HuntingtonsInMind mental health study afternoon

480 professionals attended two mental health courses. The graph below represents the percentage of attendees whose understanding, knowledge and improved ability to care had increased.

The results



What’s happened at a glance

5

Events

Events held 23
Number of attendees Over 1000

6

Membership

Members 4811
Number of people signed up to the online mailing list 4246

7

Website visitors: 284,000

Top visted pages:

- What is Huntington's disease
- News
- Support near you

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Finances

The trustees are pleased to report an unrestricted income of £2,158,146 and restricted funds of £225,977 .

8

Social Media

We are reaching more and more people via social media sharing knowledge and understanding of Huntington’s disease.

Main social channels:
YouTube Total video views 350,000.
339 subscribers
Facebook followers 17,108. Reach 71,796
Instagram followers 3046. Reach 27,606

What our charity beneficiaries said about us

We thought no one understood us until we met you

Our family has had the support of the Huntington's Disease Association at a time of severe emotional stress. It was the only place that could possibly understand the complexities of a family member being diagnosed with Huntington's disease and the impact of that on all concerned. Though one or two family members are accessing the service, it has a trickle effect which enables you to support others in the best way possible."

A welcoming and informative weekend where there is no shortage of chat and laughter as well as the opportunity to make new friends.

JHD Weekend attendee

What you said about us

"The most useful thing I find as a carer of someone affected by Huntington's disease is finding others who are in the same situation, whether that is just following someone who posts on social media regarding Huntington's ...It is so comforting to meet others who are in a similar position to you

The support has been so important whilst growing up and dealing with Huntington's disease - knowing there is someone there who will listen and completely understands makes such a difference!

I learnt about the Huntington's Disease Association after a few years of looking after her. The Specialist Adviser was amazing. He ran sessions in the nursing homes to provide information on Huntington's disease and how best to help patients and he provided help with continuing healthcare (CHC). Our adviser helped me to learn about the disease and give me advice at various stages when needed."

Did you know we have 22 Specialist Advisers covering England and Wales?

Events

We continued to offer online events which can be convenient as are available on demand but were pleased to be able to include a return to some in person events.

Highlights

Volunteer Awards

Five awards were given at this celebration event

JHD Weekend Calvert Trust

It was great to return for another action-packed weekend in the Lake District

Awareness

Huntington's in Mind was the campaign for awareness month, looking at how mental health is affected by Huntington’s disease. Putting lived experience at the heart of the campaign three people shared their story .

#HuntingtonsInMind

- TV coverage - 2 million opportunities to see
- The #HuntingtonsInMind hashtag reached over 1.8 million people
- Print and online coverage - reach of 100.8 million people
- Total stakeholder support on social reach of 4,293,883 people
- Our social media ads garnered over 387,809 impressions

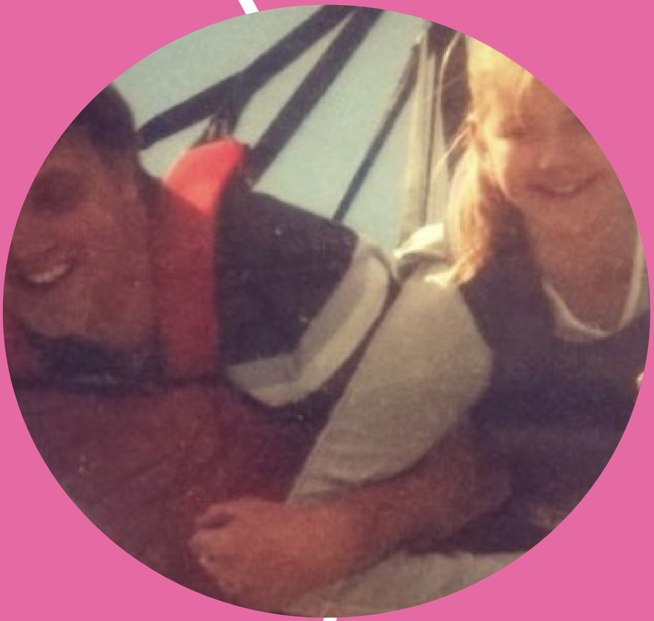
This means more awareness of how Huntington’s disease affects mental health allowing us to create change through our Policy and Public Affairs work.

Championing the community

People sharing stories - helping reduce the stigma associated with the disease. Thank you to everyone who shares their story to support others affected by Huntington's disease .

Huntington's disease at school - Lemarnie's story

#HuntingtonsInMind - Demi's story



Read more stories from the community on the website www.hda.org.uk/stories

What’s next?

As our five year strategy came to an end we spoke to our community to establish:

- What we should do more of
- What we could do better
- What do you want from us over the next five years

The results of this consultation led to our new five year strategy. This has five goals these will be at the heart of everything we do. The goals are ambitious, under each goal we have set out exactly what our ambitions are.

Our community is resilient. Together we will build a better life for people affected by Huntington's disease.

1. We will ensure everyone affected by Huntington's disease gets the care and support they need
2. We will help make each day with Huntington's disease the best possible day
3. We will make sure the voices of people affected by Huntington's disease are heard and are at the heart of everything we do
4. We will not rest until everyone with Huntington's disease has access to treatments
5. We will be a resilient charity

Get in touch

Find out more about
what we do:

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Huntington's Disease Association

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Huntington's Disease Association

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Design by the Huntington's Disease Association

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