

Huntington's disease - you have the power to change lives

HUNTINGTON'S
DISEASE ASSOCIATION
NORTHERN IRELAND



Families at the heart of all we do

Why families in Northern Ireland are struggling

People with Huntington's need long term care, and while most people are cared for at home by family, most also need full time nursing care towards end of life. **Yet, there is only one Huntington's disease nurse specialist in Northern Ireland, and their services can only be accessed by people living in the Belfast or South Eastern Trust.**



? **HDANI is asking: how is it fair that care depends upon where you live within Northern Ireland?**

Unlike other parts of the UK, in Northern Ireland there is no:

- Huntington's disease strategy
- Co-ordinated care pathway for individuals and families
- Access to clinical trials
- HD research site
- Specialist family planning service to prevent passing on the faulty gene



? **HDANI is asking: how can this comparison to other parts of the UK be considered acceptable?**

What we need you to do

We want: A co-ordinated regional approach to the management of Huntington's disease with equitable, person and family centred clinical and social care pathways from the point of predictive diagnosis to end of life care.

We believe: Despite clear commitments by statutory bodies over the past decade the situation has not improved for HD families. We believe therefore, that HDANI are best placed to co-ordinate the design of a HD framework, given their unique expertise, clinical links, knowledge of international best practice and most importantly, the confidence of the Huntington's disease community.



**PLEASE
HELP
US!**

Every person should have timely access to the same information and services from the point of diagnosis regardless where in Northern Ireland they live.



About Huntington's disease

Huntington's disease is a rare and hereditary disorder of the brain which causes people to deteriorate physically, cognitively, and mentally.¹ There is currently **no cure** for Huntington's disease or any way to stop it getting worse. Most people die within twenty years of the start of physical symptoms.¹

RARE DISEASE

Huntington's disease affects between 1 in 10,000 and 1 in 20,000 people in the UK and Ireland.¹

10 ↔ YEARS ↔ 25 DISEASE PROGRESSION

Huntington's disease typically progresses slowly over a 10-25 year period.¹

SYMPTOMS OF DISEASE

The symptoms of Huntington's disease include problems with movement, thinking and cognition, and difficulties with mood.¹

30 ↔ AGE ↔ 50 SYMPTOMS APPEAR

The symptoms of Huntington's disease usually begin to appear between the ages of 30 and 50.¹

JUVENILE HUNTINGTON'S

About 5-10% of people develop symptoms before the age of 20 (known as Juvenile HD).¹

LATE-ONSET AFTER THE AGE OF 60

About 10% of people develop symptoms after the age of 60 (known as late-onset).¹

The impact on the family

Huntington's disease can have a **devastating impact** on families. Children conceived naturally by somebody with Huntington's disease have a **50:50 chance of inheriting** the gene themselves.¹

In addition, many families find their lives completely disrupted by the presence of Huntington's disease within the family unit. It can be **distressing for family members to watch** somebody developing and exhibiting symptoms and deteriorating, and many family members take on **caring responsibilities**, sometimes full-time.



WHOLE FAMILIES AFFECTED

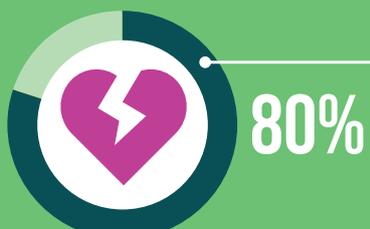
New survey findings

The Huntington's Disease Association Northern Ireland recently took part in a community survey alongside other organisations representing families from across the UK and Ireland.² The aim of the survey was to find out how living with the disease impacts different people within a Huntington's family unit. **These results are from people who responded from across Northern Ireland.**²

Family relationships



100% of people who have tested positive for Huntington's feel concerned about their children having their lives dictated by the disease.²



80% of people who have tested positive for Huntington's say that it has damaged their relationships.²



88% of family carers say that the disease has changed their relationship with their loved ones forever.²

Impact on life course



100% of people with Huntington's have lost their job or had to stop working prematurely as a direct result of their Huntington's disease.²



100% of people with Huntington's have experienced significant problems with their mental health.²

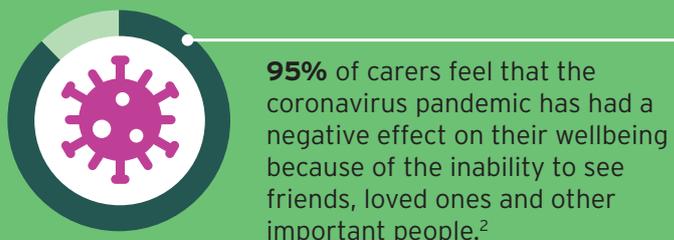


80% of people with Huntington's suspect they have been made fun of in public.²

Impact on carers



100% of people who have tested positive for Huntington's believe that it has as much impact on their partner as it does on them.²



95% of carers feel that the coronavirus pandemic has had a negative effect on their wellbeing because of the inability to see friends, loved ones and other important people.²

The true impact of Huntington's disease is often **not fully visible** as it affects not only those experiencing symptoms but also those who have tested positively but do not yet have symptoms, the people at risk of developing Huntington's and the family members of those living with the symptoms of the disease.

What is needed



64% of carers wish more celebrities or high-profile people would find out about Huntington's and support the Huntington's community.²



91% of carers one told us that most people they have told about Huntington's disease do not know what it is.²

Despite the devastating impact that Huntington's disease has on individuals and families living with it, public understanding and **awareness is very low**, which is particularly noticeable in comparison to other neurological diseases such as dementia, Parkinson's disease and MND. There is a desire within the community to continue raising awareness amongst the public to help improve public understanding of the signs and symptoms, as well as **improving access to treatment and support services**.

In the survey, **64% of carers wish more celebrities or high-profile people would find out about Huntington's and support the Huntington's community.**²

Support from high profile individuals is particularly important to help lead the way with public awareness. In the survey, **91% of carers one told us that most people they have told about Huntington's disease do not know what it is.**²



"HDANI is proud to help shine a light on the experiences of people living with Huntington's disease in Northern Ireland, where people continue to be denied equal access to the essential services necessary to help patients and their families. Huntington's disease is a devastating not only for those living with the disease but for everyone around them. It is vital that we raise awareness so that we can improve equitable access to specialist support services for the many families that cannot access specialist care.



**Sorcha McPhillips, Chief Executive,
Huntington's Disease Association Northern Ireland (HDANI)**



"My father has Huntington's disease and I am at risk, I do not feel ready yet to find out if I have the gene myself. When my Daddy became ill I was a young teenager yet had to take on caring responsibilities alongside my brother. Huntington's has an impact on the whole family and so even though it is a rare condition it affects so many more people than the numbers suggest. It is really isolating and lonely, and it would help so much if there was more awareness.



Laura, Derry

HDANI Contributors

Photo Montage
Ashley Clarke,
Northern Ireland

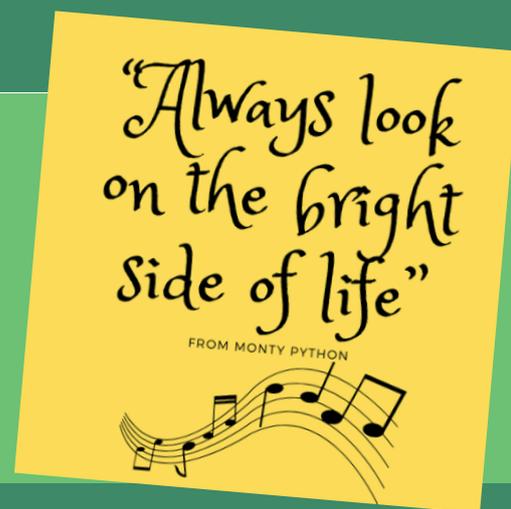


My husband Mickey tested positive for the gene in 1999, after his Mum became symptomatic. We decided to have kids in 2005 - John (14) was the first PGD baby in Northern Ireland with 3% chance of HD and Annie (10) has less than 1%. We lost Mickey's mum (age 66) in 2015 to HD. We will never forget her.

Moira McNulty,
Northern Ireland

Song lyric which was instrumental for me staying positive & keeping me sane when getting the diagnosis.

Heather Hooisma,
HDANI



Huntington -
A Lifelong Journey,
Richard,
Northern Ireland

Huntington by Magdalena Van Renterghem

There was something about her, something,
I could not recognise,
Not then, I was way too young.
But I saw the delicate difference
That is making forty-year-olds older
Even before the body is worn-out.

There was something about her.
While her steps danced softly
In slow-motion,
As her arms followed uninvited.
She lost direction chaotically
The grip on her movements loosened.

There was something about her.
With the hopeless intense process
Still to be who she once was:
Bright, caring, clear-headed
Until her mouth didn't follow her words
And sentences chattered into distorted sounds

There was something about her.
With the years going by
Braincells disappeared, one by one.
Destroyed her body, more and more.
A default of the genes, an unequal
Battle, however brave it is struggled against.

There was something about her.
Until one day she became seventy.
Still little sparks in her eyes,
A burst of sound
Who will ever know, who shall ever measure
The dying before one actually died.

There was something about her, something
That I will recognise now, in the
Endless suffering, in the
Unmasked forced introvertness.
There was something about her, something
That now has got a name.

My Daddy
Laura Clark,
Derry, Northern Ireland

My Daddy

My Daddy is a hero,
He fights a battle every day,
Never backing down,
H.D won't get in his way.

My Daddy is a hero,
He is armed and primed for the fight,
His opponent is no match for him,
He fights with all his might.

My Daddy is a hero,
An army he has got,
We face the fight together,
H.D doesn't have a shot!

My Daddy is a hero,
He'll fight till his last breath,
His armour is that smile of his,
One that can never be met.

Who do HDANI connect with?

We are determined to reach as many people as possible to provide services to HD families, raise awareness and improve standards of professional care.

As of 27th May 2021

134

People living with Huntingtons disease in NI

648

Other HD family members in NI

3850

Health and Social Care Staff

1488

Other Service Providers and Organisations

6224

Follow us on our Facebook, Twitter, You Tube and Instagram pages



How many people in Northern Ireland have Huntington's disease

It is estimated that there are

285

people with HD and

1035

at risk of inheritance.

Can you help us grow our numbers?

Find out more at: www.hdani.org.uk or call **07733935863**

HDANI works throughout Northern Ireland providing support, information, advice and social connections to those living with the impact of Huntington's disease. We run regional support groups, provide telephone and face to face advice and support as well opportunities for families to connect through our events and befriending services.

We also work closely with medical professionals to advocate for the most effective care for our clients and lobby the Executive for improved and efficient services. We provide training and awareness raising events and keep our service users informed of the latest research and medical advances in the quest for effective treatments, and ultimately a cure. The Association is dependent on a small but dedicated team of staff and volunteers who are committed to providing the best possible outcomes to our service users.



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References

1. Huntington's Disease Association Northern Ireland. About HD. Available at: <http://www.hdani.org.uk/cgi-bin/generic?instanceID=2> [Accessed 4 May 2021].
2. Family Matters Community Survey. Conducted online 23 March to 21 April 2021. Results from 63 respondents in Northern Ireland.