

Huntington's disease briefing: what you need to know



Huntington's Disease
Association of Ireland

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.



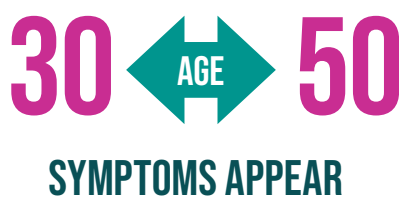
Children conceived naturally by somebody with Huntington's disease have a 50:50 chance of inheriting the gene themselves.¹



The disease typically progresses slowly over a 10-25 year period.¹



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



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



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



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

The impact on the family

Huntington's disease can have a **devastating impact** on families. As well as worries about **children and grandchildren inheriting the disease**, 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.



Huntington's in Ireland

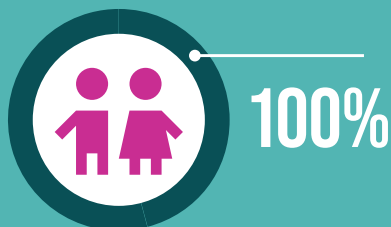
It is estimated that there are approximately **700 people in Ireland currently living with Huntington's disease**, but that there are more than **3,000 people living at risk**. However, these figures are based on Northern Ireland studies as there has been no epidemiological study of Huntington's disease in Ireland.²

3,000
PEOPLE LIVING
AT RISK

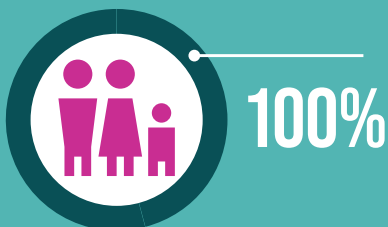
New survey findings

The Huntington's Disease Association of Ireland recently took part in a community survey alongside other organisations representing families in the UK.³ 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 Ireland.**³

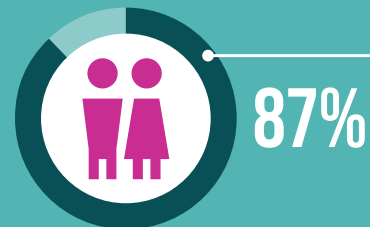
Family relationships



100% of people who have tested positive for Huntington's feel concerned about their children having their lives dictated by the disease.³

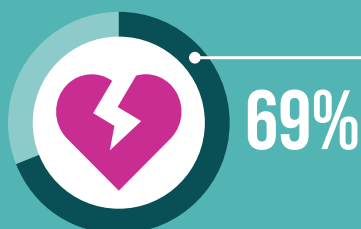


100% of people who have tested positive for Huntington's feel afraid of moving to a more advanced stage of the disease because of the impact on their family.³



87% of family carers say that the disease has changed their relationship with their loved ones forever.³

Mental health and wellbeing



69% of people who have tested negative for the gene themselves but that have watched a parent or relative go through more advanced stages of Huntington's, said the experience has been extremely difficult or has ruined their life.³

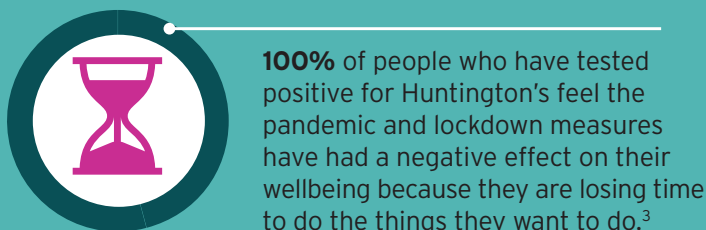


98% of family carers felt that Huntington's disease has negatively impacted their loved one's emotional wellbeing.³

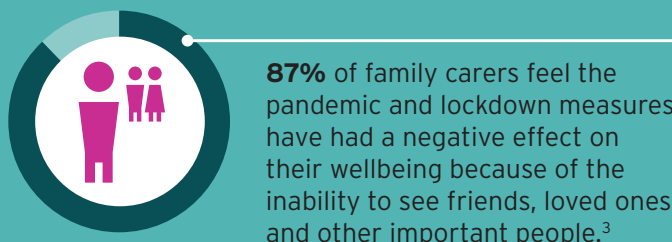


100% of people who have tested positive for the gene but are not yet symptomatic have worried about when to share their Huntington's status.³

Impact of coronavirus



100% of people who have tested positive for Huntington's feel the pandemic and lockdown measures have had a negative effect on their wellbeing because they are losing time to do the things they want to do.³



87% of family carers feel the pandemic and lockdown measures have had a negative effect on their wellbeing because of the inability to see friends, loved ones and other important people.³

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, people at risk of developing Huntington's and the family members of those living with the symptoms of the disease.

What is needed

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**.

The survey showed that **100% of people who have tested positive for the gene but are not yet symptomatic wish more high-profile people would support the Huntington's community**.³

Support from high profile individuals is particularly important to help start conversations about access to care and support services. The survey showed that **76% who care for a loved one with Huntington's do not feel they have appropriate access to services**.³

“Huntington's disease affects families over generations. It is often referred to as 'a disease of families'. The complex symptoms and the hereditary nature of the disease, impacts the physical and mental health, the wellbeing and the relationships of each family member but is most challenging for the person living with the disease. Equitable and timely access to specialist services and resources is vital. We want to highlight the many challenges encountered throughout the Huntington's disease journey so that those affected will have access to the necessary supports to enhance their quality of life.”

Patricia Towey, Information and Services Coordinator,
Huntington's Disease Association of Ireland

“My husband has Huntington's, as does my brother in law. Our whole family is affected, it has been a very difficult journey, with many of us, including the youngsters, taking on caring roles that are extremely difficult. There is so little public awareness, we really need people to understand Huntington's like they understand other conditions, to help families feel less alone.”

Bernie, Dublin

The Huntington's Disease Association of Ireland is a national voluntary organisation, established by family members, to provide support, information and advocacy to people and families living with Huntington's disease. We also aim to raise awareness and increase understanding of Huntington's disease among health and social care professionals, policy makers and the general public.

Find out more at: www.huntingtons.ie.

National Information & Support Service Helpline 1800 393939.



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References

1. Huntington's Disease Association of Ireland. What is Huntington's Disease? Available at: <https://www.huntingtons.ie/What-is-Huntingtons-Disease> [Accessed 4 May 2021].
2. Accurate prevalence and uptake of testing for Huntington's disease (thelancet.com). Is Huntington's disease twice as prevalent as we thought? <https://en.hdbuzz.net/006> [Accessed 4 May 2021].
3. Family Matters Community Survey. Conducted online 23 March to 21 April 2021. 145 respondents from Ireland.