

HUNTINGTON'S
DISEASE ASSOCIATION
NORTHERN IRELAND




Families at the heart of all we do

STRATEGIC
PLANNING

STRATEGIC PLAN

2024 - 2029

Foreword from our CEO	2
A note from our Chair	3
What is Huntington's Disease?	4
The Amaryllis	4
About HDANI	5
Our Mission Statement	5
Our Vision	5
Theme One: Connecting	6
Theme 2: Supporting	7
Theme 3: Informing	8
Theme Four: Advocating	9
Theme Five: Resourcing	10



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.

Original poem by Amy D

Foreword from our CEO

I have found the past eight years with HDANI an incredibly challenging, sometimes frustrating but always rewarding experience. Change is not always easy to achieve and sometimes difficult to accept. I joined a small organisation with a very close-knit group of families bonded by a common struggle and since then the Association has spread its wings to provide meaningful support to hundreds of people across Northern Ireland. This type of impact cannot be achieved without running a charity effectively and efficiently, like a business, while remaining focused on the people we are working for. HDANI's mission is to secure the best quality of life for those impacted by HD and to work with others to increase understanding and management of the disease while pursuing a world free from Huntington's.

Through a dedicated team of staff and volunteers, we have helped people at every step of their HD journey providing information, advice, and practical and emotional support and chances to connect with their peers. The Covid pandemic really exposed just how vital our connection with the HD community is and how much they rely on us.

We have also improved the level of understanding and quality of care received from health and social care providers through the delivery of hundreds of hours of HD training and advocacy. We have gathered evidence about where the people impacted by HD live in Northern Ireland and how the disease affects them and their families and used this information to campaign for better services. We also joined forces with other groups to lobby on wider issues such as carers' rights and the rights of people with disabilities.



We helped raise more public awareness throughout the region through our *Family Matters* campaign with our HD charity partners in Ireland, England, Wales, and Scotland. Using the real-life stories of people living with HD, like our amazing Heather, we were able to share the impact that the disease has on people's lives and in doing so, improve understanding and reduce the stigma they face.

We have the benefit of an energetic network of thousands of colleagues around the world working to support families, change policy, provide care to those living with HD, develop treatments and ultimately find a cure for the disease. I am incredibly grateful to our dedicated team of staff and volunteers, to the funders and fundraisers who make our work possible, to our partners in health and social care who respect our expertise and above all to our service users who trust us to help them navigate their HD journey. I am excited to lead HDANI in this next chapter of our work.

Sorcha

Sorcha McPhillips,
Chief Executive,
May 2024.

A note from our Chair



It has been my privilege to chair the HDANI Board of Trustees since 2019. Huntington's Disease is such a devastating degenerative illness affecting the whole family. Yet, I am humbled and constantly amazed by the resilience and fortitude of everyone that I meet who has been touched by this hideous condition.

As we set out our strategy in this document for the next five years, I want to take this opportunity pay tribute to our management team and staff for their dedication, care, empathy and compassion. I am confident that our fantastic team will transform this strategy into reality.

Finally, lets hope that, by 2029, all the exciting research developments into tackling HD, will have borne fruit and that this disease will be another consigned to history!

Gerry

Gerry McDermott
Chair of the Board of Trustees
May 2024.



Original artwork of the Foyle bridge by our HD service user Simon to raise awareness of mental health.

Please be patient with me

Please be patient with me.
I have Huntington's Disease.
I like to have the same routine,
and I can't do things with ease.

Please be patient with me.
My words are slow and stumbly.
Please give me time, wait and listen,
it's a lot of effort for me.

Please be patient with me.
Emotions to me are abstract.
I do not mean to be so stubborn,
but I can't control how I act.

Please be patient with me.
My thoughts aren't always complete.
I don't understand why things have to change,
and my brain gets stuck on repeat.

Please be patient with me.
I remember how life used to be.
I used to do everything all by myself,
but now it gets done for me.

Original poem by Laura C

What is Huntington's Disease?

Huntington's Disease is a rare genetic neuro-degenerative disorder which gradually causes a person to lose control of their thoughts, feelings, behaviour and movement. Although there is a juvenile form of the disease it mostly strikes people in mid adulthood. Over the course of the disease, usually between ten and twenty years, a person will become entirely dependent on the care of others and many will be unable to communicate or swallow.

HD is caused by a genetic flaw and is inherited by both men and women. It is the ultimate family disease because if you have it there is a 50% chance each of your children will get it and if anyone in your family has HD there is a chance you will have a caring role. Given the nature of the disease, people can end up caring for multiple generations of loved ones or several family members simultaneously- both an incredible burden and an amazing gift.

The physical symptoms of HD are often compounded by depression, social isolation, stress, anxiety, frustration, fear and the guilt of potentially passing the disease on.

In Northern Ireland there are hundreds of people struggling with the symptoms of HD at any one time, many more hundred are at risk of developing the condition and their family and friends will be living with the consequences of the disease. HDANI works with, and on behalf of, all of the people impacted by Huntington's Disease.

There are hundreds of studies, clinical trials and research projects taking place around the world so while there is currently no cure - there is hope.

“ It may seem just a cup of tea and a wee chat about their kids or small things – but it is with people and a safe space where everyone else knows Huntington's so you don't have to mention it – or you can.”

- Service user



The Amaryllis

The 'Amaryllis', the international symbol of Huntington's Disease, represents a double image of a head and shoulders as the flower of a growing and vibrant plant.

The reduced size of the head and shoulders of the white inner part of the flower symbolises the diminution in a person caused by Huntington's Disease. The leaves represent the protection, support, purpose, growth, and development of the Huntington's community worldwide in its search for a cure and treatment.

About HDANI

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, act as a link to other services, advocate for our clients, as well provide opportunities for families and individuals to connect with each other through our events.

We also work closely with medical professionals to help shape and inform the care they provide to our service users and lobby policymakers for improvements in the design, accessibility and delivery of services.

We provide training and awareness-raising events and keep the HD community informed of the latest research and medical advances in the quest for effective treatments and ultimately a cure.


HDANI is dependent on a small but dedicated team of staff and volunteers who are committed to making a meaningful difference in the lives of our service users.

Our Mission Statement

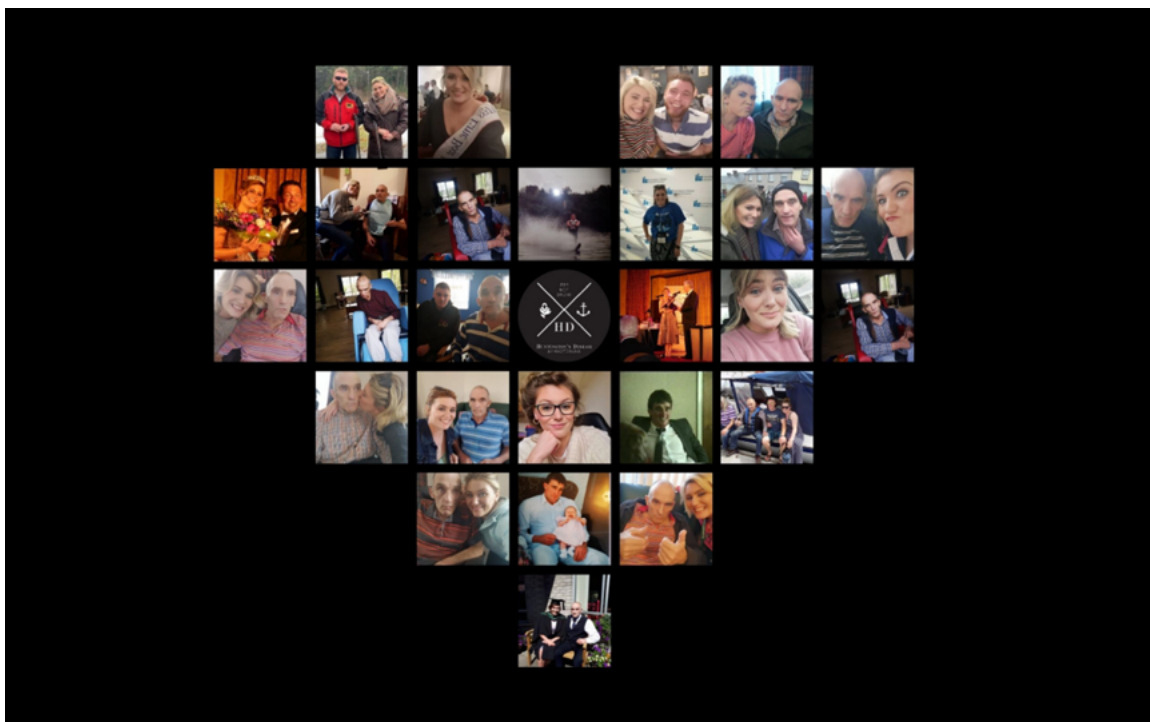
A world free from Huntington's Disease and, until that point, one in which all those affected are accepted and supported.

Our Vision

HDANI's mission is to secure the best quality of life for those impacted by HD and to work with others to increase understanding and management of the disease while pursuing a world free from Huntington's.

 ***There are more people hearing about HD but every time I see a doctor they say "I did something about it in training years ago" - doctors and nurses don't know much about it. Some look it up but many are not helpful or don't have the time."***

- Service user



Theme One: Connecting

Our Goal

To reach as many people as possible impacted by HD and to facilitate events and activities to connect them with each other and relevant services to improve their well-being, increase their capacity to cope, share knowledge and experiences, and reduce social isolation.

Our Objectives

To achieve our goal, we will:

1. Continue to develop our community outreach work and referral pathways with health and social care partners to reach more people affected by HD.
2. Maximise opportunities for service users and their families to connect on a local and regional level via HDANI events, social activities, support groups and online interactions.
3. Work in partnership with other service providers to enable HDANI service users to actively engage in their local community.
4. Further develop our activities, events, and programmes to strengthen our youth engagement and opportunities for young people to build friendships.
5. Ensure that opportunities for engagement enable connections between HDANI teams, Trustees, and the HD community.



Theme Two: Supporting


Our Goal

To optimise the delivery of HDANI services to those impacted by HD to ensure that we provide timely and meaningful help to service users and their families.

Our Objectives

To achieve our goal, we will:

1. Ensure as many people as possible impacted by HD in Northern Ireland have access to appropriate support and accurate information about the disease.
2. Explore how we can develop/adapt our current service model to optimise the impact of HDANI's emotional and practical support for those affected by HD.
3. Continuously engage with service users to make sure that the way we communicate with them and the services we deliver best meet their needs.
4. Help service users and their families to understand their entitlements and access appropriate financial, practical, medical and social supports.

 ***It is a place where people can relax knowing that if you spill your tea or forget a name people will understand; anywhere else you'd be embarrassed and feel you have to explain your symptoms."***

- Service user



Theme Three: Informing

Our Goal

To increase awareness and understanding of HD and reduce stigma to improve patient care and outcomes for families.

Our Objectives

To achieve our goal, we will:

1. Maintain a comprehensive range of information and educational resources (both online and printed) and communicate relevant updates on research, policy, and service developments.
2. Refresh how we use social media and other platforms to increase awareness of HD and our work to better connect with people affected by HD, relevant stakeholders, and the public.
3. Attend external networking events and cultivate relationships with other service providers to improve their understanding of HD and help them work more effectively with people impacted by the disease.
4. Extend our information, educational and training programmes for relevant statutory, private, and voluntary organisations.



It was horrendous over Covid -the stress and not getting out. Felt like banging you head off the wall. Having contact is so important."

- Service user



Theme Four: Advocating

Our Goal

Use our evidence-based approach, working in partnership with others, to influence policy, and the delivery of services and promote opportunities for the development of HD research in NI.

Our Objectives

To achieve our goal, we will:

1. Lobby elected representatives, policy, and decision-makers to develop and deliver appropriate, equitable, accessible services and resources to those impacted by HD.
2. Support the development of HD research including working with key stakeholders to establish and support an Enroll-HD site in Northern Ireland.
3. Collaborate with partners to advocate for the rights of those affected by HD and their families.
4. Empower service users to share their lived experience of HD to contribute to research, increase understanding of the disease and influence policy and practice.
5. Improve the way we capture information about our service users and their experiences to better illustrate the need for and impact of our work.

 ***We are a family – if someone gets to the stage of falling over we help them up and no one looks down on them.”***

- Service user



Theme Five: Resourcing

Our Goal

To ensure that we have the financial resources, skills, operational infrastructure, and processes necessary to deliver high-quality, impactful, and sustainable services in compliance with required governance standards.

Our Objectives

To achieve our goal, we will:

1. Develop and implement a fundraising plan to diversify our sources of income generation to improve our sustainability.
2. Explore how we can develop our volunteer base.
3. Ensure our team of staff and volunteers feel valued and supported with access to supervision, well-being services and working conditions which promote staff retention.
4. Continue to provide training and development opportunities to support our team members to learn, grow and connect.
5. Review our systems and processes to enhance management capacity and organisational efficiency.
6. Support Board development to ensure that we have the skills, expertise, and leadership in place for Trustees to deliver effective governance oversight.



Without them (HDANI) there are lots of times I wouldn't be here today. They are like a family."

- Service user



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