Huntington's Disease Association

Strategy

2023-2027

Together we will build a better life for anyone affected by Huntington's disease

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An inspired community

The Huntington's disease community is a driven community,

Driven to raise awareness

Driven to get better care

Driven to support each other

The Huntington's Disease Association is driven by the inspiration and resilience of the community.

Our volunteers, fundraisers, supporters, and campaigners who support our work help highlight the reality of living with Huntington's disease.

Our trustees and our staff are motivated and dedicated by the Huntington's disease community.

The focus of the community and the charity is to support all affected by the disease. All work hard to make a better life for those affected by Huntington's disease.

It's important that we don't work alone. Working with other charities, researchers, clinicians, health and social care professionals, pharmaceutical companies, government and decision-makers deepens the understanding of Huntington's disease's impact on people's lives and helps bring about change.

Everyone has a role to play to help bring about a better life for people with Huntington's disease.

Building

ON WHAT HAS BEEN ACHIEVED

In 2018 we committed to achieving six goals. Despite the pandemic hitting in the middle of our last five year strategy we have achieved those goals. But there is so much more to be done. Including:

Working closely with researchers and pharmaceutical industry partners, alongside regulatory bodies to ensure an effective treatment for Huntington's disease remains a priority and will be made available to those who it can treat.

Working in an ethical way and being sensitive to the environment.

Raising awareness and tackling stigma, discrimination and health inequalities.

Expanding the care and support we offer, making it available to the community in a way in which they benefit the most, and making it accessible to all.

Our vision remains a better life for people with Huntington's disease. By working with the community we will be tenacious in reaching our new goals and ambitions over the next five years.

Our GOALS

We have achieved a lot over the past 50 years. Our goals for the next five years will be at the heart of everything we do and have come from listening to our community, You have told us what you would like to see. 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

Goal ONE

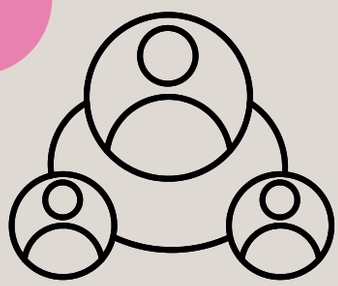
We will ensure everyone affected by Huntington's disease gets the care and support they need.

Goal ONE

We will ensure everyone affected by Huntington's disease gets the care and support they need.

Our ambitions

1



Anyone affected by Huntington's disease has the best support and is aware of the Huntington's Disease Association

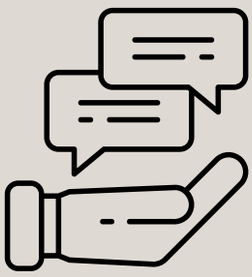
2

Everyone can access high-quality care including a multi-disciplinary team

3

People are able to make an informed choice about genetic testing

4



People know what advice and support is available

Goal TWO

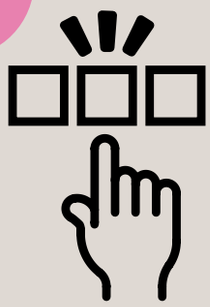
We will help make each day with Huntington's disease the best possible day.

Goal TWO

We will help make each day with Huntington's disease the best possible day.

Our ambitions

1

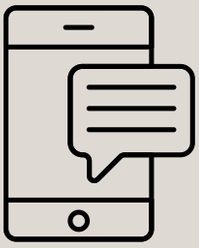


People understand the choices they can make to live with Huntington's disease

2

People have the best quality of life available

3



People have access to tools that can make life easier

Goal THREE

We will make sure the voices of people affected by Huntington's disease are heard and are at the heart of everything we do.

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We will make sure the voices of people affected by Huntington's disease are heard and are at the heart of everything we do.

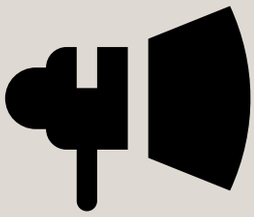
You have told us you want more people to understand the disease. We will reach more people affectedby Huntington's disease wherever they are in England and Wales. We will listen and involve you in how we talk about Huntington's disease.

Our ambitions

1

Our work is driven by people affected by Huntington's

2



We will understand and advocate the needs of everyone affected by Huntington's disease

3

We will increase the reach of Huntington's Disease Association
and work with all communities affected by Huntington's disease

4

We will increase people's skills to enable them to support people living with Huntington's disease

Goal FOUR

We will not rest until everyone with Huntington's disease has access to treatments.

Goal FOUR

We will not rest until everyone with Huntington's disease has access to treatments.

Our ambitions

1

We will continue to support the community in accessing any new treatments

2

We will advocate for equity of access to research opportunities

3

We will support our partners in the global Huntington's disease community, to find treatments for the disease

Goal FIVE

We will be a resilient charity.

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We will be a resilient charity.

To reach our ambitious goals we will be as resilient as our community. We will continue to build strong partnerships as together we can achieve more. We will discover people who will help us grow stronger and connect us with more people.

Our ambitions

1

Everyone feels valued and welcome

2

The charity is financially stable, well governed and with a clear plan for managed growth

3

Our staff and volunteers are invested in and supported

4

The charity is well connected through partnerships

5

The Huntington's disease community has active champions

Get in touch

Find out more about
what we do

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Huntington's Disease Association

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Registered charity no. 296453

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

Design by the Huntington's Disease Association

Published March 2023 - First edition

Inspired by our community