



## Strategic Plan

2019 – 2023

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*PLEASE NOTE THAT THIS STRATEGIC PLAN HAS BEEN EXTENDED TO 2023 DUE TO THE IMMINENT MERGER OF HUNTINGTON'S NSW ACT INTO HUNTINGTON'S AUSTRALIA.*

V. 2.1

Approved by the Board  
November 2021



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## VISION

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We support people affected by Huntington's disease to live their best life by shaping a future which is supportive, inclusive and empowered.

## MISSION

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We provide leadership, support, education and advocacy to empower individuals, organisations and professionals to best meet the needs of people affected by Huntington's disease.



# CORE VALUES & BEHAVIOURS

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We operate with:

- Ethics and with integrity  
*We will always act honestly, openly and directly with our constituents and the community to promote the best interests of the HD community.*
- Commitment to inclusion  
*We want to see all people impacted by HD treated with equity and confidentiality by governments, other institutions and their communities.*
- Empathy  
*We will recognise the personal hardship and sacrifice of many in the HD community.*
- Engagement  
*We will actively listen to our HD community, to inform shared decision making and action to address people's concerns and goals.*
- Close connection to our community  
*Our Association is owned by and governed on behalf of our members. We will seek to understand what our members and others in the HD community tell us and respond to their expressed aspirations and concerns to the best of our ability.*

## Prevalence

In NSW and ACT there are an estimated:

- 600 - 700 people with manifest (symptomatic) Huntington's disease, based on an estimated prevalence of 7.5/100,000 and an uncertain level of under-reporting
- 2,000 - 2,200 people at risk of Huntington's disease – having a parent or grandparent with HD
- 5,000 people affected as families and carers.

## Community Location

Using the ERP data (ABS 2018) it is estimated that the HD community live in the following regions:

- 62% - Greater Sydney (inclusive of Central Coast & Illawarra Shoalhaven area)
- 33% - Rural and regional NSW
- 5% - Australian Capital Territory

## National Body

Although there is currently not an active national body representing the state Huntington's Associations, we are working with our sister state organisations towards the highest level of awareness and support from government and the community. In order to achieve this, we need a strong and united voice. Having an effective national relationship with all states working together can support this outcome. Also, given each Association has limited funding we will share ideas/actions etc. rather than duplicate where possible. NDIS organisational funding criteria and other drivers indicate the advantage of establishing a national consortium.



# GOALS & OBJECTIVES

The Association will invest its resources in the following key focus areas:

- Information
- Education
- Support
- Awareness
- Advocacy

Each focus area is articulated as a goal with associated objectives.

<b>Goal 1: To be the HD INFORMATION channel for community members and care professionals within NSW and ACT</b>
Objectives:
<ul style="list-style-type: none"><li>• Review our resource library to promote current best practice and create knowledge pathways for stated-based materials</li></ul>
<ul style="list-style-type: none"><li>• Design plain English resources that are accessible to everyone affected by HD</li></ul>
<ul style="list-style-type: none"><li>• Source and publish services and supports that are HD friendly for each local health district</li></ul>

<b>Goal 2: To ensure specialised HD EDUCATION is available to HD community members and care professionals within NSW and ACT</b>
Objectives:
<ul style="list-style-type: none"><li>• Co-design a model of care education program to ensure people with HD are supported by quality staff and organisations who understand HD</li></ul>
<ul style="list-style-type: none"><li>• Co-design a community education program that promotes strategies for coping, care and support</li></ul>
<ul style="list-style-type: none"><li>• Collaborate across the spectrum of sectors to identify and reduce knowledge gaps.</li></ul>
<ul style="list-style-type: none"><li>• Promote specialised HD support and education opportunities</li></ul>

<b>Goal 3: Provide HD-specific SUPPORT that improves the quality of life for those impacted by HD</b>
Objectives:
<ul style="list-style-type: none"><li>• Facilitate people with HD having access to support groups and social programs</li></ul>
<ul style="list-style-type: none"><li>• Facilitate carers of people with HD having access to support groups</li></ul>
<ul style="list-style-type: none"><li>• Ensure people with HD eligible for NDIS have access to support coordination and other capacity building services such as counselling and behaviour support</li></ul>
<ul style="list-style-type: none"><li>• Support children and young people impacted by HD</li></ul>
<ul style="list-style-type: none"><li>• Seek out and facilitate access to high quality services which fill service, support and knowledge gaps</li></ul>



<b>Goal 4: Raise AWARENESS of HD in communities where people with HD live and more broadly</b>
Objectives:
<ul style="list-style-type: none"><li>• Develop and maintain tools to engage key stakeholders through social media and our website</li><li>• Connect with people to raise visibility of our mission</li><li>• Ensure people can recognise and recall what HD is and want to support the cause</li><li>• Establish an ambassador program to help spread the word, recruit fundraising participants and promote HD</li><li>• Represent the HD community at relevant industry forums and conferences</li><li>• Run selected events to engage those affected by HD and those supporting them</li></ul>

<b>Goal 5: Respond to the concerns and aspirations of our members through ADVOCACY that aims to improve government policies and services within disability, health and social care and justice systems.</b>
Objectives:
<b>STATE</b>
<ul style="list-style-type: none"><li>• Lobby the NSW and ACT Governments to fund HD specialist social workers in each LHD</li><li>• Lobby Governments to adequately fund Huntington's NSW ACT</li><li>• Campaign for appropriate care for people with HD within the justice system</li></ul>
<b>COMMONWEALTH</b>
<ul style="list-style-type: none"><li>• Campaign for HD specialist community services in regional NSW and ACT</li><li>• Campaign for NDIS planners and providers to understand the needs of people with HD</li><li>• Campaign for HD specialist residential services in regional NSW and ACT</li></ul>



# GOVERNANCE, MANAGEMENT & FUNDING

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In order to achieve these objectives, we need a well-run organisation and appropriate income streams, so a further two key focus areas are:

## A: Governance and Management

We will:

- Expect high performance from the Board of Directors
- Instil rigorous business practices and strong internal controls for accountability and risk
- Maintain financial viability
- Increase community engagement including via a Community Advisory Committee
- Measure the Board's effectiveness through an analysis of skills needed matrix and an annual self-evaluation
- Measure our effectiveness through person-centred outcomes, using the NSW Human Services Outcomes Framework.
- Build academic evidence base and evaluation

## B: Funding

We will aim to generate income from the following sources:

- a) Government
  - a. State – NSW Health / FACS / other
  - b. ACT – Health / other
  - c. Federal – including NDIS (and in partnership with other State HD Associations)
- b) Fundraising
  - a. Trusts, foundations and corporate grants
  - b. Community appeals
  - c. Events (own and others')
  - d. Bequests
- c) Philanthropy
  - a. Private sponsorship - Pitches to funding networks
  - b. Corporate sponsorship
  - c. Crowd funding



# BUSINESS PLAN

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Each objective above is developed into the Association's business plan with associated KPIs.

Further detailed plans have been or are being developed for:

- Service delivery including ways to measure outcomes
- Marketing & Communications / Media
- Advocacy
- Community Engagement
- Fundraising
- Financial (income and expenditure) modelling based on activity and participation rates as appropriate to the service or activity.