



Huntington's
NSW ACT

Strategic Plan

2019 – 2022

V. 1.0

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Vision

We support people affected by Huntington's Disease to live their best possible life, while striving to eliminate the factors that make our organisation necessary.

Mission

Provide leadership in Huntington's disease information, education, awareness, support and advocacy

We might not do all of this ourselves: we will also facilitate, promote and support all these wherever we find them.

Core organisational values & behaviours

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 social justice

We want to see all people impacted by HD treated with equity by governments, other institutions and their communities.

- Compassion

We will recognise the personal hardship and sacrifice of many in the HD community, which impels us to advocate for their interests.

- Respect

We will actively listen to our HD community stories, 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 will work with our sister 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 indicate the advantage of establishing a national consortium.

Goals and objectives

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

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- Information
 - Education
 - Services
 - Awareness
 - Advocacy
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Each focus area is articulated as a goal with associated objectives.

Goal 1: Be the peak organisation providing HD **INFORMATION** to community members and care professionals within NSW and ACT

Objectives:

- Promote knowledge acquisition and sharing
- Everyone affected by HD has access to information in a form suitable to their needs
- Information is up to date, high quality and accessible
- Promote service and support linkage and referral points
- Promote access to up to date and accessible research reports

Goal 2: Ensure high quality **EDUCATION** is available to HD community members and care professionals within NSW and ACT

Objectives:

- People with HD are provided services by people and organisations who understand HD
- Provide the HD community with strategies for coping, care and support
- Provide access to HD related forums and conferences

Goal 3: Provide HD-specific **SERVICES** that improve the quality of life for those impacted by HD

Objectives:

- People with HD have access to support groups and social programs
 - Carers of people with HD have access to support groups
 - People with HD eligible for NDIS have access to support coordination
 - Children and young people impacted by HD have access to support
 - Build academic evidence base and evaluation
 - Seek out high quality services which fill service, support and knowledge gaps
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Goal 4: Raise AWARENESS of HD in communities where people with HD live and more broadly

Objectives:

- Develop and maintain tools to engage key stakeholders
- Promote specialised HD support and education opportunities
- Represent the HD community at relevant industry forums and conferences

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.

Objectives:

- Lobby Governments to adequately fund Huntington's NSW ACT
- Lobby the NSW and ACT Governments to fund HD specialist social workers in each LHD
- Campaign for HD specialist residential services in regional NSW and ACT
- Campaign for HD specialist community services in regional NSW and ACT
- Campaign for NDIS planners and providers to understand the needs of people with HD
- Campaign for appropriate care for people with HD within the justice system

Governance / Management / Funding

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 / Management

We will:

- Expect high performance from the Board of Directors
- Instill rigorous business practices and strong internal controls for accountability and risk
- Maintain financial viability
- Increase community engagement
- Measure our effectiveness through person-centred outcomes.

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
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Business plan

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

Further detailed plans will be 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.