# YOUR VOICE MATTERS:

## Demand Action for Huntington's disease



## Huntington's Australia Advocates for a Better Future for HD

**Huntington's disease (HD)** is an inherited degenerative neurological condition affecting the brain and central nervous system. It progressively impairs mental and physical abilities, eventually leading to the loss of critical functions such as walking, talking, eating and reasoning. Its impact extends beyond those diagnosed, deeply affecting their families and caregivers as well.

## The Reality of Huntington's disease in Australia

**8 to 10 people** per 100,000 are diagnosed with HD in Australia.

**1,066 people with HD** are currently on the NDIS, and it is estimated that **2,500 Australians** are living with the disease.

Family members and carers also bear the burden of HD, facing immense **emotional and financial strain**.

**Isolation** is a key suicide risk, impacting **19% of people with disabilities**.

People with HD are **2 to 7 times more likely to die by suicide**.

**24% of people with disabilities in regional and remote areas** lack adequate care due to limited services.

**People with HD in rural areas** face barriers to primary care and rely more on emergency departments.

**Low digital literacy and limited internet access** create healthcare challenges for First Nations communities, where in-person care is crucial.

## What Needs to Change?

Huntington's Australia is calling for targeted funding and policy reform to:

### Expand specialist HD services

Increase access to expert care across Australia, particularly in regional and remote areas

### Increase funding for education and awareness

Improve knowledge and understanding of HD among healthcare providers and the community

### Enhance mental health support

Expand non-clinical counselling that supports, assists and enables clients and carers.

## Advocating for Systemic Change in the Neurological Community

Huntington's Australia works alongside the Neurological Alliance Australia (NAA) to push for systemic reforms that benefit people living with neurological conditions, including:

**Strengthen the NDIS** by enhancing access and support, ensuring people with HD and other neurological conditions receive the services they need

**Enhance telehealth services and digital accessibility** to improve access to care and support.

**Ensure equitable healthcare access for First Nations communities** with culturally appropriate models of care.

## Use Your Voice: Contact Your MP Today

We need your help to ensure HD is on the political agenda. **Contact your local Member of Parliament (MP)** www.bit.ly/federalmember and urge them to support funding that improves the lives of Australians impacted by HD.

**Download the sample letter** and send it to your MP today. Every voice matters in making HD a priority for policymakers.

Download Now

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## About Huntington's Australia

Huntington's Australia (HA) is the peak national body dedicated to supporting individuals and families impacted by Huntington's disease (HD) across Australia.

Whether you're at risk, have tested positive or negative, are experiencing symptoms, or have received a diagnosis, we are here for you. Our support also extends to the families, carers, friends and loved ones who share this journey.

Through advocacy, education, and compassion, we strive to bring comfort and hope to those impacted by HD.

Huntington's Australia

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