HAVE YOUR SAY IN 2026
SURVEY RESULTS

In July 2026, Huntington's Australia (HA) opened our annual 'Have Your Say' community survey to the public. We invited input from people through our social media and email list, including clients, members, donors, participants, stakeholders, and supporters.

We sent out over 4,000 emails to people on our mailing list, and shared posts and reminders on our Facebook, Instagram, and LinkedIn accounts to increase our reach. We received **222 responses** to the survey. This marks an increase of **more than 26%** compared to our 2025 survey, which recorded 175 responses.

WHO OUR COMMUNITY IS

We asked people where they come from and why they connect with Huntington's Australia. Here's what you told us:

1. Participants were in all states and territories of Australia. NSW, WA and QLD had the most responses.
2. Our community are people living with HD, carers, family, donors, health professionals and service providers.
3. More than 50% of respondents have been with HA and their respective state association for over 7 years.

SERVICES THAT ARE MOST IMPORTANT

We asked people how important our services are to them. **Here are the top four responses:**

- **Education and Training**
- **Social Work and Counselling**
- **Support Coordination**
- **Support Groups**

This year, you ranked **Support Coordination** and **Education and Training** as most important, similar to 2025. You also told us that **Social Work and Counselling** services and **Carer or Family Support Groups** are also important.

LEVEL OF SATISFACTION

We asked individuals to rate their level of satisfaction with the services they've used. People were mostly 'Very Satisfied' with Support Coordination, Social Work and Counselling, Phone and Email Support, and Resources and Information.



7% increase | 6% decrease | Stayed the same

NEW SERVICES AND SUPPORT YOU WOULD LIKE HA TO OFFER

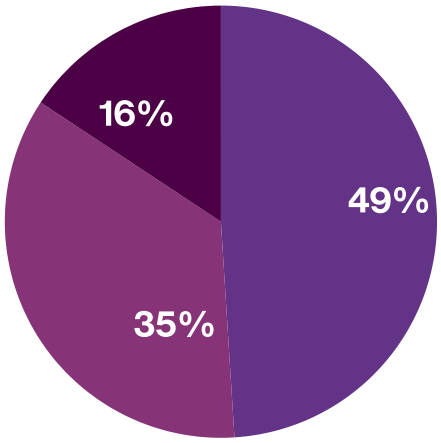
This was an open-ended question to which 87 people responded. Below is a summary of the services or programs that our community would like us to introduce, or potential gaps in support.

- Provide a local list of HD specialists
- Help for youth, young adults and family
- Expanding services to regional and remote areas
- More support groups and information

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WHAT WE DO WELL



- Support and care (family and carer support, regional and local support, counselling, patient care, professional resources, support coordination services, training and education)
- Awareness and advocacy (fundraising, website updates, public awareness, online information platforms, national advocacy)
- No feedback given

"Just by being there! People that understand the difficulties, especially emotional, associated with having a family member with HD. Referrals to HD specific support groups and services."

"Advocates for people with HD at a national and state level. HA really cares about supporting people with HD."

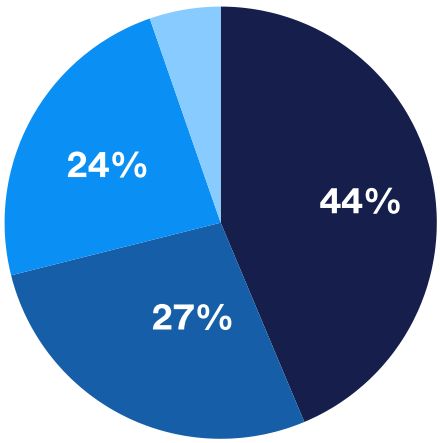
"Support and help, especially when dealing with NDIS. Also with personal support when I have reached out."

WHERE WE CAN IMPROVE

" I'd love to see more medical professionals (doctors, nurses, ambulance) and even the public more aware of the disease."

"It would be good to have some sort of list available with recommended health professionals to contact. It would be great to get more community awareness and understanding which would lead to more support and fundraising. I see so much support and funding for MND compared to Huntington's but understand how difficult this can be. "

"More support groups, informal meetings, and chances to get together and meet each other and sit and chat."



- Specialised support and outreach (emotional and personal support, NDIS, disability and benefits support, referral services, support groups)
- Awareness and advocacy (information distribution, communication channels, increasing awareness in public)
- Training and education (information distribution, trial updates, training for health professionals)
- No feedback given