HAVE YOUR SAY IN 2025
COMPLETE SURVEY RESULTS

In July 2025, Huntington's Australia (HA) ran the 'Have Your Say' survey, inviting input from everyone on our email list including members, clients, participants, donors, stakeholders, and supporters. It was also promoted on social media to encourage broader participation.



Of **3,190 emails** sent, we received **175 responses**, resulting in a 5.5% response rate. In 2024, 2,549 emails generated a 7% response rate. While slightly lower, this still falls within the typical range of 5–20%.

PURPOSE OF HUNTINGTON'S AUSTRALIA

We asked people what they thought was the purpose of HA. **Here are the top three responses:**

1. To raise **awareness** of HD (through education, advocacy and lobbying)
2. To **support** the HD community (people with HD, carers and families)
3. Provide **information** on research, treatments and better care

SERVICES THAT ARE MOST IMPORTANT

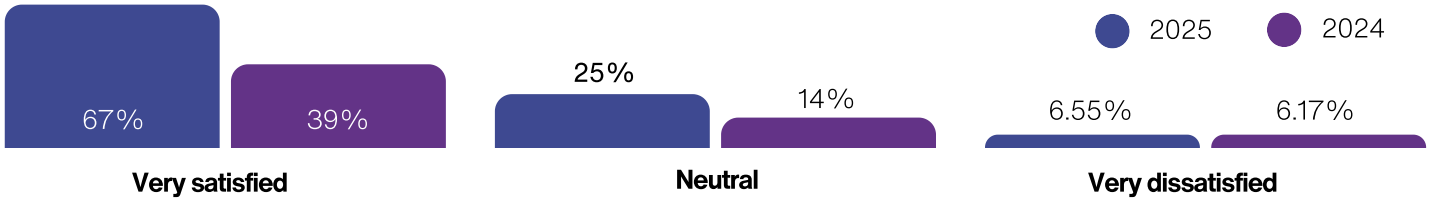
We asked people how important our services are to them. **Here are the top three responses:**

- **Education and Training**
- **Resources and Information**
- **Support Coordination**

These responses are similar to 2024; however, last year we listed family support, one-on-one support, and welfare support separately. This year, they have been combined under specialist social work and carer or family support groups.

LEVEL OF SATISFACTION

We asked individuals to rate their level of satisfaction with our services overall, as opposed to breaking it down. Here is a sample of responses compared with last year. In 2024, 40.14% of respondents marked 'not applicable,' with comments in later questions noting that the organisation was too new to answer.



73% increase | 76% increase | 6% increase

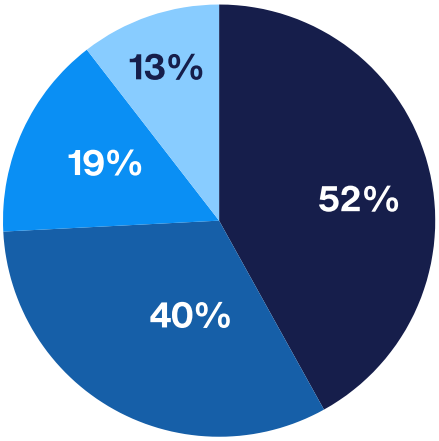
NEW SERVICES OR PROGRAMS YOU WOULD LIKE TO SEE

This was an open-ended question in which 75 people responded, of these 19 people answered no comment or nothing. Below is a summary of the services or programs that our community would like us to introduce.

- More support groups and more counselling
- Allied health services (OT, physiotherapy and PBS)
- Conference/forum (in person for carers and health professionals
- Information sessions (financial planning, genetic testing)

HAVE YOUR SAY IN 2025 SURVEY RESULTS

OUR STRENGTHS



- Specialised support and Outreach (emotional and personal support, disability and benefits support, referral services, support groups)
- Awareness and advocacy (fundraising and events, advocacy, information distribution, communication channels
- Training and education (information distribution, trial updates, training for health professionals)
- Unsure or too early to tell

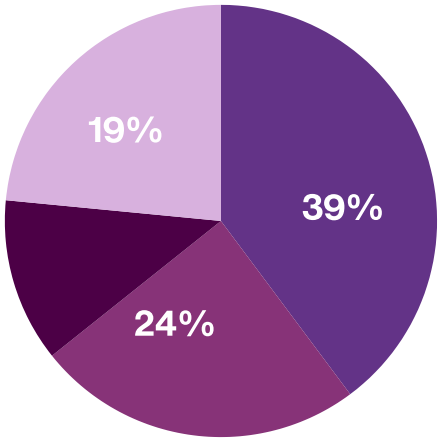
"They tell me what might happen next. They make me feel supported through impossible situations and decisions that must be made. They look at the health of the family unit and not just the person with HD. I feel like supporting someone with HD is being in the dark and the HD specialist social workers have a little torch to light the way."

"You are a very connected, engaged, and caring organisation. HA always makes an effort to inform its participants of the current developments in the area of research and the events it helps organise."

OUR WEAKNESSES

"Supporting isolated families where they are the only ones in town and feel neglected and alone. Employ more social workers who can spread the burden on the few employees who are struggling to liaise with families spread over huge distances."

"Its my opinion Huntingtons families should (not) be pressured to fundraise. It takes away from the absolutely exhausting task of caring. It's the one disease that is so challenging, it's not that they are disinterested or not engaged. I don't think people with HD should be made a spectacle of. My apologies I don't mean to negate HD Australia's attempts at helping but this is my true opinion."



- Support and care (family and carer support, regional and local support, patient care, professional resources, support coordination services, training and education)
- Awareness and advocacy (website updates, public awareness, online information platforms, have more contact)
- New activities (youth service, service directory, genetic support)
- Unsure of providing good feedback