

HA Highlights

The 2026 Have Your Say results are in

What we learned from this year's community survey

As an organisation that exists to serve and support the HD community, Huntington's Australia must do it well. Each year, we ask the public for responses in our Have Your Say survey, allowing us to do just that.

The annual survey asks questions about how people utilise HA's support and services, where they think we can improve, and what we're doing well. With your responses, we shape our direction over the coming months and years, so that it's most effective.

In July, **we sent out the survey and received a record 222 responses.** Read on to discover what we learned from the 2026 Have Your Say community survey, and how it will guide us in the future.

Who responded and how do they connect with HA?

As a national organisation, we were pleased to receive responses from all states and territories, with the majority from NSW, WA, and QLD.

We received responses from a wide range of people within the HD community, including those living with HD, carers, and family members. We also heard from health professionals, service providers, donors, and others, making it a diverse group.

According to the results, the Huntington's Australia services that were most important to our community were:

- Education and training
- Social work and counselling
- Support coordination
- Support groups

Although they were the highest-rated, people also told us that they relied on HA for a range of other services, including community events, information, and updates.

What are we doing well?

According to responses, **74% of people said they were very satisfied or satisfied with Huntington's Australia's services.**

Specifically, 49% of respondents were most satisfied with the support and care we offer, such as family and carer support, counselling, patient care, professional resources, support coordination, and training and education.

Additionally, **35% of people said our awareness and advocacy efforts were most useful**, including fundraising, website updates, public awareness, online information platforms, and national advocacy.

What can we do better?

The Have Your Say Survey is important for highlighting certain areas that might need improvement. This year, respondents told us they **wanted more specialised support and outreach, including NDIS, referral services, and support groups.**

They also told us that they'd like to see more help for youth, including those living with juvenile HD and as family members, and an expansion of services to regional and remote Australia.

How your responses shape our direction

With your answers, we can continue to shape the services we offer to support the HD community better. Some of our plans in the coming year include:

- Recruitment of additional Community Programs staff in TAS, WA and NSW.
- An updated HA website, including regular sharing of the latest research developments and practical information.
- Building a list of networks in areas such as neurology, insurance, and legal.

↖ **Want the full results of this year's survey?** Download the report from the 'Resources & Research - Publications' section of our website. *Thanks for having your say!*

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NDIS News

Learn about a recent update from the NDIS on the HD Planner Pathway.

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Around the Community

Find out what's happening around the community, including stories from our regional and remote visits.

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Focus on Fundraising

It's been an exciting few months in fundraising, with plenty of events still to come in 2026.



> ...we are gearing up for one of my favourite times of the year – Walk 4 Hope! I'm really looking forward to seeing everyone, along with your families, friends and, of course, your furry friends, as our community comes together to connect.

CEO Insight

Words Lenni Duffield

It is hard to believe we are already heading towards the pointy end of the year! There continues to be so much happening across Huntington's Australia, with some significant achievements to celebrate across advocacy, services, community engagement and fundraising.

One of our most significant achievements has been the successful lobbying for, and subsequent implementation of, the NDIS Specialist Planning Pathway for people with Huntington's disease. This has been an important advocacy priority for HA and represents a major step forward in improving the experience of people with HD within the NDIS. We are already seeing encouraging results, with not only an increase in referrals to HA, but importantly, positive outcomes for participants accessing the new pathway.

We have also had some wonderful news for our Tasmanian HD community, with a successful funding outcome from the Tasmanian Government to support HA to deliver services and supports across the state. This means we can now move forward with recruiting a dedicated HD Community Practitioner in Tasmania, strengthening the local support available to individuals and families.

There has also been another significant advocacy milestone for our community. Following almost a decade of advocacy by many, including HA, legislation banning genetic discrimination in life insurance was passed in April 2026 and comes into full legal effect on 8 October 2026. This is an incredibly important reform for the HD community, those who are considering genetic testing and for other Australians impacted by genetic conditions.

And now we are gearing up for one of my favourite times of the year – Walk 4 Hope! I'm really looking forward to seeing everyone, along with your families, friends and, of course, your furry friends, as our community comes together to connect, raise awareness and support the work of HA.

There is also plenty happening in fundraising. A special mention must go to Grant, who is preparing to swim the English Channel in support of his wife, Annette, who carries the Huntington gene, and the wider HD community. At the end of August, Grant heads to the UK before attempting the



34km crossing in September – potentially more than 14 hours of swimming through cold water, rough tides and whatever else the Channel throws at him! We will all be cheering him on.

Across all of this, HA continues to grow its reach and services, connecting with more people impacted by HD across Australia. Thank you to our staff, Board, volunteers, supporters, fundraisers, partners and, most importantly, our wonderful HD community for continuing to make this possible.

I look forward to seeing many of you at a Walk 4 Hope event soon!





NDIS NEWS

Huntington's Australia welcomes the new NDIS HD Planner Pathway

After almost two years of advocacy by Huntington's Australia, the Huntington's community, researchers, supporters, and other HD organisations, we welcomed the introduction of the NDIS HD Planner Pathway for people living with Huntington's disease on July 1.

Affecting both current and future eligible NDIS participants, the new Pathway includes changes that recognise the need for faster, more personalised access to support and planners for people living with HD.

Huntington's Australia is hopeful about the impact these changes can have on people seeking the support they deserve through the NDIS. Learn more about what the Pathway entails, what's changed and how to access it.

What's different about the new Planner Pathway?

The NDIS HD Planner Pathway makes it easier and quicker for eligible people to get the support they need. If you have HD and are already an NDIS participant, or are applying now, here's what these changes mean for you:

- NDIS access request applications are now reviewed within five days. You still need to meet all eligibility criteria and provide the required evidence, but once you are eligible, the decision to join the scheme is made quickly.
- Once you're approved for an NDIS plan, you'll be fast-tracked and handled by a specialist planning team. This means you will have a dedicated planner allocated who will support you throughout your entire NDIS journey.
- These dedicated HD Planners have the skill, knowledge and expertise to manage and support HD appropriately.
- If your support needs change, the NDIS will review your plan in real time, even in the event of sudden changes.
- If you have more than one family member with HD on the scheme, you can request the same Planner to manage your entire family.

The Planner Pathway is a formal recognition by the Australian government that many people with Huntington's disease cannot wait on lengthy timeframes for their support needs to be reviewed and addressed. Thanks to these changes, more people will be able to get the support they need, when they need it.

How do you access the Planner Pathway?

If you are already on the NDIS, you do not need to do anything to access the new HD Planner Pathway. Existing participants or nominees are being contacted directly by their newly allocated Planner. However, if you have not yet received information, please talk to your NDIS Support Coordinator if you have one or call the agency directly on 1800 800 110.

Huntington's Australia has put together a detailed guide to the NDIS HD Planner Pathway, available on our website.

For more information, visit **huntingtonsaustralia.au/introducing-the-ndis-hd-planner-pathway/.**

We're hopeful that these changes are the beginning of a system that's more supportive and responsive to the individual needs of people living with HD.

QLD Ipswich Support Group




SA Coffee & Co.









SA Museum Visit






WA Carer Luncheon



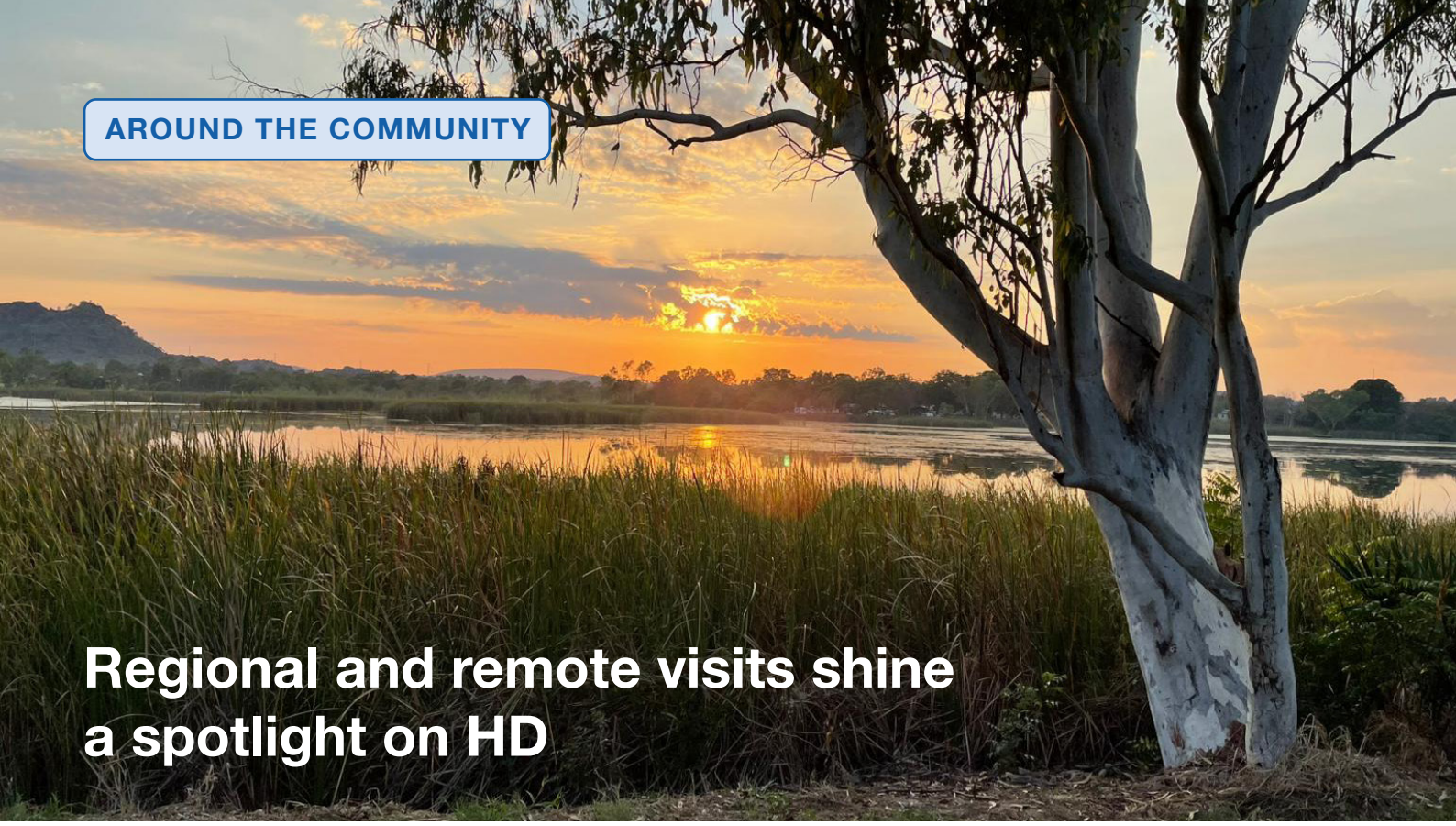




WA Day Centre World Cup







Regional and remote visits shine a spotlight on HD

One of the key areas of focus at Huntington's Australia is ensuring that our support extends beyond metropolitan areas. Among issues like lack of medical specialists and resources, people impacted by HD living in rural and remote Australia also face greater isolation. As a result, we're doing our best to improve outreach to these areas.

This past quarter, we've been lucky enough to visit some regional parts of Queensland and remote Western Australia.

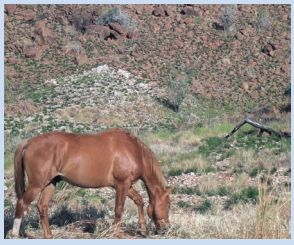
HA's Maggie Spiers celebrated 20 years of working with the HD community, spending the past few years building relationships in the Kimberley. Recently, she joined Melanie Clark, Huntington's disease Study Coordinator at Perron Institute, and the Far North Huntington's Mobile Clinic on another visit to WA.

Their goals for this trip were to ensure that people with progressing Huntington's were included in cultural activities, to drop off donations of clothing and home goods in Kununurra, and to act as a liaison between some local people living with HD and local service providers.

In regional Queensland, HA's Tressa Byrne visited families in Toowoomba and Bundaberg at their local support groups. She also received a wonderful photo from a community-run group that meets every month in Townsville and have done so for over a decade.

Huntington's Australia supports individuals, families and carers impacted by Huntington's disease, throughout Australia. Although we cannot always provide in-person support due to our not-for-profit resources, we offer a range of remote services to reach as many people as possible. This includes support coordination, counselling, and a monthly carers' support group where people can connect with other facing similar experiences, share knowledge, and find understanding along the way.

WA Remote Visit







QLD Regional Visit







We're here to help - *Let us know how we can.*
Get in touch at admin@huntingtonsaustralia.au or by phone at **1800 244 735.**

FOCUS ON FUNDRAISING

A shout-out to our fundraisers

Words Layla Valinoti, Marketing & Communications Officer

At Huntington's Australia, we're lucky to have a supportive community that helps us raise funds for people impacted by Huntington's disease.

Each month, we hear from some truly amazing individuals and organisations who are undertaking, or have already completed, fundraising initiatives. Learn some of their stories here, and how they're making an impact.



A winning night in Kalamunda

What better time than July to celebrate Christmas, raise some money, and spread awareness for Huntington's disease? WA's Kalamunda Districts Rugby Union Club held its annual Christmas in July celebration to do just that – and generously donated its proceeds to Huntington's Australia.

As a rugby club and close-knit community, Huntington's disease is especially close to their hearts. Kalamunda's Premier Grade Manager and club sponsor Joe recently lost his wife Aine to Huntington's disease. So, along with other members who've been personally impacted by HD in their families, it was an especially meaningful cause for everyone to get behind.

The joyous night consisted of karaoke, a prize-packed raffle, and a jersey auction for the Kala Kweenz – the women's premier team of the Kalamunda Districts Rugby Union Club. All up, they raised an amazing $10,600 for Huntington's Australia, and had a ball doing it. Huntington's Australia gives our sincerest thanks to everyone at the club.



A special way to spend an 80th birthday

Each year, Sacha celebrates her birthday in style. This year was no different, as she rang in her 80th birthday with a glorious party with family and close friends on the waterfront at Watsons Bay.

In keeping with tradition, Sacha asked attendees not to bring gifts. Instead, she asked each person to make a donation to Huntington's Australia in her name.

Sacha's family has been personally impacted by Huntington's, including her sister-in-law and two nieces, all living with HD. "With more funding and more research and development, one day HD will be a defunct disease," she says. Thanks for the special birthday gift, Sacha.



Emily's marathon fundraiser

Recently running the Sydney Marathon with a fundraising goal of $1,000, Emily went above and beyond, instead raising over $3,000. With her best friend Helen impacted by Huntington's, the marathon presented the perfect opportunity to raise much-needed funds and awareness.

"Through her, I've seen firsthand the impact HD can have, not only on the individual but also on the people who love and support them. Despite the challenges she faces, she continues to inspire me with her strength, resilience and positivity." Emily and Helen also share educational videos about HD on TikTok, which you can view on her account @ EmilyVSharp.

An amazing feat, and an amazing friendship. Thank you, Emily.





Walk 4 Hope is on the move

It's September, which means Walk 4 Hope is officially underway. This special annual community walk is a chance for people across Australia to come together and walk in solidarity for people impacted by Huntington's disease.

Brisbane's Walk 4 Hope kicked off the celebrations, and we were treated to a glorious day of early Spring weather. We want to give a huge thank you to everyone who attended, all of our special volunteers who make the day possible, and to every business and individual who donated prizes for our raffle.

Hoping to attend a Walk 4 Hope this year? Register at walk4hope.org.au for detailed information on each location, including maps and timetables. Can't attend a scheduled walk? You can still take part with a virtual event. Ideal for people living in areas where walks aren't scheduled or who need a time or location that suits them better, it's a great opportunity to be involved.

If you do attend, we'd love to hear from you. Send us your pictures and comments to fundraising@huntingtonsaustralia.au, or tag us on social media.



Tamara (T-Dogg) selling her handmade accessories at the Eltham Design Market in August

As an NDIS participant, Tamara connects remotely with HA's Support Coordinator Cherie, and receives support from specialists in Melbourne, which have been invaluable in helping her continue to live independently.

Do you have a story you'd like to share with our community? We'd love to hear it. Email admin@huntingtonsaustralia.au with more details, and we'll be in touch.

T-Dogg Takes on the Eltham Design Market

Words Tamara and support worker Guy

On Saturday, 1 August 2026, Tamara — better known to her friends as T-Dogg — worked alongside her support workers to set up a stand at the Eltham Design Market.

With a career in the Australian fashion industry, Tamara spent years designing men's and women's accessories, including watches, wallets, handbags and belts, for iconic brands such as Mambo, Deus Ex Machina and renowned Australian designer Clemens Rübiro. Her eye for colour, style and design has always been about more than creating beautiful products — it has been about helping people express who they are.

In 2018, Tamara was diagnosed with Huntington's disease. While there is currently no cure, Tamara refuses to let the disease define who she is.

Instead, she has chosen to create.

Earlier that week, Guy, a new support worker, teamed up with T-Dogg to get creative and design some eye-catching signage to attract market-goers to her bespoke jewellery. With great enthusiasm and confidence, they worked together to create a stand worthy of the T-Dogg brand.

By the end of the market day, after plenty of photos with happy bracelet buyers, T-Dogg packed up her stand with a huge grin. She could look back on a successful day, proud of what she had achieved and already looking forward to doing it all again — and even better — in November.

So, be sure to come down to the Eltham Locals Makers, Artists and Designers Market on November 22 and meet the maestro herself — T-Dogg!

WHAT'S HAPPENING?

Community Support Groups for the period of October - December



NEW SOUTH WALES

Group	Date
Newcastle/Hunter Carer's Group	8 October, 12 November, 10 December
Newcastle Support Group	12 October, 14 December
Central West NSW Carer Support Group	17 November
Central Coast Carer Support Group	14 October, 9 December
West Ryde Carer Support Group (Northern Sydney LHD)	7 October, 4 November, 2 December

QUEENSLAND

Group	Date
Gold Coast Support Group	26 November
Sunshine Coast & Gympie Support Group	13 November
Logan/Redlands Support Group	11 December
Ipswich Support Group	1 December
Brisbane South Support Group	22 October
Brisbane North Support Group	18 November
Toowoomba Lunch Support Group	30 October

SOUTH AUSTRALIA

Group	Date
Coffee & Co	7 October, 4 November, 18 November, 2 December, 16 December

WESTERN AUSTRALIA

Group	Date
Day Centre Support Group	14 October, 28 October, 11 November, 25 November, 9 December
North Suburbs Carer Support Group	19 November
South Metro (Rockingham) Carer Support Group	21 October
Southwest Support Group	3 December
WA Carers Lunch	17 December (Christmas Lunch)

We update this list regularly. For the latest information, check huntingtonsaustralia.au/support-groups or our Facebook page.

Visit our website for more information: huntingtonsaustralia.au/support-groups

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