Frequently Asked Questions: Update on TAS Operations

Funding and service changes

1. Why is the agreement with the Tasmanian Department of Health ending?
Huntington's Australia (HA) previously held a one-off funding agreement with the Tasmanian Department of Health, which ran from July 2021 to June 2025. This agreement partially funded the full-time HD Specialist position held by Lauren Ward.

Due to the recent Tasmanian state elections, the Department of Health informed us in June 2025 that the agreement has been extended until December 2025, but they have made it clear that the funding period has ended and is unlikely to be extended again.

2. Will Lauren be replaced?
Not at this stage. Unfortunately, we do not currently have the funding to replace the position. Our priority is to secure state funding in the next state budget cycle, which would allow us to reinstate a dedicated Tasmanian HD Specialist.

Commitment to TAS community support

3. How will I get support without a local HD Specialist?
Rest assured, our commitment to the Tasmanian HD community has not changed. We will continue to provide support remotely through our national team of HD Specialists, alongside our Community Programs Team Lead, Monica Cazzoli.

4, What types of support are still available for the Tasmanian community?
We continue to offer a range of support services remotely, including:

- Individual counselling and support
- Social work
- Education and training
- Local NDIS coordination: Our local NDIS Support Coordinator, **Tamara Lawson**, is based in Hobart and continues to work with clients and families across the North, Northwest and South regions.

5. What about local services, like our support groups?
Some of our local carer support groups are now well-established and self-sustaining. We also encourage attendance at our national online carer support groups. Visit our website for session details and schedules.

For essential local services, contact:

- NDIS Access Partners
  - North Mission Australia (03) 6212 6879
  - North West Baptcare 1800 290 555
  - South Baptcare 1800 290 555
- Northern Palliative Care Service (03) 6777 4544
- Huntington's Clinical Services and Case workers
  - North (03) 6777 4985
  - North West (03) 6477 7737
  - South (03) 6166 6783
- Carers Tasmania Statewide (03) 6144 3700
- Advocacy Tasmania 1800 005 131

If you need immediate crisis support, contact:

- Access Mental Health Tasmania: 1800 332 388
- Lifeline: For anyone experiencing a personal crisis, contemplating suicide or caring for someone in crisis, dial 13 11 14
- Emergency services: In case of an emergency, dial 000

Advocacy, community fundraising and next steps

6. How much money was raised at Walk for Hope Launceston and where will it go?
We are incredibly grateful that Walk 4 Hope Launceston raised over $9,500. Those funds are pooled nationally and used to support the HD community across Australia, through individual counselling, social work, education and training.

7. What have we done to try and secure this funding?
We are actively advocating for ongoing support and the reinstatement of this crucial funding. In December 2024, we submitted a detailed community consultation report to the Department of Health, outlining the critical need for HD support, and the proposed use of funding, but we have received no response from the department to date.

This year alone, we've pursued external funding, submitting five grant proposals specifically for Tasmania and ten nationally. HA representatives have also met with relevant government contacts and HD partners in Tasmania to advocate for continued support. A meeting with the Minister of Health's office was held on 28 October, and with another scheduled in the coming weeks.

8. What are the next steps in securing funding?
We will continue our advocacy efforts, including the upcoming meeting with the Minister of Health. We will also prepare a community consultation submission by November 2025 for consideration in the 2026-2027 State Budget, to be announced in May 2026.

9. What can I do to help advocate for local services in TAS?
One of the most powerful ways to advocate is by sharing your personal story with decision-makers. We encourage members of our HD community to:

- Contact your local MP: write or email your Tasmanian State Member of Parliament (MP) and the Minister for Health. Share how the loss of the local HD position impacts you, your family, and your ability to access necessary support. Highlight the high prevalence of HD in Tasmania and the crucial need for targeted, local services that go beyond NDIS coordination. Mention your support for Huntington's Australia's ongoing efforts to secure long-term funding for a permanent, dedicated HD Specialist role in the state.

- Show your support publicly: use social media to raise awareness about the need for local HD services. Share your story, post about Huntington's Australia's advocacy efforts and tag your local MP to help build momentum and visibility.