

April 2026

Impactupdate

The positive difference you make for people living with MND.



Expanding care,
strengthening community



Until there's a cure, there's care

OUR IMPACT

ASSISTIVE TECHNOLOGY PROVISION

MND Victoria's Support Services are delivered to people living with MND in Victoria, New South Wales (bordering with Victoria) and Tasmania.

Services focus on supporting people to live better for longer, remain active in their community, and remain safe in their environment, through the provision of six key program areas.

Here are the last six months at a glance (1 July – 31 December 2025).



TOTAL NUMBER OF
PEOPLE WHO RECEIVED
EQUIPMENT:

409

(92 new to the service)

EQUIPMENT ITEMS
PROVIDED:

2,265

PEOPLE WITH EQUIPMENT
AT 31 DEC 2025:

483

REQUESTS FROM ALLIED
HEALTH PROFESSIONALS
TO THE EQUIPMENT
SERVICE:

1,254

(often for more than one piece
of equipment)

EQUIPMENT ITEMS
RECOVERED:

1,419

COUNSELLING SERVICE



COUNSELLING HOURS
PROVIDED

492

PEOPLE SUPPORTED BY
COUNSELLING SERVICE:

215



Until there's a cure, there's care

ADVISOR AND SUPPORT COORDINATION



PEOPLE SUPPORTED
BY MND VICTORIA:

764

VIC: 666, TAS: 77, NSW: 21

HOURS OF SUPPORT
DELIVERED BY MND
ADVISORS:

15,584

VIC: 13,369, TAS: 1,854,
NSW: 361

NEW MEMBERS
WITH MND:

149

VIC: 132, TAS: 17

PEOPLE WITH MND
REGISTERED AT
31 DEC 2025:

638

VIC: 552, TAS: 59, NSW: 17

REPORTED MND
DEATHS:

125

VIC: 103, TAS: 18, NSW: 4

EDUCATION, CLIENT AND CARER SUPPORT



EDUCATION AND CARER
SUPPORT SESSIONS RAN:

85

PARTICIPANTS IN
EDUCATION AND CARER
SUPPORT SESSIONS:

985

CARERS SUPPORTED
THROUGH RESPITE AND
WELLNESS ACTIVITIES:

310

CARERS SUPPORTED
INFORMALLY:

710

ENQUIRIES ANSWERED:

998

VOLUNTEER ENGAGEMENT



VOLUNTEER HOURS:

1,021

Contributed

REGISTERED/ACTIVE
VOLUNTEERS:

91

DONATIONS AND FUNDRAISING



BEQUESTS:

\$952,721

GRANTS AND TRUSTS:

\$123,689

DONATIONS:

\$189,746

MND VICTORIA EVENTS:

\$174,796

COMMUNITY EVENTS:

\$119,330

MERCHANDISE:

\$12,611

CEO MESSAGE

It's a privilege to have joined MND Victoria as CEO, and have the opportunity to lead this wonderful team at a time of growth and innovation across all our services.

MND Victoria has a rich history of making a real difference to the lives of people living with MND. Starting from humble volunteer-led origins 45 years ago, today we are an organisation full of passionate professionals, offering education to health providers, carer support programs, personal advisory support for every MND journey, equipment loans, counselling, and more.

Everything we have done for the last 45 years, and will continue to do, is borne out of a real commitment to providing the best possible care and support to people living with MND and their loved ones.

When looking back over the last few months, I'm struck by how committed and resilient MND Victoria's staff and community prove to be. There's been an increase in need for our services, due to growing numbers of people impacted by MND, as well as a lot of uncertainty this financial year with funding, particularly from the aged care reforms. Our teams have been navigating these challenges admirably whilst remaining focused on delivering person-centred support.

We've expanded our support co-ordinator and advisor team, presented our insights into MND care to a global audience, supported a new community walk event, advocated directly to government for better funding and outcomes for our community, prepared for a new genetic counselling service launching this year, and consistently delivered two truck-loads of equipment every day.

When reading through this Impact Update, you'll find more details on many of the achievements touched on, and highlights of other achievements as well. I encourage you to pause and reflect on the efforts of the MND Victoria team and wider community, who show true dedication to improving the lives of those with MND.

To our generous supporters, I want to share a personal thank you. We're able to provide high quality services to people with MND because you continue to support us. Thank you for helping to make the last 45 years possible.

Over the next six months, and beyond, we'll be continuing to put our community's needs front and center. We will continue advocating for improved funding and support, whilst pursuing further opportunities to expand our support service offering. Most importantly we'll continue providing the amazing care and support for which we are best known.

In coming months I hope to meet many of you personally to listen to your feedback and understand how best to support those living with MND, because until there's a cure, there's care.

Mary-Jane Stolp
CEO – MND Victoria



SUPPORT COORDINATION AND ADVISOR SERVICES

Proactive engagement in the Support at Home changes

In the months leading up to the November 2025 rollout of the Support at Home program, MND Victoria Advisors proactively prepared for the transition.

The team closely monitored the aged care reforms and participated in sector briefings and training opportunities to ensure they remained well-informed and ready to support people through these changes.

Both ahead of the transition and since its implementation, the team has actively engaged with assessors to build greater awareness of the complexities of MND. This has included reaching out to offer education and training sessions, as well as developing written factsheets to support a better understanding of the condition and its progressive nature.

As the reforms have set in, MND Victoria, alongside MND Australia, have been advocating for further reforms to better support people living with MND.



At every opportunity, MND Victoria continues to represent the voices of people living with MND, their families, and carers. Through advocacy, education, and collaboration with the broader aged care sector, we are committed to ensuring that the evolving Support at Home system is responsive, equitable, and better equipped to meet the needs of those affected by MND.



Expansion of our MND Advisor and Support Coordinator team

The number of people requiring support from MND Victoria has been steadily increasing year on year. In response, we've expanded our team, ensuring that we continue to deliver high-quality, responsive, and person-centred support to individuals and families living with MND.

Two new Advisor and Support Coordinator roles were created, one to service the Albury/Wodonga and surrounding regions, and one to work with flexibility across Metropolitan Melbourne. These roles have enabled us to strengthen our reach and responsiveness.

After an initial trial of the Program Assistant role, which proved to promote greater equity and support across the team, and improved outcomes for people living with MND, we've introduced two additional Program Assistants.

Our Program Assistants work alongside our MND Advisor and Support Coordinators, supporting the administrative navigation of systems such as the NDIS and My Aged Care. By streamlining administrative processes, our Advisor and Support Coordinators get to dedicate more time to what matters most: supporting people living with MND and their families.

ACCESS & EDUCATION

Global Collaboration in Action

In 2025, MND Victoria contributed to both national and international knowledge-sharing forums, showcasing Victorian expertise in MND care while strengthening global collaboration.

At the International Alliance of ALS / MND Allied Professionals Forum in Canada, Victoria Tull (Access & Education Team Leader) presented MND Victoria's innovative equipment service model, co-developed with Amy Schneider (Equipment Service Team Leader, MND Victoria) and Alicia Gibb (FlexEquip Manager, MND NSW).

The session highlighted collaborative approaches to equipment provision that support timely access and improved quality of life for people living with MND.



The forum brought together association representatives, health professionals, researchers, policy and advocacy leaders, and lived experience representatives from across the world to share emerging evidence, practical innovations in care, and strategies to address the complex challenges faced by people affected by ALS / MND.



Closer to home, MND Victoria staff also played an active role in the 12th MND Australia Care Forum, held as part of the PACTALS 2025 Congress in Melbourne, with Victoria Tull and Jo Whitehouse (General Manager – Support Services) on the organising committee.

Team members, including Victoria Tull, Amy Schneider, David Cox (Team Leader & MND Advisor), Bethany Bradhurst (Counsellor) and Meg O'Connor (Supporter Experience Officer), contributed through oral and poster presentations, lived-experience panels, session chairing, and exhibition support.

Participation in both forums enabled staff to bring back key learnings to inform local practice, including strategies to support social connectedness, improve early recognition and referral pathways, strengthen psychological and end-of-life care conversations, and develop innovative programs to better support families and younger carers affected by MND.

Insights highlighted the diversity of global experiences with MND, the importance of lived-experience perspectives, and the role of genetics and advocacy, directly informing new initiatives such as the MND Genetic Counselling Service launching in 2026.

MND Victoria's extensive involvement and recognised expertise on national and international stages underscores the organisation's leadership and lasting impact in advancing care, advocacy, and innovation for people living with MND and their families.



CARERS

Carers Lunch

Caring for someone with MND can be challenging, in many varied ways. Family members and friends tend to know that their life is going to be different, that things aren't going to follow the same plan, but the isolation and questioning of yourself can sneak up on you.

It can be hard to go out—it's logistically difficult, there's a lack of time, a lot to organise and a lot on your mind. All of life's tasks, and the load that's being carried, can be overwhelming. Carers may not even be sure that they can label themselves a carer, thinking they're not really doing that much. On top of it all, it may feel like no one seems to understand what you're experiencing.

Who would have thought that simply coming to a free lunch could be just what was needed?

At our Carers Lunches, you'll meet people who *just get it*. Their experiences are all a bit different, but they genuinely get it—you don't even have to explain anything to them, just listen and find yourself nodding. By the end, you'll feel a bit more human about what you're going through, you'll notice you've had a laugh, taken a few deep breaths, and enjoyed a lunch made (and cleaned up) by someone else.

You'll come away feeling a little lighter, a little less alone, and a little more supported. You'll be so glad you went, and you might even go again—that's what we hope the impact of attending a carers lunch is for family members and friends.

To find out more about our Carers Programs, email asalmon@mnd.org.au



If you ask someone who's attended, they'll say something like this:

"Attending was the best decision I've ever made. I found great support and solidarity from the other carers, and the facilitator, Andrea, is very special—she's a very good listener."

"I've had a particularly crappy time lately and dithered about whether to come or not, but I'm so glad I did. The conversation and immediate rapport (bypassing all the usual small talk) with fellow MND carers never fails to lift me up and leave me feeling like I can keep going."

"I had a great time at lunch yesterday. I realised how quickly the group got down to the nitty gritty of their lives as carers; sharing their challenges, their lives, their wins and facing the future without their loved ones. Quite profound discussions over a chicken salad and a chai latte."

"It was such a welcome break to come out to have a tasty lunch that someone else cooked, that someone else paid for, and that someone else cleared up after! And the cheerful conversation that ranged widely and was conducted with such positivity was a tremendous boost."

COUNSELLING SERVICE

Helping people with MND feel less alone

When people think about counselling, they sometimes imagine a place where problems are analysed and solutions provided. In reality, the work is often quieter than that.

For people living with MND, and for the people who love and support them, life involves continual changes and adjustments. Alongside the necessary professional, clinical and practical supports, our counselling service offers something a little different: a space to pause.

Over the past six months, MND Victoria's Counselling Service has received 90 new referrals, and behind each referral is a person or family coming to terms, in their own way, with the realities of MND.

People come to counselling at many different points in their MND journey. Some have only recently received a diagnosis and are still trying to make sense of what it might mean for their future. Others are partners, parents or children who find themselves navigating the practical demands and emotional weight that caring can bring. Sometimes people come simply because they need somewhere to express freely and openly without judgement.

Feedback from people who use the service is consistently positive. Many clients and families speak about the relief of having somewhere they feel listened to and understood—a place where they don't have to carry things on their own.

Counselling cannot remove the very real challenges of living with MND. But it can help people and families feel less alone. Our counselling service was created over two years ago to meet this need, and it will continue to be here—a place where people can pause, speak openly, and be met with understanding.



Photo Credit: Vitaly Gariev-unsplash

VOLUNTEER SERVICE

Volunteers are the heart of MND Victoria

Volunteers are central to the organisation, contributing their knowledge, skills, and experience to enhance the quality of life for people living with MND and their families.

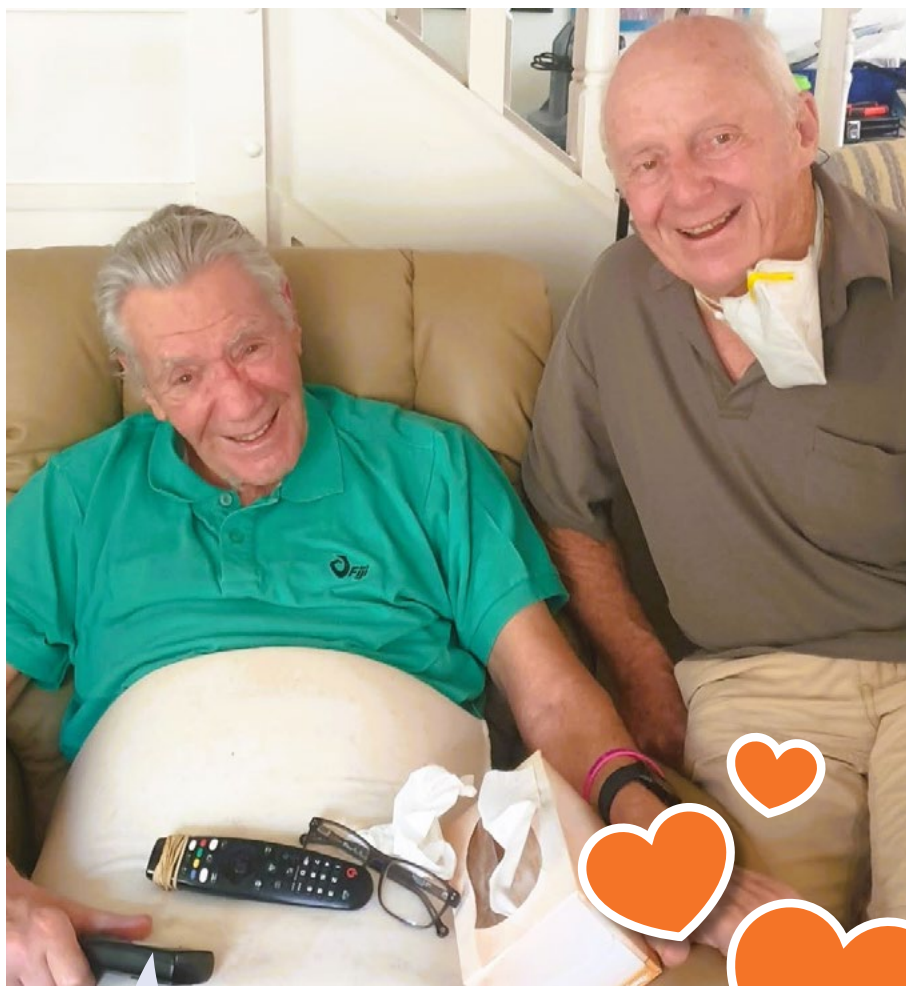
Volunteers are involved across a range of roles—such as social visiting, hand and foot massage, life stories projects, and tech support. MND Victoria works to match each volunteer's interests, skills, and availability with suitable opportunities. Volunteers receive preparation, ongoing support, and education to enable them to make a meaningful impact.

The difference our Social Visiting Volunteers make

The Social Visiting Volunteer Program provides companionship and connection for people living with MND. Volunteers visit individuals in their home, residential care, or another agreed location to spend time together, have a chat, share a cuppa, or engage in simple activities.

The program focuses on reducing social isolation and creating meaningful connections. Volunteers offer friendly conversation, emotional support, and a listening ear, helping individuals feel more connected to their community.

While volunteers do not provide personal care or medical support, their visits can make a meaningful difference by offering companionship, encouragement, and a sense of connection. For people living with MND, having someone visit regularly can provide comfort, support wellbeing, and create an opportunity to share time with someone outside their immediate care network.



Greig and his MND Victoria volunteer, John

"I was diagnosed with MND in December 2024, and the support from MND Victoria volunteers has meant a great deal to me. One volunteer, John, regularly checks in and provides a valued social connection outside my family through our weekly chats. He's retired and has even taken up ice skating—I joke that he's training for the Winter Olympics and that one day he will turn up in the Australian team uniform. Those conversations make a real difference to my wellbeing, and I'm very grateful to John and all MND volunteers for the wonderful support they provide." Greig

Interested in volunteering? Contact volunteers@mnd.org.au

COMMUNITY SUPPORT

Walking together for MND

Beautiful community walks have long-been a highlight of springtime at MND Victoria. These community-organised walk events foster connections, show local support, and raise vital funds for MND Victoria.

Last year we walked together in Bendigo, Pakenham, and, for the first time, in Mornington.

The inaugural Mornington Walk was organised by Janet Hough, who was diagnosed with MND in 2023. Following her diagnosis, Janet was motivated to create a community for other people living with MND in the Mornington area, and started up our Mornington Peer Support group.

Our community walk events are opportunities for people in Bendigo, Pakenham, and Mornington to come together, raise awareness, show solidarity to everyone living with MND, and say thanks to MND Victoria.

We all look forward to them every year!



COMMUNITY SUPPORT

Team Malcomson's Marathon Effort



At October's Melbourne Marathon, the MND Victoria team cheered on people running for a purpose: to raise vital funds to support people living with MND access care and support.

In exchange for participating in the Melbourne Marathon, our runners raised vital funds for MND Victoria.

All of our marathon runners captured our hearts. One team, Team Malcomson, captured the nation's hearts.

After Ross was diagnosed with MND in 2024, his sons Trent and Kane, and son-in-law Caleb, decided that they wanted to run the Melbourne Marathon for MND Victoria—and they wanted their dad involved the entire way.

Trent, Kane, and Caleb took turns pushing Ross in a special wheelchair throughout the entire marathon track. At Marvel stadium, Ross crossed the finish line on his own two legs alongside his boys.

Trent shared a bit about their journey:

"After Dad's diagnosis with MND in September 2024, we found the support for Dad and our family provided by MND Victoria to be extraordinary.

"We saw a post on the MND Victoria Facebook page offering charity running spots in the sold-out Melbourne Marathon and jumped at the opportunity to share in such a significant sporting achievement whilst raising valuable funds for such a great charity.

"Dad has been a very physically active and fit person his whole life. He's achieved several massive sporting milestones but never ticked off a marathon.

"We were very proud of being able to support MND Victoria, and were exceptionally humbled by the generosity of everyone that contributed. **We raised \$60,000 for MND Victoria which we are incredibly proud of as a family.**

"It was a fantastic day, the support we received from other runners and the general public in the crowd was phenomenal. The applause dad received in the MCG when we crossed the line was one of the best experiences of my life.

"I would encourage anyone thinking about doing it to give it a try—both Kane and my wives are currently training for the 2026 marathon, so it's been great to watch them start their training.

"Take your time with your training. We started 10 months out and built up our distance gradually. Once the fitness started to build it was one of the most enjoyable and rewarding things I have ever done. The opening few runs were incredibly challenging but we stuck to it.

"Marathon day was described to me as the "victory lap" and I do agree with that, it's the culmination of months of hard work."

If you'd like to run in the upcoming Melbourne Marathon as a charity place runner, get in touch with the team at community@mnd.org.au!





SATURDAY 16 MAY 2026
LAKE SIDE STADIUM, ALBERT PARK

*Walk, run or roll to put your
#Care in Motion for people with MND.*

SCAN TO REGISTER



MND VICTORIA

265 Canterbury Road,
Canterbury, VIC 3126 Australia
Phone: (03) 9830 2122
Freecall: 1800 777 175

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🌐 www.mnd.org.au
f www.facebook.com/MNDVic
📷 www.instagram.com/mnd_vic
in www.linkedin.com/company/mndvic

We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands in which we live, work, and learn. We recognise and respect the enduring relationship they have with their lands and waters, and we pay our respects to Elders past, present, and emerging.