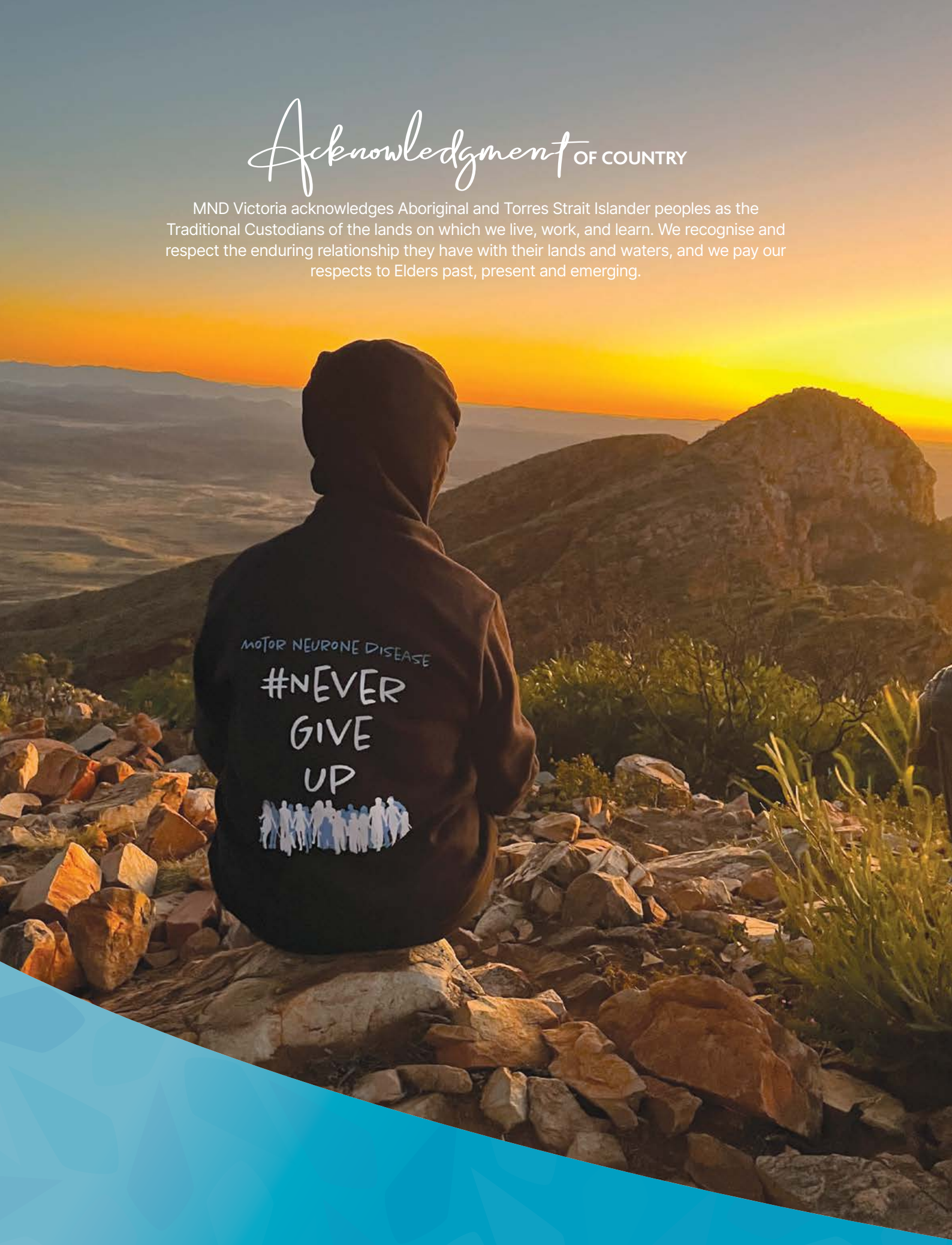
mnd Victoria

ANNUAL REPORT 2024

AT MND VICTORIA, *we understand*

Acknowledgment OF COUNTRY

MND Victoria acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands on 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.



Our VISION, MISSION AND VALUES

OUR VISION

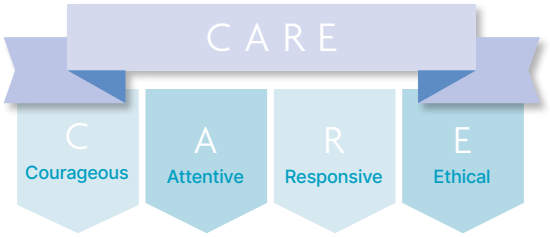
The best care until the world is free of MND.

OUR MISSION

To provide and promote the best possible care and support for people living with MND.

"People living with MND" includes people who have been diagnosed, those yet to be diagnosed, carers, former carers, families, friends, workmates, and any other person whose life is – or has been – affected by MND.

OUR VALUES



OUR OBJECTIVES

OBJECTIVE 1

Ensure the availability of a broad range of high quality services and supports for people living with MND.

OBJECTIVE 2

Advocate for the needs of people impacted by MND to be fully and equitably met.

OBJECTIVE 3

Promote, support and deliver research into care, treatment and cure for MND.

OBJECTIVE 4

Increase awareness and support for MND Victoria.

OBJECTIVE 5

Underpin our strategy by remaining sustainable.

THE CORNFLOWER

The blue cornflower (Centaurea cyanus) is the symbol of hope for people living with MND around the world – hope for finding the cause; hope for the development of treatments; and hope for a cure. The cornflower represents positive hope for the future – a future without MND. The cornflower was chosen for its fragile appearance but hardy nature. Like the cornflower, people living with MND show remarkable strength in coping with this devastating disease.

Our IMPACT 2023/24

MND Victoria operates across Victoria, New South Wales (bordering with Victoria), and Tasmania. Each of our operations, from client and carer support services to community engagement and fundraising, has a profound impact upon the community. Review some of our facts for the 2023/24 year.

ASSISTIVE TECHNOLOGY PROVISION

Read more on page 8

NEW CLIENTS RECEIVING EQUIPMENT:
182

EQUIPMENT ITEMS PROVIDED:
4,904

CLIENTS WITH EQUIPMENT AT 30 JUNE:
414

REQUESTS FROM ALLIED HEALTH PROFESSIONALS TO THE EQUIPMENT SERVICE:
1,938
(often for more than one piece of equipment)

EQUIPMENT ITEMS RECOVERED:
2,574

COUNSELLING SERVICES

Read more on page 11

NUMBER OF COUNSELLING HOURS:
163

NUMBER OF PEOPLE SUPPORTED BY COUNSELLING SERVICE:
69

ADVISOR AND SUPPORT COORDINATION

Read more on page 12

PEOPLE SUPPORTED BY MND VIC:
820
VIC: 717, TAS: 82, NSW: 21

HOURS DELIVERED TO CLIENTS BY MND ADVISORS:
22,666
VIC: 20,772, TAS: 1,527, NSW: 367

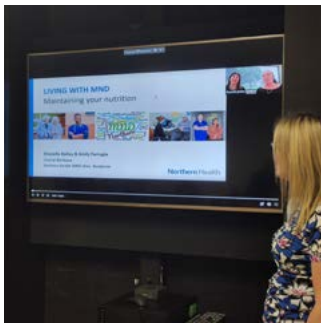
NEW MEMBERS WITH MND:
255
VIC: 223, TAS: 27, NSW: 5

PEOPLE WITH MND REGISTERED AT 30 JUNE:
597
VIC: 524, TAS: 54, NSW: 19

REPORTED MND DEATHS:
212
VIC: 184, TAS: 26, NSW: 2

EDUCATION, CLIENT AND CARER SUPPORT

Read more on page 14



TYPE OF RESOURCE SENT OUT:

523
Welcome Packs

260
GP Information kits

4,678
MND e-news
(8 editions)

2,635
Health Professionals
e-news (8 editions)

567
Number of carers supported through respite and wellness/ education activities

MND VOLUNTEER ENGAGEMENT

Read more on page 18

VOLUNTEER HOURS:

3,763
Contributed

REGISTERED/ACTIVE VOLUNTEERS:

108
Includes 21 new volunteers

DONATIONS AND FUNDRAISING

BEQUESTS AND TRUSTS:

$3,014,020

DONATIONS:

$883,314

INVESTMENTS:

$624,086

MERCHANDISING:

$29,401

MND VICTORIA EVENTS:

$567,387

COMMUNITY EVENTS:

$266,614

CONTENTS

President AND CEO MESSAGE

Across the last year, we have once again seen an increase in the number of people living with MND in Victoria. This has increased demand for all the services we provide. To meet this demand, we have worked hard to increase the amount and range of services available to the MND community. We continue to work to identify gaps in support and opportunities to grow our services to meet these needs.

In 2023/24 we supported 717 people living with MND in Victoria – compared with 597 in 2018/19.

In response to this increase in demand, we have expanded our teams to ensure we have both the human resources to provide the support needed and the financial resources to maintain these services.

We have grown our Support Services with:

- the addition of our expert MND Counsellor
- expansion of our MND Advisor and Support Coordination Team
- an additional role in our Volunteer Engagement Team
- bringing our Equipment Service fully in-house and expanding the Equipment Team to ensure prompt, high-quality services.

With the support of Perpetual Impact grants, we have added a new wheelchair-accessible vehicle to our fleet. This vehicle is available on loan for clients of MND Victoria and their carers for up to two weeks. We have had so much positive feedback about the difference this makes to individuals and families wanting to go on anything from a day trip to a holiday.

We have also expanded our Community Engagement Team to ensure that we can raise the funds needed to provide services, advocate for the needs of people living with MND to be met, and remain deeply engaged with the MND community and our supporters.

We are so fortunate to have a dedicated and committed team of staff, who display both passion for their work and professionalism in its delivery. We highlighted just three of the many members of our team who have been impacted by MND in June 2024 – Amy, our Equipment Service Team Leader, Daniel, our Community Engagement General Manager, and Sarah, one of our MND Advisors and Support Coordinators – who all lost their fathers to MND. Amy, Daniel and Sarah – as well as many more of our team – show such strong commitment to our mission to provide the best possible care and support to people living with MND and their family and carers, born from their own experiences living with and losing a loved one to MND.

We look forward to being able to continue to expand the services and supports on offer to people with MND and their families in Victoria – and thank all our donors and supporters for their continued generosity towards MND Victoria.

'Until there's a cure, there's care.'

David Lamperd
President

Kate Johnson
CEO

STATE COUNCIL
(AS AT 30TH JUNE 2024)

David Lamperd* – President
Katharine Barnett* – Vice President
Jeremy Urbach* – Treasurer
Wayne Pfeiffer*
Duncan Bayly* (until February 2024)
Chris Beeny
Jodie-Ann Harrison Fitzgerald*
Angeline Kuek (leave of absence October 2023 – June 2024)
Napier Thomson
Chloe Williams
Maryanne McPhee
Ann Elkins* (from October 2023)
Todd Johnson* (from May 2024)

**Has a personal association with MND*

Vale DUNCAN BAYLY

It is with profound sadness that we acknowledge the passing of Duncan Bayly, a valued member of the MND Victoria State Council, who died in February 2024. Duncan's journey with motor neurone disease began in 2007, during a working holiday in the Netherlands. Despite the challenges posed by his diagnosis, Duncan embraced a spirit of resilience and hope that profoundly impacted all who knew him.

Duncan's commitment to the MND community was unwavering. He led two remarkable fundraising rides from Amsterdam to London, which showcased his dedication and determination to raise awareness and support for the cause. Upon returning to Melbourne, Duncan, alongside his devoted wife Kat, continued to be a beacon of inspiration on our State Council. Their shared philosophy of looking forward and cherishing what they had, rather than dwelling on what was lost, became a guiding light for all.

Duncan's contributions to MND Victoria were invaluable. His tireless efforts, profound intelligence and curiosity, and compassionate heart have left an indelible mark on our organisation and its mission. His legacy will endure through the continued work of the Association, reflecting the principles he lived by and the hope he inspired.

Duncan's impact on our State Council and the wider MND community will be remembered with deep gratitude and respect. We extend our heartfelt condolences to Kat and all who were touched by Duncan's extraordinary life.

Rest in peace, Duncan. Your good work will live on in the hearts and efforts of those you have inspired.

Our ADVOCACY

MND VICTORIA'S PARLIAMENTARY EVENT

Iwan Walters – Parliamentary Secretary for Disability, invited MND Victoria to hold an event at Parliament House, to which he invited all Victorian MPs. Held in July 2024, this event was attended by many parliamentarians alongside MND Victoria staff, volunteers, clients and families. Attendees heard from Iwan, MND Victoria CEO Kate Johnson and Emma Vulin, State Member for Pakenham – who was recently diagnosed with MND.

However, the highlight of the event was 9-year-old Finn Cadman, who spoke of his "Glampa's" MND diagnosis and journey so far. Finn also discussed the inequity of access to government-funded supports between those eligible for the NDIS and those who are not – and therefore access supports through Aged Care Services. This was a fabulous opportunity for MND Victoria to highlight our organisation, the work we do, and the gaps in service for people living with MND in Victoria.

We have had a number of follow up meetings with MPs and look forward to strengthening these relationships to improve supports for Victorians living with MND and their families.

NATIONAL PARLIAMENTARY FRIENDS EVENT

MND Victoria works closely with the State MND Associations across Australia and with MND Australia. Together we work to raise awareness nationally of the unmet needs of people impacted by MND, and advocate for better funding and support to meet these needs.

State Council President David Lamperd and State Councillor Wayne Pfieffer attended MND Australia's Parliamentary Friends of MND event held in Canberra in June 2024. At this event the unmet needs of people living with MND were highlighted and the National Lived Experience Network was launched. Attendees heard from MND Australia President Andrew Danson, Chair of the Lived Experience Network Jane Simpson, and Minster for the NDIS Bill Shorten.

WARREN ACOTT'S MOW DOWN MND

In March 2024, Warren 'Woz' Acott decided to journey 800kms on his ride-on mower to campaign to make MND a notifiable disease. Woz, who was diagnosed with MND in June 2023, travelled from his hometown in Toolleen in country Victoria to Parliament House in Canberra, collecting some 14,000 signatures along the way. He personally delivered this petition to Prime Minister Anthony Albanese and held an audience with the PM where he discussed the horrible reality of living with MND.

Woz's courage, tenacity and good old Aussie spirit are inspiring, and we are in awe of his commitment to spreading awareness about MND through his uniquely epic journey. Although MND has not been made notifiable, Woz and the Mow Down MND team did an incredible job of raising awareness of MND, and raising funds for MND Victoria and MND Australia – and $550,000 of federal government funding has been allocated to the Australian Institute of Health and Welfare for more comprehensive reporting on neurological conditions.

INCREASING OUR ADVOCACY

MND Victoria now has a Media and Advocacy Coordinator. We will be focussing more intensely on advocating for the needs of people in Victoria impacted by MND to be better met – and on awareness of our Association – through political advocacy, media, and community awareness in the coming year.

Research

For many years, MND Victoria has partnered with supporters who raise significant funds for MND research. These funds are allocated to research programs through MND Research Australia. In the 2023/24 financial year, the following grants were provided:

SUPERBALL XVI RESEARCH GRANT

Lead investigator: Dr Samantha Barton

Institute: University of Melbourne

Title: Could Schwann cells be exacerbating motor neuron dysfunction in MND?

By characterising the contribution of Schwann cells in MND, this project will investigate a potential druggable target – if we preserve Schwann cell function, could we also rescue motor neuron function?

JENNY SIMKO RESEARCH GRANT

Lead investigator: Dr Luke McAlary

Institution: University of Wollongong

Title: Deep mutational scanning to define and predict the pathogenicity of existing and future SOD1 mutations.

This project plans to systematically investigate every existing and possible mutation that can occur in the SOD1 gene to generate a database that will allow genetics counsellors and clinicians to effectively diagnose patients and more quickly begin offering care and support to them and their families.

> *The opportunities for our allied health staff to participate and provide meaningful contributions to the body of evidence for MND clinical care is so rewarding and re-energising."*
>
> **Recipient of the Ella Whaley MND Victoria Research Grant**

ELLA WHALEY MND VICTORIA RESEARCH GRANTS

MND Victoria was grateful to receive a significant bequest in 2020 and created the Ella Whaley MND Victoria Research Grants. We commissioned allied health teams from Calvary Healthcare Bethlehem to complete the following research projects:

Extension of Neck Weakness in MND Observational Study

This project aims to:

- Improve on the accuracy of our previously suggested prevalence of neck weakness in MND by following participants through to the end of their disease process.
- Explore the relationship between neck weakness onset and mortality in people with MND.

Exercise Interventions for People with Motor Neuron Disease: A Systematic Review

There are increasing reports that exercise may reduce secondary deconditioning and improve disease specific and functional outcomes. Clarity around the efficacy of exercise interventions across the course of the disease, optimal type of exercise, and how phenotypic presentation should be considered in the prescription of exercise, are needed to guide clinical practice.

Assistive TECHNOLOGY

OUR ASSISTIVE TECHNOLOGY SERVICE MOVES TO RINGWOOD

MND VICTORIA'S Jewel in the crown

Our world-class Equipment Service is the crown jewel in the support we provide to people living with MND. For years, we had been using a third party to assist with this service. In 2023, we were in a position to bring this service fully in-house and in November, the MND Equipment Service Warehouse was established in Ringwood.

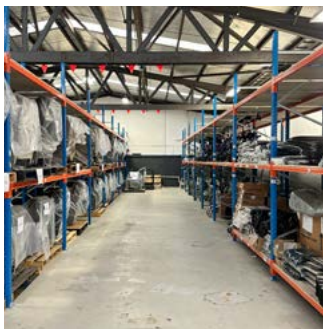
The Equipment Service Warehouse was officially opened on 15 April 2024 by Labor MP Iwan Walters, the Parliamentary Secretary for Disability, and our CEO Kate Johnson.

Having the Equipment Service in-house means we can operate all aspects within our own team and ensure we can deliver this service at the highest quality, every step of the way. As well as processing equipment requests, our brilliant Equipment Service Team oversee the housing, delivery, collection, cleaning and maintenance of over 3,400 items in our extensive library. Every one of these high-end assistive technology items is provided at no cost to people living with MND and helps them maintain maximum independence and ensure their safety.

Our Equipment Service is dedicated to a continuous improvement process, which is designed to enhance and refine our ability to provide and promote the best possible care and support for people living with MND. This ongoing effort focuses on optimising every aspect of our service – from the efficient and timely dispatch of equipment to the quality of our client interactions for collections and repairs. By continually assessing and improving our practices, our team aims to provide the best care until the world is free of MND.

We are excited to now have a greater level of control over the quality of this service to ensure a smooth process from start to finish. This venture is only possible due to the wonderful support and generosity we have received from the MND community and beyond – so thank you to everyone who has contributed to this milestone achievement.

> *These items from your library make a massive difference to my quality of life, and I'm sure other recipients are equally grateful for such a visionary initiative as the MND Equipment library."*
>
> **Person living with MND**



Support SERVICES OVERVIEW

MND Victoria's Support Services deliver services 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, and remain active in their community and safe in their environment, through the provision of six key program areas:

COUNSELLING SERVICE

We have recently expanded our services to include an in-house counsellor who provides emotional adjustment support and advice to people impacted by MND.

ADVISOR AND SUPPORT COORDINATION SERVICE

MND Advisors provide support to people living with MND to assist them to live as long as possible with the best quality of life possible.

EDUCATION AND CLIENT SUPPORT

The Education and Client Support Service provides comprehensive education and information support to people impacted by MND. Support groups, information sessions and educational programs are available for anyone impacted by MND to join.

CARER SUPPORT PROGRAMS

When someone is diagnosed with MND, their loved ones are also living with this disease. It is important that carers also receive the information, support and assistance they need to manage the caring role. We have a range of supports available both online and in person that are facilitated by our dedicated Carer Support Team.

VOLUNTEER PROGRAMS

Volunteers are the heart of MND Victoria. Our volunteers bring a wealth of knowledge together with a wide range of skills and experiences to MND Victoria. Volunteers enhance the work of staff and help provide opportunities for improved quality of life for people living with MND and their families.

ASSISTIVE TECHNOLOGY PROVISION

MND Victoria has developed an extensive range of assistive technology equipment, available free of charge to people with MND.

Counselling SERVICES

In 2023, MND Victoria completed an internal research project looking at grief and bereavement support available to people living with MND and their families.

The research showed that people living with MND and their families wanted access to counselling and emotional support from a professional who has a deep understanding of the impacts of an MND diagnosis – meaning they don't have to explain the effects of the disease to yet another health professional. It also showed that access to a counselling service needed to be easier and more timely – rather than having to see a GP for a referral and a mental health care plan then sit on a waiting list for weeks to months to receive support. Our clients and their carers needed prompt access to an MND Counsellor with no need for a doctor's referral.

Our State Council approved a full-time counselling role and a free counselling service for people impacted by MND, funded through our campaigns and donations. Beth joined the team in January 2024 in this new counselling role.

The MND Counselling Service offers person-centred, responsive, and timely emotional support to people diagnosed with MND and their loved ones. The person living with the diagnosis is considered the primary client. The service offers individual, family or couples' counselling for clients and their families – and is available in person, online or by phone.

On average, the service receives 15 new referrals each month and 3-4 counselling sessions are booked each day.

This service has been a very welcome one and we are privileged to be able to meet this additional need for the MND community.

> *Sue* mentioned during a conversation that after Beth's counselling input, she noticed a significant positive change in John* and his mood despite only a little engagement. Beth has a great way with clients, very much highlighted through the general feedback I am hearing from those engaging with the service.*

> *During a home visit with Jane*, she mentioned the counselling service and described Beth as 'beautiful'. Jane spoke about one session when she was upset, which affected her breathing. Beth spoke with her reassuringly and during the conversation, Jane realised she was no longer upset and her breathing had returned to normal.*

** Names have been changed*

Advisor AND SUPPORT COORDINATOR SERVICE

DON'T GIVE UP | MARTIN LEACH'S STORY

When we asked Martin for one piece of advice that has guided him through life, he replied: "Don't give up". Those three words highlight the determination and resilience that has shaped his life and made him the person he is today.

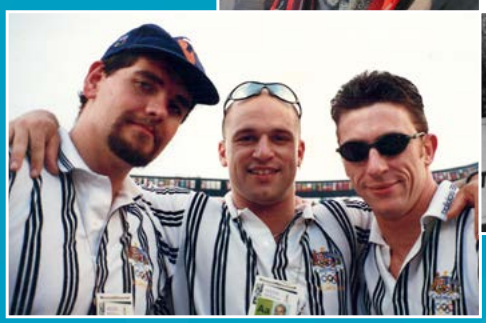
Martin was diagnosed with MND in 2022, but his admirable spirit existed long before his diagnosis. Back when he was 13, Martin decided to take up weightlifting and was soon the epitome of a "promising junior". Though that all changed when Martin broke his elbow during a training exercise when he was 16.

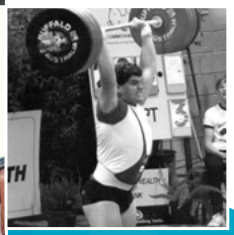
Despite this, Martin refused to succumb to discouragement. Instead, he channelled his setback into fuel for his determination after countless doctors told him he would have to give up weightlifting. Martin's simple answer: "No".

"The more they said I'd have to give it up, the more my future ambition to represent Australia slipped away from me... the more determined I became."

Martin went on to represent Australia over 20 times in weightlifting, placing 5th at the World Championships. He trained hard for 18 years, often lifting up to 30,000kg in a single day. But tragically, a dislocated shoulder shattered Martin's dreams of being in the 1988 Olympics and ended his athletic career.

It was the trials and tribulations of being an athlete that allowed Martin to go on to be the caring, empathetic high-performance sports coach that he was. "It was my understanding of human failure that made me a better coach than an athlete, in my opinion."





In 2020, Martin went for an annual check-up at the doctors. What was meant to be a routine appointment led to noticing a limp, which led to a discovery much more insidious. After lengthy investigations, Martin was diagnosed with MND in 2022. Three months later, he discovered he had renal cancer. A 1.5kg tumour was removed from his abdomen and Martin was given three months to live.

But despite the horrific circumstances, the odds were in Martin's favour. He's part of the 40% of people who respond positively to the cancer treatment, and he has well and truly outlived his initial life expectancy. His children, who were 16 at the time of his diagnosis, have now had their 18th birthdays. Though having stepped back from his business, the business is still flourishing. Martin's refusal to "sit on his hands" has led him to becoming an advocate for MND Victoria and raising thousands of dollars for the care and support of others impacted by MND.

Throughout his journey, Martin has exemplified the power of resilience and the importance of facing adversity with courage and tenacity. Not only is he working towards ensuring he makes the most of his time with his loved ones, Martin also strives to give back to the MND community.

An MND and cancer diagnosis was never going to stop someone like Martin. Being the determined person he is, Martin saw his diagnosis as an opportunity to leverage his passion for challenge and philanthropy into something that could help so many.

As Martin continues his journey with MND and cancer, his message resonates loud and clear: "Don't give up." His story serves as an inspiration to all, a reminder that even in the darkest of times, there is strength in perseverance, and hope in the human spirit. Martin's journey is a testament to the power of determination – a legacy that will endure.

EMMA VULIN'S STORY

Emma Vulin MP is the State Member for Pakenham. She was diagnosed with MND in April 2024.

Even before my official diagnosis, MND Victoria provided support to me and my family. When we thought motor neurone disease was a real possibility, I called MND Victoria and sobbed. I asked if they could help me with some information to explain it to teenage children.

Joyce was there to hear me, and she provided useful information immediately and started the process of allocating me a Support Coordinator. A couple of weeks later David Cox – my MND Advisor and Support Coordinator – came to our home. He listened to us for hours, and he explained everything that MND Victoria had to offer both me and my family.

David and the team at MND Victoria guided me through the NDIS application process and helped coordinate care at Calvary with a neurologist, occupational therapist and physiotherapist. I have been fortunate enough to also borrow some equipment to help make my day-to-day life that little bit easier as my body slowly degenerates.

Having suffered a significant stroke eight years ago, I think I had a new perspective on life after that event. But with the stroke, I guess I had never thought about end of life as I was continually showing improvement.

It was different with the terminal diagnosis of motor neurone disease. It has really made me think about my children, what I need to achieve in a short time, what things I need to set up for their future and what I can do to make things easier for my loved ones. On this journey, having MND has forced me to slow down – not because I necessarily want to but because my body no longer gives me the choice.

Apart from the sadness of coming to terms with the diagnosis, there are things I feel anxious about sorting out – like legal documents such as power of attorney, my will, banking, superannuation and passwords, as well as planning a funeral and the practical stuff like sorting through everything I own. It's sometimes hard to face the administrative tasks when movement is getting more difficult, and I get tired so much more easily.

Probably the most important thing we have gained by being part of the MND Victoria family is the chance to meet other people either suffering with MND or people who have been closely affected in some way. The friendships and the ability to ask others about changes, ideas or just how they feel is truly the best part, and for that I am grateful.

We are lucky to have guidance and support from so many from the MND community, MND Victoria and others who truly care about the motto 'Until there's a cure, there's care'.

> *"Our Advisor/Support Coordinator came and was so helpful that it was like the sun rising on a dark day, a sign of hope and light when all was gloom. They worked through all the challenges very calmly and thoroughly, and it was very much appreciated."*
>
> **Sister of person living with MND**

Education, CLIENT AND CARER SUPPORT

NATIONAL MND AUSTRALIA CARE CONFERENCE

MND Victoria co-hosted the MND Australia Care Conference, held at the Florey Institute of Neuroscience and Mental Health in Melbourne on 28 August 2023.

The Conference provided a great opportunity to hear from experts in the field of MND and to network with health professionals, clinicians, academics, service providers, those living with MND and their carers.

The theme of the conference was 'Caring in a Complex Environment', and attendees were encouraged to "get comfortable with complexity." The diverse program featured topical themes including psychological well-being, non-invasive ventilation (NIV), physical exercise, carer support, voice banking and neuro-palliative care. There was an emphasis on the importance of building a multi-disciplinary team to ensure holistic care, optimising interdisciplinary communication, and taking a proactive approach to managing care needs.

The after-event networking opportunities provided a relaxed and welcoming environment to discuss the highlights of the program whilst building and developing important connections within the MND community. Attendees left the conference with a broader understanding of complex issues, adding to their growing 'tool-kit' of strategies, ready for application to their respective personal and professional MND connections.

CARERS CAN VIDEOS: FightMND GRANT

In late 2023, MND Victoria received a $150,000 grant from FightMND to develop a series of five educational videos aimed at supporting carers of individuals with MND.

Identifying a gap in carer education, the Carers Can Project was launched to address common care challenges through these videos, which will serve as interim resources for carers awaiting specialist support. A reference group, including staff and experienced carers, was formed in January 2024 to guide the project.

Topics were selected based on community feedback and include:

- managing comfort in bed
- self-care
- communication changes
- eating difficulties
- fatigue

Featuring input from health professionals and carers, the videos are currently in the final editing stages and will be released in late 2024, accompanied by fact booklets for additional support.

CARER SUPPORT PROGRAMS

Providing care to a person living with MND can be physically, emotionally, and psychologically difficult. Whilst many carers highlight the privilege and reward of being able to care for a loved one, it is important that carers also receive the information, support, and assistance they need to manage the caring role.

MND Victoria offers a number of free programs that aim to support carers in their role of caring for their loved one with MND.

"My husband, Kevin, was diagnosed with MND in 2017. His MND is slow-progressing, which makes life a little bit easier for us. He is still mobile and able to shower himself, but I do all the cooking and cleaning, drive him to all of his medical appointments, and am the general go to for all his needs.

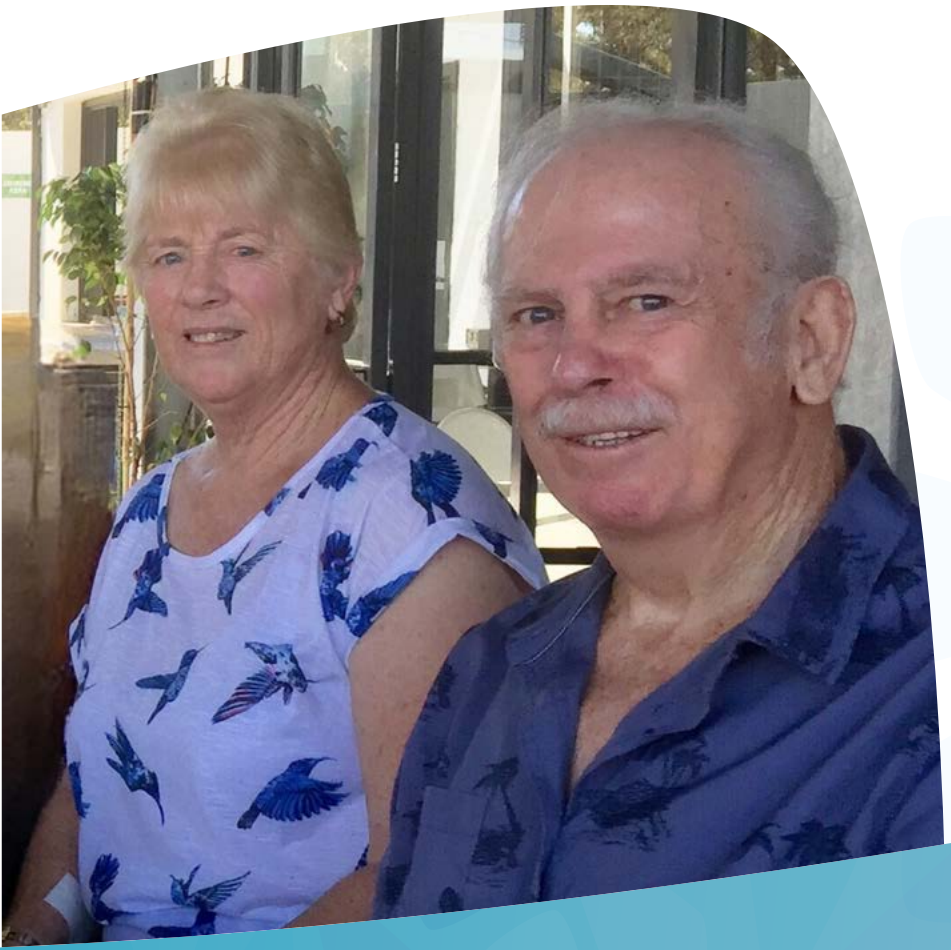
"The Carer Support Programs are really wonderful and help to give me a bit of time out away from the routine. I've used the **Carer Respite Funding** to have someone help with the gardening, which Kevin used to love doing but isn't able to anymore. We were also able to use the funding to have a really nice dinner out for our anniversary.

"I've also gone to some really lovely **Wellness Retreats** and **Lunches**. Kevin even came to one. They are a great way of talking and connecting with other carers and having some time out. You also learn a lot from the guest speakers and enjoy the activities too.

"The **Kitchen Table Conversations** are really good. There are often interesting people who do presentations, and everyone who comes along is able to share their own stories and worries.

"These programs are a real bonus to have. To be able to rely on other people going through the same thing as you, to have a chat and a break away from the routine at home, it's emotionally so supportive."

Helen
Carer



> *It was so good to come and connect with others who are on a similar journey. The presentations were excellent and encouraged important discussions. We feel extremely well supported in this journey."*
>
> **Wife of person living with MND**

Community ENGAGEMENT

AT MND VICTORIA, WE UNDERSTAND

An MND diagnosis is life-changing, not only for the person diagnosed but also for their loved ones. For every person diagnosed with MND, it is estimated that a further 14 loved ones will live with the effect of MND forever.

Amy, Daniel and Sarah are just three of a number of staff members at MND Victoria who have lost a loved one to MND, or who have a loved one currently living with MND. Each of their fathers was a great influence in their lives, so much so that they are dedicating their careers to helping people just like their dads. They know the value and importance of MND Victoria's services, and this passion drives them every day. For them, **it's personal**.

Amy leads the Equipment Service, which helps people living with MND remain safe, independent, and connected with their community; Daniel manages the Community Engagement team, raising awareness of MND and the funds that underwrite our care and support services; and Sarah is an MND Advisor and Support Coordinator, guiding people along their MND journey from the beginning until the end.

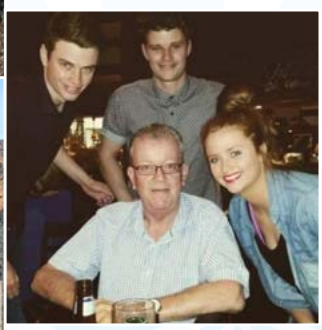
At MND Victoria, we understand. We know how vital the right care, support and assistive equipment is on the MND journey. Every staff member is a compassionate, caring and committed professional united in MND Victoria's vision: **'The best care until the world is free of MND'.** We're here for all Victorians, every step of the way.

Every year, the depth and quality of our services continue to improve; and that is thanks to the enduring support and generosity we receive from our donors. Every single dollar we receive is used to grow and expand our services with our mission always in mind: **'To provide and promote the best possible care and support to those living with MND'.**

We have walked this journey many times and will continue to do so until the day we are no longer required. **Because until there is a cure, there is care.**

Earlier this year, Amy, Daniel and Sarah wrote heartfelt letters to their dads, filling them in on everything they've missed since they passed. We hope these letters give some insight into the people who work at MND Victoria and the passion that drives our organisation.

www.mnd.org.au/letter-to-dad



THE GREAT MND RELAY 2024

The Great MND Relay has established itself as the signature event for the MND community. Each year, we introduce a new concept of what the challenge component will be for the event, designed to raise awareness of MND and acknowledge the work of MND Victoria.

In 2024, we hosted the third year of The Great MND Relay which united over 1,100 participants to take on a 251-minute challenge. The 251 represented the number of people diagnosed with MND in Victoria in the last year. Our community fully embraced the challenge and made it a day to remember.

The atmosphere at Lakeside Stadium was buzzing with excitement as participants, families, and the wider community gathered for the same cause. From the morning start to the final lap, the enthusiasm and dedication to raising awareness and funds for MND was undeniable and inspiring.

We witnessed over 1,100 people come together and complete over 29,000 laps through walking, running, or rolling – raising over $350,000! It was a monumental day, and The Great MND Relay has proved to be more than just an event – it's a powerful day where the MND community unite, connect, and help make an impact.

Our team was thrilled to welcome attendees from across Australia, and we are incredibly grateful to all those who attended, volunteered, or donated to The Great MND Relay. We are already looking forward to next year and seeing this special event continue to grow.

SHUT UP! FOR MND 2023

This year we were once again inspired by our challenge-taking community and their involvement in the Shut Up! For MND campaign. On 21 September 2023, over 250 people took on the challenge of going without speaking for 6 or 12 hours, raising a monumental $117,000!

Shut Up! For MND continues to be such a powerful campaign, highlighting the fact that more than 80% of people with MND will lose their ability to speak or have difficulty speaking.

Our official Shut Up! For MND Ambassador, Sofia Levin, embraced her social media presence by sharing ways people could get involved in the Challenge and the fun of nominating your networks to Shut Up! We loved seeing our community utilise their social media as a method to raise awareness and funds as part of their participation in the campaign.

One of this year's participants, Tiarna (pictured right), beautifully captured the importance behind the Shut Up! For MND Challenge when she said: "Earlier this year I lost someone very important to me to this disease and it was heartbreaking watching everything unfold. It was particularly difficult watching him lose his voice and the ability to sing – something he's previously loved doing. Many people battling MND, like him, lose the ability to speak and communicate vocally. I want to stand beside those fighting and try to understand the smallest bit of what they are experiencing, and advocate for those who have lost their voices completely."

Thank you to everyone who participated, supported, or donated to Shut Up! For MND. It is indescribable how meaningful it is to raise awareness about the communication difficulties so many people living with MND face every day.

Volunteer ENGAGEMENT

VOLUNTEER PROFILE – MEET SALLY

Sally volunteers in the Bereavement Call team. She brings a nursing background to this role, and feels that her time working in neonatal wards especially has given her the comfort to converse in the death and dying space with families.

More importantly, Sally has a personal connection with MND Victoria. She cared for her husband through his illness, accessing equipment through MND Victoria as needed. She was inspired to volunteer as a way of giving back – she had admired the way families were supported and wanted to be a part of that assistance.

When queried about what qualities may be helpful in making bereavement calls, Sally suggested that empathy, understanding, quietness, acceptance, and listening are important elements needed in the role. Furthermore, to have experienced loss (not necessarily through MND – "There are many ways of losing", Sally notes) would possibly help support these other qualities.

Sally says the challenge in the role is that you are speaking to a stranger. You don't know their story; you are trying to pick up on their emotions so that what you say might be of help to them at their level of grief.

For Sally, volunteering at MND Victoria gives her a sense of self-worth, of giving back to the community. She finds it very satisfying when she senses that she has made a connection, and that her call has helped someone else.

When asked what she would like others to hear about volunteering at MND, Sally was full of praise for the volunteer program. She has found each manager over her 15 years with MND Victoria has created a personal connection with their volunteers. Moreover, volunteers are supported in their roles, offered training and, importantly, gratitude. As a consequence, volunteers feel valued.

VOLUNTEER PROGRAM IN ACTION

Chris is a retired nurse who volunteers in the Hand and Foot Massage team. She initially volunteered at MND Victoria's head office in Canterbury, however, it was when she joined the Massage team that she knew she'd found her place.

Chris visits Neville fortnightly to provide him with a gentle and relaxing hand and foot massage. Neville looks forward to Chris' visits, not only because her massage helps him to relax and feel comfortable, but also because their chats – about anything other than MND – are a time to look forward to.

When asked what she has learnt through her volunteering at MND, Chris' words are: "Working with people with MND certainly makes you think. Live every day as it comes."

In 2022, Neville worked with another volunteer to write and print his Life Stories. The Life Stories project involves sitting with a client over a number of one-hour sessions and listening to the stories they want to tell – an occasional question or prompt is usually all that is required to keep stories flowing. The volunteer both records the conversation and takes notes that are later transcribed, with scanned photos and mementos added to create the finished bound product for the client.

Neville notes the process of recording his Life Stories was both challenging and rewarding but he is now very happy to have stories of his life recorded to be shared with his children and grandchildren.

Our SUPPORTERS

OUR RELATIONSHIP WITH FISHER LANE

Fisher Lane Mobility (FLM) and MND Victoria have had a relationship for over 20 years through the supply of much-needed equipment that helps people living with MND have a safer and more independent quality of life.

FLM have a long and committed history in the healthcare industry, and the team has immense expert knowledge of mobility equipment and how to best support people with a disability through their products. MND Victoria's world-class Equipment Loan Service has consistently grown over our 43-year history, and FLM has been on the journey for a large part of that time.

The relationship between both organisations began to flourish back in 2022 when FLM sponsored the incredible Sarah Solomon on MND Victoria's Larapinta Adventure with Impact Trip. Sarah is an exceptionally talented and world-renowned Occupational Therapist in the MND space, and is closely linked with the FLM team and MND Victoria team. This sponsorship also led to one of FLM's Directors, Ben Colquhoun, joining Sarah and the large team of dedicated MND Victoria supporters on this incredible outback adventure. Ben heard first-hand stories from people who have been impacted by MND in one way or another, and the reasons why they decided to take on the adventure for themselves whilst giving back to MND Victoria.

The FLM and MND Victoria teams have become somewhat of a family who work together proactively, share knowledge, and take a genuine interest in our respective missions, which align so well. The FLM team are amazing supporters of our major events and campaigns. Staff took part in

Shut Up! For MND and the business had a strong presence at The Great MND Relay with one of the most eye-catching and beneficial activations at the event.

In late 2023, MND Victoria made the giant move of bringing our Equipment Service in-house which meant we were now operating a warehouse and all the logistics that come with it. FLM have been doing this for years and without hesitation, the team offered any assistance and expertise we could possibly need.

On top of an already beautiful and beneficial relationship, FLM came on board 12 months ago as a major partner of our incredible Take-A-Break Program. This program is very special and unique, and aims to provide "no-strings-attached" funding with no delay for people with MND to 'take a break' from this devastating disease. The reality is that without this significant funding, the Take-A-Break program would no longer exist.

MND Victoria thank the FLM Directors Anthony, Kate, Sean, and Ben, and the whole organisation for supporting MND Victoria in such tangible ways. The Take-A-Break Program truly fulfils the cultural values of both our organisations and, simply put, it achieves the joint objective: to make a difference in people's lives.

BEQUESTS

The Estate of Judith Crook
The Estate of Patricia Cook
The Estate of Christine Blandthorn
The Estate of Valerie Meich
The Estate of Annemaree Foley
The Estate of Ronald Patterson
The Estate of Betty Morris
The Estate of Janet Paterson
The Estate of Richard Chenoweth
The Estate of Jean Barnden
The Estate of Graeme Walker
The Estate of Sarah Taylor
The Estate of Mary Palmer
The Estate of Edna Bastian

TRUSTS AND FOUNDATIONS

George & Edith Ramsay Charitable Trust
Australia Post – People of Post
The John and Mary McAlister Howden Charity Trust

ORGANISATIONS

Fisher Lane Mobility
FightMND

GOVERNMENT FUNDERS

Australian Government Department of Health
Victorian Government Department of Health
Victorian Government Department of Families, Fairness and Housing
Hume City Council

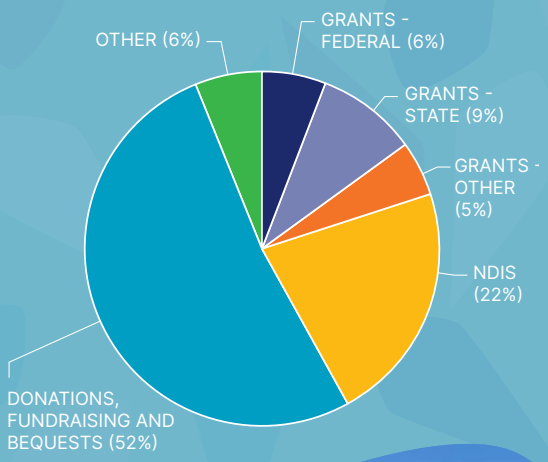
Financial IMPACT 2023/24

The 2023/24 financial year was indeed an eventful one, highlighted by the grand opening of our new Equipment Warehouse and the establishment of our new Counselling Service, which ensures we can provide a more holistic support network for those with MND, their family, friends and carers.

From a financial perspective, the Association enjoyed a solid year, recording an operating profit of $1.9m thanks to some one-off extraordinary bequests. If we were to exclude this extraordinary bequest income, we would have recorded an operating deficit of $1.1m, which highlights the importance of our fundraising initiatives. We now provide a long list of services to our community that are unfunded by government grants or the NDIS, which we can afford to deliver thanks only to your support.

As can be seen on the right, State and Federal grants account for just 15% of our income, and NDIS fee-for-service income is just 22%. The bulk of our income comes from the community we serve through donations, fundraising and bequests.

INCOME BY SOURCE



State and Federal grants and fee-for-service NDIS revenue provide funding only for the bare essentials. It is thanks to our community that we have been able to provide the following non-funded services to our clients, their families and carers.

This year, your support has allowed us to invest in the following otherwise unfunded programs, projects and services for people living with MND:

ADVISOR AND SUPPORT COORDINATOR SERVICES
$1,371,000
provided to clients outside the scope of funding provided by government grants or the NDIS

NEW ASSISTIVE TECHNOLOGY EQUIPMENT
$573,000
to make life more comfortable

THREE NEW MOTOR VEHICLES
$70,000
so our MND Advisors can visit those we support

A NEW WHEELCHAIR MOBILITY VEHICLE
$102,000
for loan so that people living with MND can get out and about

NEW EQUIPMENT WAREHOUSE SETUP COSTS
$109,000
to allow us to better respond to assistive technology needs

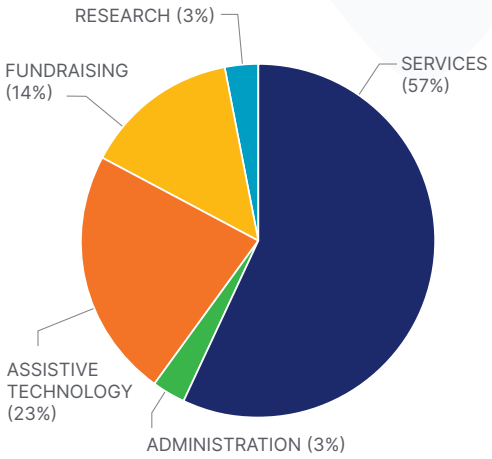
A NEW COUNSELLING SERVICE
$150,000
available to clients and their family and carers

PROFESSIONAL ENGAGEMENT AND EDUCATION SERVICES
$150,000
provided to the wider neurological and allied health community

CONTRIBUTIONS MADE TO UNIVERSITIES AND SCIENTISTS
$277,000
to help them find a treatment, cure or research ways to make life more comfortable

INVESTMENTS IN VOLUNTEER TRAINING
$80,000
to support our wonderful group of volunteers

EXPENDITURE BY TYPE



Regarding where we allocate our resources, 80% of our expenses are for either the provision of direct support services through our network of Advisors and Volunteers, or the provision of assistive technologies. Community engagement and communication expenses represent 14% of our costs, and a further 3% is spent on administration expenses. In FY23/24 we also made contributions to universities and institutions searching for a treatment or cure for this debilitating disease, which represented a final 3% of our total expenses for the year.

Our Association remains in a solid financial position thanks in no small part to the careful stewardship of management and the good governance provided by our State Council. The greatest thanks, however, must be reserved for our community of supporters, who continue to generously donate both financially and by volunteering their time. The level of service we provide the community is vastly superior to what we could offer if we relied only on government support. Together we are making a difference.

Callum Terrill

Chief Financial Officer

MOTOR NEURONE DISEASE ASSOCIATION OF VICTORIA INC

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