



# IMPACT REPORT 2024

Continuously striving to improve  
the quality of life and support of  
people living with MND, their carers  
and families.

# ABOUT MND NSW

MND NSW provides information, support and education for people living with motor neurone disease, their families, friends and carers in NSW, ACT and NT. We also provide information and education about motor neurone disease for health, community and residential care professionals.

## 2023-2024

**VICE PATRONS:** Melinda Gainsford Taylor, Kevin Langdon OAM, The Hon. Mr. Justice Peter W. Young OA

**AUDITOR:** Walker Wayland NSW

**MND NSW BOARD: President:** Lara Kirchner **Vice Presidents:** Amy Critchley, Anita Richter **Treasurer:** Nick Shaw **Board Members:** Kirsten Harley, Roger Henshaw, Sara Pantzer, Ralph Warren, and Kirsty Barber

## GOALS

1. People with MND in NSW/ACT/NT access the best care and support
2. Preeminent voice of MND in NSW/ACT/NT
3. Equity in MND NSW services for rural/ remote and urban members
4. Supplier of choice for equipment provision in rapidly progressing neurological diseases
5. Sustained income to keep going and growing to deliver needed services to the member base
6. A world free from MND through ongoing research funding

**"MY DAD WAS ABLE TO GET EVERYTHING HE NEEDED FROM MND NSW - WE ALL GOT THE SUPPORT WE NEEDED, AND EVERYONE WAS THERE TO HELP – THEY HAD SO MUCH HEART, IT WAS BEAUTIFUL. THE PEOPLE AT MND NSW ADDED A LOT OF VALUE TO DAD'S LIFE. WE'RE ALL VERY APPRECIATIVE."**

**- Louise**

# FROM THE CEO

Despite the 23/24 financial year being a difficult year for fundraising, MND NSW managed to dramatically increase our outreach, particularly to regional and remote areas.

Our MND Upskill program travelled to 30 venues offering free education to allied health professionals and carers.

A dramatic increase in FlexEquip services, including new hi-tech devices and our one-off loan pool has meant greater diversity of equipment available and a rapid response to all areas across the state.

In June, the number of people accessing the NDIS and the NDIS response rate increased dramatically due to the advocacy of MND NSW and state association network.

18 MND Planners were employed by the NDIA. Their sole role is to fast track MND participants on to the NDIS and create a consistent person centred approach to support services.

For the 24/25 financial year the MND NSW Board have decided to maintain and grow our vital education, equipment, Advisor and Coordination of Support services.

Despite the rising cost of living having a marked negative effect on donations, the Board has taken the view that these are vital services and should be grown, particularly in regional and remote areas of Australia.



# VALE KIRSTEN HARLEY

In June 2024, Kirsten Harley sadly passed away following her battle with motor neurone disease. Kirsten had been a cherished MND NSW board member since 2013.

Her MND journey began over 11 years ago, and she became a steadfast advocate for individuals affected by MND, both nationally and internationally.

Dr Harley's research carried great impact for people living with MND, and her most recent studies into enhancing the inclusivity of videogames for people with MND earned her recognition on a global scale.

In June 2024, Kirsten's dedication was further honoured with a lifetime achievement award from MND Australia, celebrating her profound impact on the MND community.

On behalf of the Board, staff, and volunteers of MND NSW, we wish to thank Kirsten for her unwavering efforts to be a voice for people living with MND, and ensuring MND NSW sought to assist those experiencing MND in meaningful ways. Our thoughts continue to be with extend Kimi, Densil, and all of Kirsten's loved ones.



## INFOLINE

**"IT'S VERY COMFORTING TO ASK A QUESTION ABOUT TRIALS AND DRUGS AND TO GET A QUICK AND STRAIGHT TO THE POINT ANSWER, WELL DONE."**

**- MND NSW InfoLine caller**

Throughout 2023-2024, MND NSW Infoline responded to over 1422 enquiries for assistance. This included 589 calls, and 738 emails. MND NSW InfoLine is often the first point of contact for people who are newly-diagnosed with MND or have a loved one with MND, and who wish to seek further information and support.

During the year, a new initiative was launched to increase the awareness of InfoLine and the types of service provided and questions answered. The InfoLine Top 5 FAQ is a monthly blog highlighting some of the most-asked questions throughout the previous month, as well as the responses we provided. This is included as a blog on our website, in our newsletters, and on social media channels, ensuring people living with MND, or those who would like to find out more about aspects of MND know more about MND NSW InfoLine and can get accurate and helpful information for their queries.

**"PHILLIP WAS SO HELPFUL AND PROMPT WITH DOCUMENTATION."**

**- MND NSW InfoLine caller**

# MND ADVISORS AND COORDINATION OF SUPPORT SERVICES

MND Advisors and Coordinators of Support Services (COS) provide important support and assistance for people living with MND and their families as they navigate their MND Journey.

At the end of the 2023-2024 financial year, 552 people in total were registered participants with MND NSW. Of these, 245 were newly diagnosed with MND and became MND NSW participants during the year.

The MND Advisor and Coordination of Support Services teams had over 8,700 hours of contact with our participants during the year, a 10% increase on the previous year. Around 60 support group sessions were provided for people living with MND, predominantly in NSW and the ACT, with some sessions held online.

As of the end of June 2024, 333 of our participants were aged 65 or above, meaning they were not eligible for the NDIS. Without the support of MND NSW, many of these participants would not have received the equipment, information and education about their condition, nor support they require to navigate their MND and the challenges it brings.

Throughout 2023-2024, 828 participants received assistance from our MND Advisors. Over the past 12 months, our MND Advisors continue to provide personalised, local support to people living with MND, their families and carers.

The Coordination of Support (COS) team provided services to 267 NDIS recipients throughout the year, assisting them in utilising their NDIS plan funding in ways that best met their support needs. 272 NDIS recipients also accessed equipment through FlexEquip - like the MND Advisor team, the COS team remain a key way to inform our participants about the assistive technology available from our organisation. By engaging NDIS participants to utilise their plan budgets to source equipment through FlexEquip, we can often save our participants thousands of dollars and ensure they are able to get equipment appropriate to their needs quickly and easily.

**"THANK YOU FOR YOUR SUPPORT AND FRIENDSHIP DURING MY JOURNEY WITH MND. YOU WERE ALWAYS AVAILABLE FOR A CHAT AND I APPRECIATED YOUR CARE AND COMPASSION AT ALL TIMES."**

**- MND NSW participant**



# FLEXEQUIP

**"FLEXEQUIP IS A LIFESAVER FOR SO MANY OF MY MND PATIENTS – AS IT IS A SERVICE WHICH RESPONDS TO MY MND PATIENT'S EQUIPMENT NEEDS PROMPTLY AND EFFICIENTLY."**

**- Manasi Thornley, Occupational Therapy Team Leader**

In 2023-2024, FlexEquip received new referrals for a massive 2,184 items of assistive technology from healthcare professionals. FlexEquip were able to provide assistive technology to support 470 participants within the past 12 months.

FlexEquip have changed the process for equipment delivery and collections within Sydney, Illawarra and Central Coast with the addition of a van donated by Open Mobility. The quality of service and response times in these areas continue to improve despite the growth and demand for the FlexEquip service.

FlexEquip continues to rapidly expand with an extensive range of equipment comprising of 2,620 items of equipment worth over \$4.7 million. Not only has the size and value increased, but a number of new items have been added over the past 12 months such as obi robotic feeders, milano highly customisable armchairs, armchairs with dual purpose standard and pressure relieving chairs, sara stedys, commode lateral supports, commode cushions, bed cradles, narrower power wheelchairs and the introduction of a large range of miscellaneous items. The miscellaneous items ensure donated items are repurposed and saved from landfill.

FlexEquip continue to engage in regular education to Allied Health Professionals with FlexEquip presentations at major forums over the past 12 months.

FlexEquip has presented at:

- 2024 MND Australia webinar series – Equipment prescription tips and tricks
- 2023 Allied Health Professionals Forum in Basel Switzerland – Cost effectiveness and environmental sustainability of the FlexEquip equipment service
- 2023 Australia and New Zealand MND Research Symposium

Not only is the quantity of referrals and items provided through FlexEquip expanding rapidly but most importantly FlexEquip continue to receive regular qualitative feedback on the importance of having services like FlexEquip through MND NSW to improve their quality of life.

**"I WOULD BE LOST WITHOUT IT - THE ROBOTIC FEEDER IMPROVES BOTH MINE, AND MY HUSBAND'S, QUALITY OF LIFE."**

**- Frances, Provided with a robotic feeder through FlexEquip**



# EDUCATION AND CARER SUPPORT

**"THE INFORMATION WAS CLEAR AND PRECISE, AND IT WAS GOOD TO TRY OUT THE FLEXEQUIP EQUIPMENT."**

**- Jean, MND Upskill for Carers attendee**

## MND Upskill

In the financial year we delivered 30 in-person MND Upskill workshops (17 for healthcare professionals and 13 for carers) across 17 locations in metro and regional areas of NSW, ACT and NT.

298 people attended:

- 203 Healthcare Professionals attended the MND Upskill for Healthcare Professionals
- 95 people including people living with MND and carers (formal, informal) attended the MND Upskill for Carers

## MND Upskill workshop impact:

- Increased understanding - 97% of participants reported an increased understanding of MND.
- Support needs awareness - 95% reported improved understanding of the support needs people living with MND may have.
- Improved confidence - 94% of respondents felt more or somewhat more confident in supporting people living with MND. This translates to more empowered support network.
- Positive feedback - We have received over 200 positive comments from participants about workshops, indicating the effectiveness and relevance of this education initiative.
- Highly recommended - 97% of workshop attendees indicated that they would recommend an MND Upskill to other carers or colleagues.

The results received through feedback surveys reflect that participants found the workshops valuable and that their learning objectives were met.

## Tailored education

Another offering in 2023-2024 for organisations looking to have more in-depth information presented to their staff about MND were our tailored education sessions. These sessions can be customised to meet the knowledge needs of a particular cohort, and at a time and location that suits their needs.

**"THE CONTENT AND DELIVERY REALLY HIT THE MARK WITH THE TEAM. WE ALL CAME AWAY FEELING FAR MORE EDUCATED ABOUT MND AND CERTAINLY MORE AWARE OF THE COMPLEXITIES. WHAT WE DIDN'T COVER IN DETAIL WITHIN THE 2 HOURS, WE ARE NOW ARMED WITH THE KNOWLEDGE OF HOW TO ACCESS THIS INFORMATION AS REQUIRED."**

**- Programmed Care, April 2024**

# EDUCATION AND CARER SUPPORT

**"I ENJOY THE CASUAL, OPEN STYLE OF COMMUNICATION IN THESE SESSIONS, THEY FEEL CARING AND SUPPORTIVE."**

**- Lani, carer and support group attendee**

## Carer Kitchen Table MND Support Groups

Throughout 2023-2024, 86 participants received assistance through our Carer Program. Assistance available to carers included MND Upskill sessions and other educational opportunities, the Carer Kitchen Table Conversations MND Support Groups, as well as other mental health and wellbeing opportunities provided by MND NSW or in conjunction with other state MND Associations.

**"THE CARERS KITCHEN TABLE CONVERSATIONS GIVE ME A SENSE OF CONNECTEDNESS AND FRIENDSHIP. IT GIVES ME THE OPPORTUNITY TO SHARE MY STORY WITH PEOPLE WHO TRULY UNDERSTAND IT BECAUSE THEY HAVE THEIR OWN SIMILAR STORY."**

**- Feedback from the Carers Group, March 2024**

## Day of Hope and Remembrance

In 2024, the Day of Hope and Remembrance was an opportunity for people to come together in hope of a future free of MND, and to remember those they have sadly lost to this challenging disease.

Professor Steve Vucic was the guest speaker at the event this year. Professor Vucic is a clinical academic, translational researcher and professor of neurology at the University of Sydney. He is the Northcott Chair of Neurology and Director of Brain and Nerve Research Center (Concord Clinical School, Concord Hospital, University of Sydney).

**"I WANTED TO CONGRATULATE YOU ALL ON WHAT WAS A SUPERB AFTERNOON. YOUR GUEST SPEAKER PROFESSOR STEVE VUCIC SPOKE VERY WELL AND ENCOURAGINGLY ABOUT THE LATEST RESEARCH EFFORTS AND ALL OTHER SPEAKERS WERE EXCELLENT. OTHER ASPECTS OF THE AFTERNOON WERE SUPERBLY ORGANISED. SAVANNAH IN PARTICULAR DESERVES OUR THANKS."**

**- Jim, Day of Hope and Remembrance Attendee**



# FUNDRAISING

During the 2023-2024 financial year, over \$2.3 million was raised through supporter events, donations, bequests and appeals to provide educational opportunities, equipment, support and more for people living with motor neurone disease and their families. Our volunteers continued to provide vital support, assisting with our fundraising, administrative activities and more, completing 659 hours of assistance throughout the financial year.

MND NSW Community Fundraising events are a popular way for the community to get involved in supporting people living with MND, or honouring loved ones experiencing motor neurone disease. In 2023-2024, \$642,097 was raised through community fundraising efforts - including personal challenges, Drink Tea for MND events, walks, marathons or other fitness events, movie nights, merchandise stalls and more.

Walk to Defeat MND events during 2023 were a significant engagement opportunity, enabling communities to come together to show their support for people currently living with MND, and Walk in honour of those they have lost to the devastating condition. Seven Walks were held throughout NSW, the ACT and NT - Central Coast, Canberra, Hunter, Illawarra, Sydney, Darwin, Penrith, and some Virtual Walks hosted by our supporters in their own communities. Donations and Walk registration fees raised a total of \$241,971.

MND NSW merchandise sales totalled \$44,677. The most popular items were our puppies (including our special seasonal Christmas puppies), cornflower seeds, pens, beanies and zip jackets and hoodies. This merchandise helps raise vital funds for MND NSW to carry out our services, and also enables our supporters to help the cause and easily engage with and promote our organisation.

The 2023 Christmas Appeal raised \$47,015, aiming to help MND NSW meet our 'Christmas Wish List' of new equipment items that were required in order to meet the assistive technology needs of participants utilising our FlexEquip equipment service. In the last financial year 56% of all FlexEquip equipment loans, 3,087 equipment items, were provided by MND NSW charitable funding.

The 2024 Winter Appeal raised \$121,253, with a focus on cough assist and salivary suction devices. These devices are expensive to purchase or hire, difficult to source, and can be crucial for the quality of life and longevity of a person experiencing respiratory symptoms as part of their MND.

The generosity of supporters who included MND NSW in their wills has left a lasting legacy, ensuring we can continue to support those facing MND. During the 2023-2024 financial year, MND NSW received \$848,838 from bequests made to the charity.

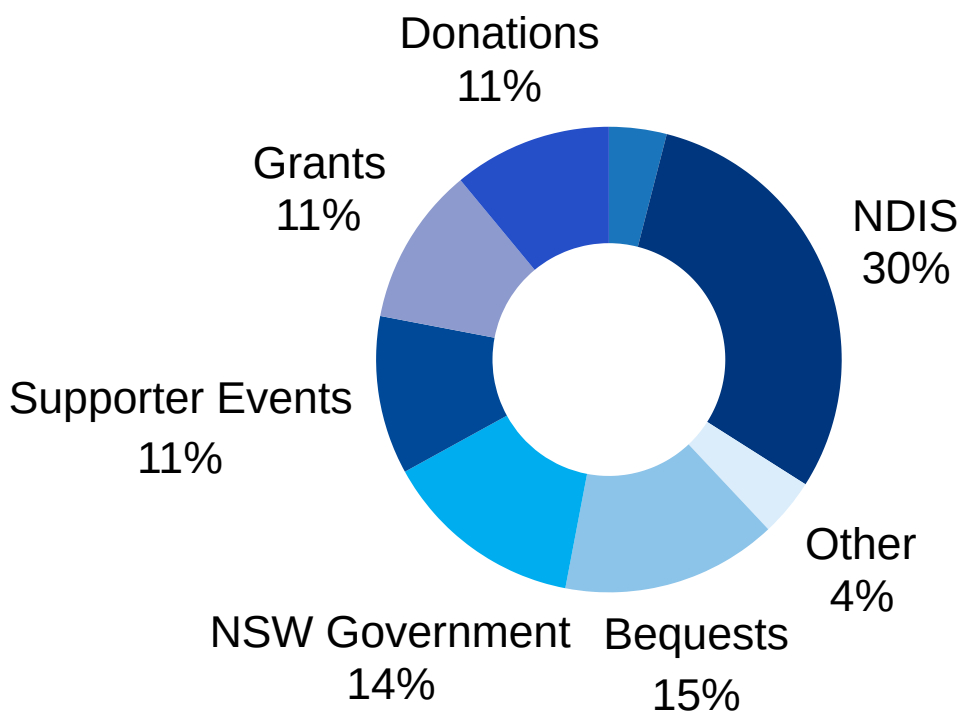
**"MND NSW HAS JUST SUPPORTED MUM AND DAD LIKE NOTHING ELSE, IT'S JUST BEEN AMAZING. I WANTED TO GIVE A BIT BACK FOR ALL THE THINGS MND NSW HAS DONE FOR THEM. "**

**- Ward, who held the Marathon for MND in honour of his father and to support MND NSW.**

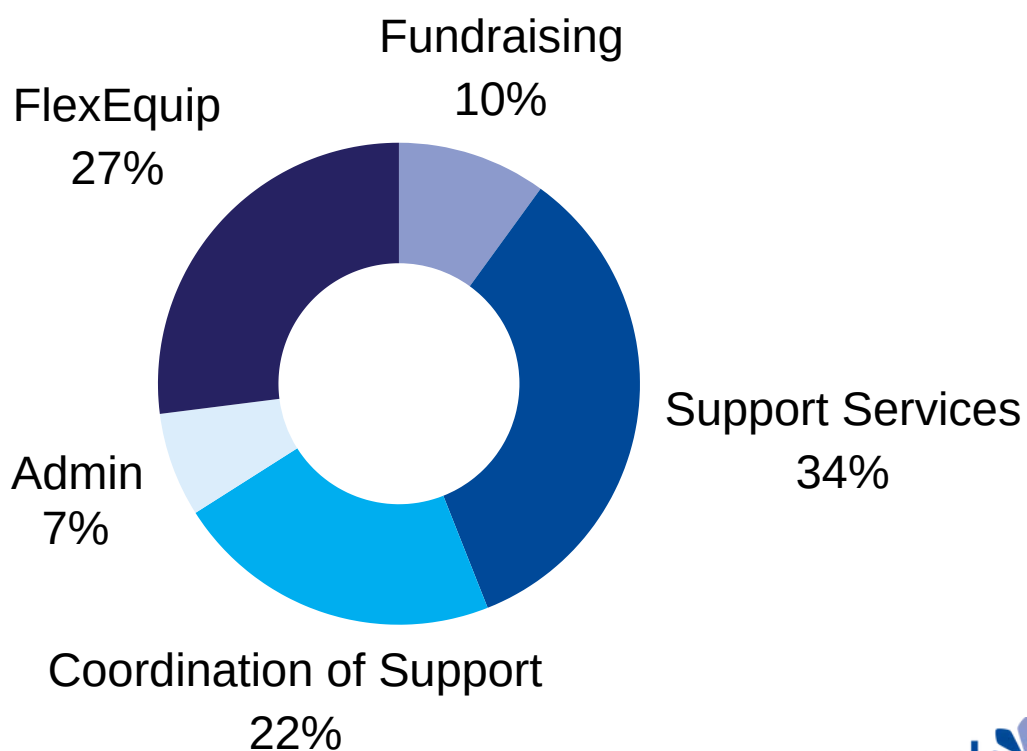


# THE IMPORTANCE OF YOUR SUPPORT

## INCOME



## EXPENDITURE



# WE NEED YOUR SUPPORT

The need for support from MND NSW has increased over the past 12 months, showing the vital need for our services and assistance. MND looks different for everyone experiencing it, making it important that MND NSW can continue to provide the support they need - but we can't do this without your support.

If you'd like to help make a real change in the lives of people facing MND, their carers and families, there are a number of meaningful ways you can get involved:

- **Make a Bequest:** Leave a lasting legacy by considering MND NSW in your will.
- **Become a Community Fundraiser:** Host or participate in community fundraising events to raise funds and spread awareness about MND and our work.
- **Volunteer:** Your time and skills are invaluable to us. Become a volunteer and contribute to our efforts in various capacities.
- **Become a Public Awareness Ambassador:** Help us increase public awareness about MND and our organisation within your community.
- **Make a Donation:** Your financial contributions make a direct impact on the lives of those living with MND. Every donation, no matter the size, brings us one step closer to improving the quality of life for people living with MND.

Your involvement and support are what enable us to provide much-needed equipment, assistance and support to those facing the challenges of motor neurone disease. Thank you for being a vital part of our journey, and for helping us make a difference in the lives of individuals and families affected by MND.

## MAKE A DONATION

- **Online:** You can make a donation online at <https://mndnsw.org.au/donate>. To leave a bequest when creating your new Legal Will, visit <https://safewill.com/mndnsw>.
- **Phone:** Contact MND NSW on 1800 777 175
- **Mail:** Post your donation cheque to: MND NSW, Locked Bag 5005, Gladesville NSW 1675, Australia

**"I WENT FROM WALKING WITH A WALKING STICK ONE MONTH, TO A MOTORISED WHEELCHAIR WITHIN 12 MONTHS. I CAN'T BE ANY MORE GRATEFUL FOR THE EQUIPMENT THAT'S PROVIDED. THE FACT THERE IS A LOAN POOL WE CAN GET THINGS FROM IS GREAT, AND IF PEOPLE LOOKED AT THE COST OF SOME OF THESE ITEMS THEY QUICKLY REALISE HOW VITAL IT IS, ESPECIALLY WHEN YOU'RE NOT IN A POSITION FINANCIALLY TO BUY ALL THIS SORT OF EQUIPMENT."**

***- Lynnette, received equipment from FlexEquip***