



2023 IMPACT REPORT



02

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.

2022-2023

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

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

FROM THE CEO



In the past year, we've sought to increase the wellbeing and quality of life of people living with MND, raising funds for Quality of Life Grants, and ensuring we reach our participants anywhere in NSW, the ACT and NT with equipment, education workshops, support groups and more.

We're also grateful to our supporters and volunteers. We know it's only through their generosity that we can continue to be there for people living with MND for as long as they need us.

We have had some great events that not only bring people together and raise awareness of MND but also support the services provided to families by MND NSW.

MND NSW would also like to acknowledge FightMND for their grant of \$95,500, which will be put towards hosting educational sessions for people living with MND, carers and healthcare professionals throughout NSW and the ACT.

Graham Opie
CEO MND NSW

04

FLEXEQUIP:

“What MND NSW and FlexEquip does is phenomenal and extremely important.”
- Lynette



In 2022-2023, FlexEquip provided equipment to 368 people, fielding 1840 referrals from healthcare workers.

A total of 1676 requests for new equipment were made during this period, with this equipment costing \$2,162,845.49.

The FlexEquip team hosted 13 training and educational workshops and webinars throughout 2022/2023, reaching healthcare professionals throughout NSW, the ACT and NT. These workshops covered topics such as EyeGaze and Mounting, communication technologies such as AAC and Voice and Message Banking, information about FlexEquip and how they can assist people living with MND, and general in-services for healthcare professionals about equipment needs for people living with motor neurone disease.

Whilst sessions took place in capital cities, many were conducted in rural and regional areas, ensuring health professionals without the opportunity to readily view specialised equipment did not miss out on learning how to use vital equipment and what is available from FlexEquip for their patients.

05

SUPPORT SERVICES:

Support from MND NSW has been amazing and very helpful. Kath from MND NSW has just been amazing, not just myself, but also to my mother as well. Really kind and caring and knows her stuff.

- Stephen

- 217 newly diagnosed enter the Service
- We have currently 530 People living with MND being supported by the team (number has remained around this all year).
- We have held a total of 96 support groups (in person and online) with a total of 409 attendees.
- We have provided education (on line and in person) to over 228 people.
- Have provided 43 Life Enhancement Grants.

Another important initiative from MND NSW Support Services was the refresh of our information brochures, combining them into a single source of information for participants.



06

SUPPORT SERVICES:

“

I do not know what I would have done without Karen Keith's help. My daughter was diagnosed with ALS 12 months ago and was given a prognosis of only 12 months in January. If I have any questions or problems, I know I can ring or email her. She has been so supportive. Thank you!

- Anita

”

Throughout FY2022-2023, the new MND NSW Participant Advisory Group was formed, aiming to improve the service offering of MND NSW for our participants.

In the Carers space, MND NSW has continued to provide support groups, information and wellbeing sessions for carers during the past year.

This includes the establishment of the MND Youth Hub, a national initiative specialising in supporting young carers of a relative living with MND.



07

SUPPORT SERVICES:

“Being the first point of contact for someone who has been or a loved one has just been diagnosed has an impact on them. Being able to have a conversation with them, and providing them with the information that they’re needing as well as letting them know that there are plenty of supports available through MND NSW provides the reassurance that they aren’t alone during this difficult period.”

- Phillip

Throughout 2022/2023, MND Info Line continued to provide important information to callers.

Close to 930 enquiries were made to the service, with contact topics ranging from general information, requests for resources such as equipment or speech cards, information on helping a loved one diagnosed with MND, through to enquiries about clinical research and genetic testing.

Of the calls and emails made to and from the service, 500 of these were for newly-diagnosed people to start the intake process, highlighting that Info Line remains an important service for those beginning their MND journey.

FUNDRAISING:

*“It’s great to get involved and see the community spirit at the walks seeing people having a good time even though some are going through tough times,
- Ian and Tracey”*

With the threat of COVID easing in 2022-2023, the MND NSW fundraising team was glad to see the return of community fundraising events, and patronage at Walk to d’Feet MND events. MND NSW supporter events raised \$628,123 in FY22/23.

Throughout the year, thousands attended Walk to d’Feet MND events across NSW, the ACT and NT, with 9 such events being held in the 2023 calendar year. Not only do these events provide an important source of fundraising, they are an opportunity for the MND community to come together and meet others in their local communities. Community fundraising events helped raise much-needed funding, as well as awareness about MND and the work MND NSW does. We are grateful for the support of our community fundraisers and volunteers.

The Otago Rail Trail Challenge held in October 2022 also raised over \$33,000 for MND NSW.



09

FUNDRAISING

In terms of appeals and fundraising initiatives, MND NSW successfully raised \$182,914 through appeals.

The 2022 Tax Appeal focused on raising general funds to support individuals aged 65+ living with MND in rural and regional areas, ensuring equitable access to equipment and support across our service areas. The 2022 Christmas Appeal raised funds for Quality of Life grants, benefiting 43 individuals living with MND, enabling them to create cherished memories with loved ones in the time they have left.

MND NSW also received substantial support from bequests, totalling over \$1.8 million during the past financial year. 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.

MND NSW's partnership with Willed also made it easier for supporters to create a Legal Will and leave a gift for MND NSW, enhancing the opportunities for individuals to contribute to our important work.



2024 GOALS:

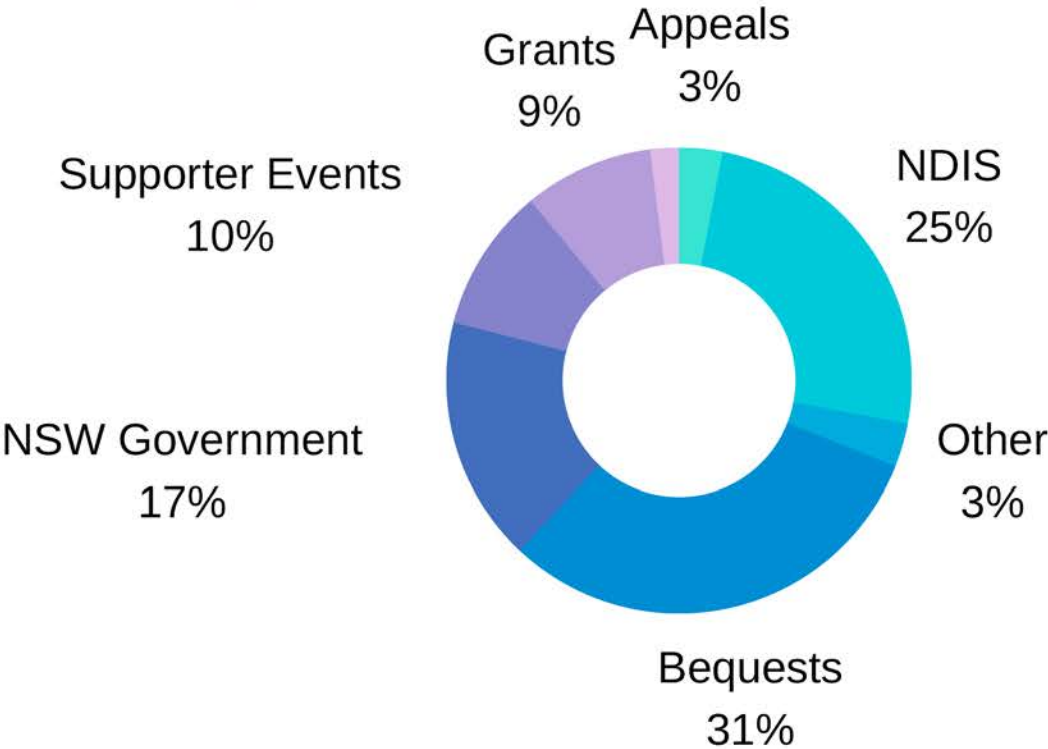
Our 2024 goals are to expand our education programs to reach people with MND their family and carers, particularly in regional and remote areas by travelling to key regional areas across NSW, the ACT and the NT. We are planning 26 face to face comprehensive education programs.

We will also expand our ability for people to trial equipment prior to loans and, thanks to the generosity of Open Mobility we have been provided a delivery van to be more responsive in providing equipment.

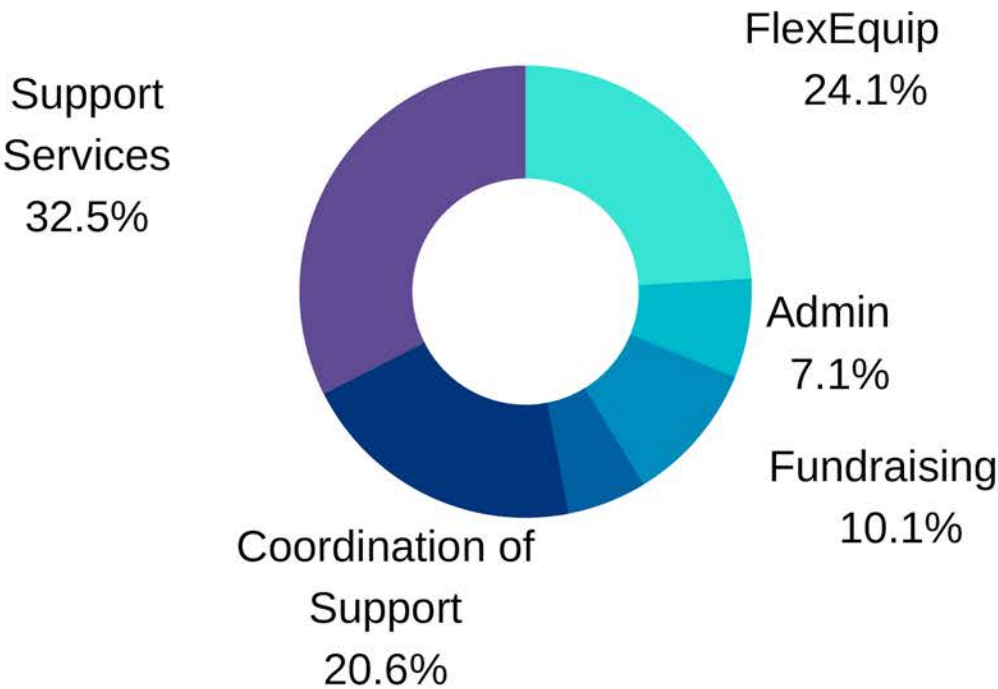


IMPORTANCE OF YOUR SUPPORT

INCOME



EXPENDITURE



12

WE NEED YOUR SUPPORT

The demand for our support and services has been on the rise, reflecting the growing need for our work. We understand that many families are facing the daunting challenges posed by MND, and we are committed to being there for them every step of the way.

If you share our passion for helping people living with MND and their families, there are several 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 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://www.willed.com.au/mndnsw/>.
- **Phone:** Contact MND NSW on 1800 777 175
- **Mail:** Post your donation cheque to: MND NSW, Locked Bag 5005, Gladesville NSW 1675, Australia