

# MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria

Support,  
Care *and*  
Love



mnd   
Victoria

Until there's a cure, there's care



# MESSAGE FROM THE CEO



## Welcome to the final edition of MND News for 2023.

It has been a very busy year for MND Victoria. We have held, and attended, many amazing events which have raised much needed funds for, and awareness of, MND and MND Victoria. These have included the "Grounded for MND" photography exhibition and events, our amazing "Great MND Relay", our "Shut Up! For MND" campaign, "Superball", "Rock Off MND" and many more. We thank all of those members of our community who have held and supported events such as these.

We always appreciate the opportunity to speak to new audiences about the impacts of MND and the care and support that MND Victoria provides for people living with MND and their families.

I have recently met with Jackson Taylor, MP for Bayswater, and Iwan Walters, Parliamentary Secretary for Disability, to discuss the needs of people living with MND and how supports could be improved with the Victorian Government's assistance.

The additional respite funding that MND Victoria was receiving from the Victorian Government up until the end of June this year has been renewed, and MND Victoria have been successful in our application for these funds. We are now once again in a position to fund respite supports for carers of people living with MND in Victoria, from now until June 2025.

We have taken on the big project of bringing our Equipment Service logistics back in-house. This has previously been supported via a third party – and we thank ALTER for their service over the years. We have leased a warehouse in Ringwood and are working to fit this out ready to commence operations in December.

We are excited to have a higher level of control over the quality of this service, and encourage your feedback as this change rolls out. You will read more about this further on in MND News.

We held our Day of Hope and Remembrance on Friday 13th of October, our 42nd anniversary, at Rippon Lea Estate. This was a beautiful and moving event attended by many – some people currently living with MND and many family members who have lost someone to MND in the past. My thanks to all of those who attended.

Our AGM was held on Monday 30th October and three retiring State Council members were re-elected to Council. We also recently welcomed Ann Elkins who has filled a casual vacancy on Council.

We were saddened by the passing of Barry Gunning in November. Barry served on our State Council for 10 years and made many significant contributions to our strategy and direction across this time. Barry was a great supporter of MND Victoria and a genuinely compassionate and kind person. Vale Barry.

Later in this edition, you will read about our new "Who is MND Victoria?" video. We are very proud of this piece and the opportunity to tell our story through the power of film. I hope you enjoy it.

As the year draws to a close, I wish to acknowledge and thank MND Victoria's amazing team of staff and volunteers for their dedication to the best possible care and support for people living with MND.

I wish you and your families a safe and happy festive season and a happy New Year.

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

**Kate Johnson**  
CEO, MND Victoria

# MND VICTORIA SAYS THANK YOU

## Annual Quality Survey Report

**To those of you who have been registered with us for years and still take the time to provide us with your feedback, and those who are new to our services this year – we give you our thanks.**

### What you told us

General satisfaction with MND Victoria services was high to very high (91% or above) – see figure 1.

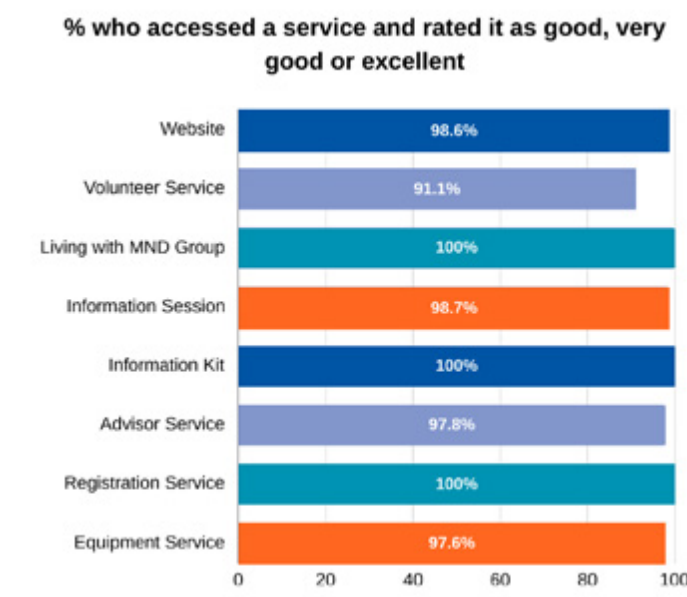


Figure 1 - Satisfaction with services

Note: Only respondents who registered with MND Victoria in the last 12 months were asked to rate the registration service and information resource provided at registration.

Equipment Service, Information Sessions, and the MND Victoria website were the most used services. The least used services were Volunteer Services and the "Living with MND" Group. Reasons for the lower uptake varied, but some people were unaware that these services were available.

### MND Advisor/Support Coordination Service

- 97.8% were happy with the MND Advisor/Support Coordinator service provided.
- 92.2% were satisfied with the level of support provided by their MND Advisor/Support Coordinator.
- 75.7% reported awareness of a written support plan.
- 98.9% of respondents were satisfied that their needs/concerns had been addressed.

### Equipment Service

79.8% of people who returned surveys used our Equipment Service. Most feedback was overwhelmingly positive (see figure 2).

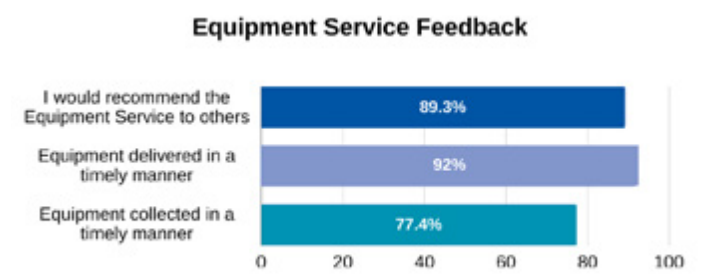


Figure 2 - Satisfaction with Equipment Service

- 1 person was unsure of what equipment is available.
- 2 people experienced a delay in receiving their equipment.
- 14 people haven't needed any equipment yet, and will consider the MND Victoria Equipment Service if their needs change.



## Carer Support Services and Volunteer Services

We asked whether people knew about our Carer Support Programs and Volunteer Services. Knowledge of these services has increased in the past 12 months, following several initiatives that were aimed at raising awareness.

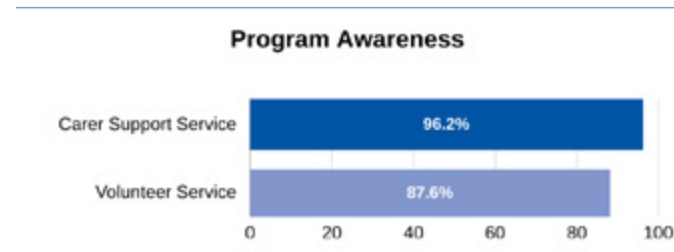


Figure 3 – Carer Support Program and Volunteer Service knowledge

- 20.5% of respondents have accessed one or more of the MND Victoria Volunteer Programs.
- Reasons given for not accessing the service included the respondent's physical location, being too busy, and mobility issues.
- 24 people indicated that they do not need the Volunteer Service (some added that they are well supported or have just been diagnosed and have not yet needed the service).

We asked those who access the Volunteer Service what their perception of benefit is for this service. All people accessing Life Stories, Social Support Visiting, and Social Chat Volunteers reported benefit, with the majority reporting great benefit. Hand and Foot Massage was reported as beneficial by all but one recipient - responses to massage are known to vary across people with MND.

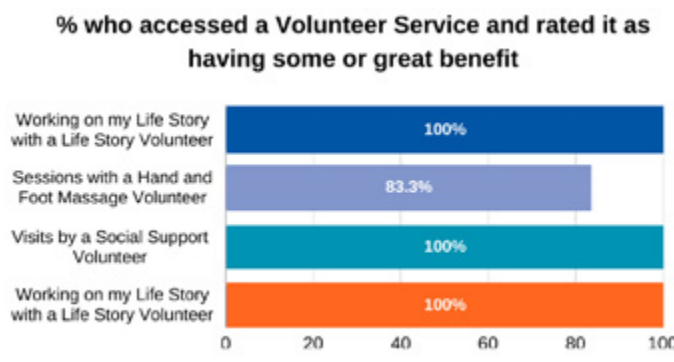


Figure 4 – Rating of experience of Volunteer Services

## Overall service feedback

We asked about the conduct and manner of MND Victoria staff and volunteers. 70 people entered comments, and these have been summarised in a word cloud (see figure 5).



Figure 5 – Word cloud summary of feedback



## Day of Hope and Remembrance

Coinciding with our 42nd anniversary, we held our 'Day of Hope and Remembrance' event at Rippon Lea Estate in October.

It was an evening for people to come together in solidarity and strength for those who are living with MND and those who have lost their lives to MND.

Guests heard from Natalie Parke, who shared her story of caring for her husband, Bruce, who is currently living with MND. You can read their story of 'Support, Care and Love' on page 4.

Georgia Byrne and Katie Weston provided beautiful music throughout the evening, and our brand new 'Who is MND Victoria?' video premiered. More about this video is on the back page of this newsletter, along with a link to view it.

Thank you to everyone who gathered with us for such a touching tribute event where we could be surrounded by love, support, and understanding. It truly was a memorable evening.

## SHUT UP! FOR MND 2023

We are incredibly grateful to everyone who took part in the 'Shut Up! For MND' Challenge on Thursday 21st September. Over 230 people took on the challenge of not using their voice for 6 or 12 hours and finding other ways to communicate in support of people living with MND, raising an impressive \$117,000 in the process.

It was a moving day. A few local businesses near our head office in Canterbury took part, and it was very powerful to see so many people come together in support of the MND Community and raise vital awareness and funds.

It was challenging not being able to speak and taking longer to communicate, and it was even harder to acknowledge that this struggle is something that many people with MND face on a daily basis.

We would like to extend a big thank you to our wonderful Campaign Ambassador, Sofia Levin, and to every single person who registered, donated, and supported 'Shut Up! For MND'. We are humbled by all the messages of support, stories shared, and donations made to our educational and awareness raising campaign.

## SHUT UP! FOR MND



## Walk to D'Feet MND 2023

We may be biased, but we believe the MND Community is the most generous and supportive community. The 'Walk to D'Feet MND' events are a great example of this – it was wonderful to see everyone come together in solidarity, united as one, at the Latrobe Valley, Melbourne and Bendigo Walks.

The next edition of MND News will include a bigger summary of our three 'Walk to D'Feet MND' events, but for now we'd love to say a massive thank you to Lorraine Peters (Latrobe Valley Walk), the amazing team of staff and volunteers at MND Victoria (Melbourne Walk), Chris Whalen and Angela Whalen (Bendigo Walk), and every single person who registered, donated and supported these wonderful events.



## Freemasons Foundation Victoria

We recently received a grant from the Freemasons Foundation Victoria to purchase additional equipment items for our Equipment Loan Library.

Our thanks go to The Worshipful Master of the Lodge of Rapport, Bill Henley, who presented us with the cheque at our Canterbury Office, alongside other Lodge members and guests.





# PERSONAL STORY



[www.mnd.org.au/ChristmasAppeal23](http://www.mnd.org.au/ChristmasAppeal23)

When Bruce was diagnosed with MND in 2021, his youngest child, Shauna asked, “Are you going to die?”. There aren’t many questions tougher to hear, let alone answer. Bruce simply responded with “No, I’m not going to die now. There’s plenty of wiggles in this worm left. There’s plenty of good living to happen.” – And that’s exactly the attitude Bruce, his amazing wife, Natalie and their two children, Lincoln and Shauna, have lived with ever since.

Two and a half years on, the family have remained committed to supporting each other and living in the moment. Bruce says, “All the plans of working hard towards retirement and travelling, the thinking changed. It’s more about day-to-day for me now. It’s getting the most out of each day and doing what I can. Keeping in a routine.”

For MND Victoria’s 2023 Christmas Appeal, the family wanted to share their story to hopefully inspire others to live every day with a positive outlook and highlight the importance of “support, care and love”. **Bruce and Natalie know that without the huge amount of support they have around them, life would be so much harder.** As well as the many incredible

friends, family members, neighbours, colleagues, and many others who they have met within the MND Community, **Natalie is immensely thankful for all of MND Victoria’s services** because, as a family, they have utilised each one.

One of our newest services are our Carer Support Programs. At MND Victoria we realise that **it’s not just the person living with MND going through the journey - it’s also their loved ones** who provide varying levels of care and support, depending on how advanced their MND is. The programs provide carers with the information, support and assistance that they need to manage the caring role.

**As Bruce says in the video:**

**“Caring for me as an individual, and caring for my family who are my carers, I think is a real thing that MND Victoria does that sets them apart.”**

Natalie absolutely adores caring for her husband; however, she understands the importance of taking a break and treating herself to something that fills her cup - and that’s what our Carer Programs enable. Natalie recently attended one of the programs funded by our Carer Programs initiative and said, “I went to the Carer Wellness Program in Mornington, and it was fantastic. I met four other ladies, and we got a WhatsApp group going. We check in on each other every now and again.

*We did painting, relaxing, sharing and some laughing – and I did some crying. It was a great day, really powerful. I could see it was a relief for the other ladies to just come and do something and meet people who do understand what it’s like to care for a loved one with this disease. Because if you’re not going through it, you don’t understand.”*

If Natalie and all the other carers (who certainly didn’t ever imagine themselves in this position) aren’t supported or don’t have an avenue to look after themselves, it makes it so much harder on the person with MND, and the family and friends around them.

Along with the support Natalie provides Bruce, he says he couldn’t live as well as he is without MND Victoria being in his corner each and every day. He says, “It’s a really critical service. Understanding what we need and how we like to roll, and then being able to fit in with that and get the right person or service for me or the family, is pivotal.”

Bruce has his own MND Advisor & Supporter Coordinator who walks the journey with him. **He is also a huge fan of our world-class Equipment Service that allows him access to all the various assistive equipment that he will require as the disease progresses.** At the moment, he loves his recliner chair and special table that allow him to continue working from home whilst remaining as comfortable as possible.

As stoic and inspirational as Bruce is, he says he has learnt a lot about perspective. “I’ve always been someone who looks at things from someone else’s perspective. So, the key thing I’m concerned about is: ‘What’s my impact on other people?’ But then it really boils down to that thing that I’m no longer a burden. I will ask for help. I’m on this journey and there’s a whole lot of people on the journey with me, and they’re supporting me and lifting me up and carrying me. We’re on the journey together. But I’ve also got to be careful and understand that not everyone can do it all.”

We asked Bruce why he wanted to share his and the family’s story for MND Victoria’s Christmas Appeal to help raise funds for others impacted by MND and he said, “It’s the services. It’s the individual care. It actually impacts my life and changes it for the better. The other fundraising around finding a cure is important and great to have, but MND Victoria actually impacts the day-to-day lives of people living with MND. They change it to a positive. A cure may come, and we need to spend money on it, but we also need to spend money on the well-being of people with MND and what we can do now.”

# Support, Care and Love

**Bruce and Natalie’s Story**



# LIVING BETTER

## Sexuality and Intimacy in MND

This article has been adapted from the MND Australia factsheet 'Sexuality and Intimacy in MND'.

MND Victoria recently hosted a webinar on 'Sex and Intimacy in MND'. An article about the webinar, which includes detailed discussion and practical tips, can be found at <https://qrco.de/beZ1Uh> or by scanning the QR code below.



### About intimacy and sexuality

Intimacy and sexuality are important to quality of life and emotional well-being, and remain important to people living with motor neurone disease (MND) and their partners, regardless of age and level of disability. For some people, sex becomes more important following diagnosis, for others it becomes less important. Close physical contact, touch, and time together, become more important as a person's condition deteriorates.

### What you should know

- MND can affect intimacy and relationships but the condition itself has no direct impact on sexual function, arousal or needs.
- Having a partner who is also acting as a carer may impact relationships.
- Intimacy and sexuality may be experienced through sexual and non-sexual touch.
- Talking with a GP, MND Association Advisor, neurologist, nurse, or allied health professional regarding intimacy and sexuality may be beneficial.

### Impact of MND on intimacy and sexuality

Understanding how living with MND affects expression of sexuality and intimacy is an important first step in addressing problems that may arise. It may be reassuring to know that MND itself does not directly impact sensation, sexual function, arousal, fertility, or the ability to have an erection or orgasm. However, people living with MND and their partners report experiencing barriers to physical expressions of intimacy in their sexual and non-sexual relationships. Physical, emotional, psychosocial, and cognitive-behavioural features of MND, lack of social support, and use of assistive technology, may indirectly affect intimacy and sexuality. The need for partners to take on a caring role can also create barriers.

### Talking about intimacy and sexuality – it's not just about sex

As MND progresses, things will continue to change, and it is important to try to maintain open communication with your partner and/or loved ones about the impact of these changes, and to seek help as required.

Research highlights the need for healthcare professionals working at MND clinics to give people living with MND and their partners the opportunity to talk about intimacy and sexuality, if they wish to, as part of the assessment process. Some professionals, however, will find it difficult to raise and talk about this subject and may instead invite the person with MND and/or their partner to telephone or email with any concerns that they may have. Either approach opens the door for people with MND and/or their partner to talk about the impact of MND on their sexuality and relationships. If the

subject is not raised at clinic visits, ask for help if you and/or your partner are struggling with the impact MND is having on intimacy and sexuality. Your GP, MND Association Advisor, nurse, palliative or allied health care professional will be able to talk through your concerns and refer you to the right person. Not all barriers can be overcome but it is possible, with support, to adapt and make changes to maintain intimacy.

### What can help?

Depending on the stage of the disease, you may need to change how you do things to maintain intimacy and sex. It may take some time to adjust and feel comfortable with these changes, and it is therefore important to try to:

- Be open with your partner: talk about how you are both feeling and communicate what you can and can't do as the disease progresses, and what does and doesn't work for each of you.
- Be flexible: make changes to consider the physical impact of MND such as tiredness and fatigue, by having sex at a time when you are least tired or by trying massage and relaxation techniques.
- Be creative: try different sexual positions, ask your partner to take on a different or more active role, or consider using sexual aids (available online or from specialist shops).

MND may affect speech, however sex is often a time when people can express themselves without having to talk. You may already have a special way of communicating with your partner using signs and signals such as blowing a kiss, but you may need to try new ways of communicating and signalling how you feel. Whatever you try, a willingness to laugh together while you experiment can help to maintain intimacy.

### Who can help?

Not everyone requires help or advice when they experience barriers to physical and sexual intimacy. It is important to be aware that some of the features of MND can be managed to minimise impact on intimacy and sexuality. Talk about any worries you may have with someone from your healthcare team who you trust and feel comfortable talking to. You can do this as a couple, or separately. They will be able to talk through your concerns and, if needed, refer you to the appropriate health professional.

### How to bring it up with healthcare professionals?

Conversations about sex and intimacy are not always easy to initiate and can feel awkward. If your healthcare team does not start the conversation, you might like to ask:

- Can we talk about something personal?
- Do other people with MND find that...?
- Can we talk about how MND affects...?



# MND RESEARCH

## Current ALS Clinical Trial – PTC857 Drug Trial

International researchers are working to try to develop new treatments to help with managing motor neurone disease (MND) symptoms and slow the progression of MND. As scientists understand more about the mechanisms involved in MND, this helps to develop treatments that target specific mechanisms.

Scientists have identified several contributors to the death of cells in MND. These include:

- Inflammation
- Oxidative stress: an imbalance between atoms/molecules that cells use to kill bacteria (these are called free radicals), and antioxidants in the body. Antioxidants fight free radicals. If free radical levels become too high, this can cause damage to the body's cells and lead to disease.
- Changed levels of a substance called glutathione. Glutathione is made by the liver and plays a part in building and repairing the body's tissues, making proteins that the body needs, and in immune system function.
- Production of oxidised lipids (fatty compounds in cells that help to control what enters and leaves the cells).

Scientists are using this knowledge to develop and test treatments that can affect these processes, in the hope that this will slow down the progression of MND or help to manage symptoms.

There is a new clinical trial in people diagnosed with ALS that is testing the effect of a drug on oxidative stress in

the body. Oxidative stress increases the production of an enzyme called 15-lipoxygenase (or 15-LO for short). This then leads to several processes that lead to death of motor neurons. The trial is testing a drug called PTC857 which has been designed to block the action of 15-LO, in order to reduce oxidative stress. It is hoped that this could help prevent motor neuron death, and slow or prevent the progression of MND.

### About the PTC857 drug trial

This trial will assess the efficacy (effectiveness) and safety of PTC857 treatment in people diagnosed with amyotrophic lateral sclerosis (ALS).

### Detailed description

People taking part in the study, will be randomly allocated to 1 of 2 treatment groups: one group will receive PTC857 and the other will receive a tablet that has no effect (a placebo). The people taking part (including the doctors) will not know who receives PTC857, and who receives the placebo. Following successful completion of the treatment period, people who enter

the Long Term Extension (LTE) Period, will receive open-label PTC857 for 28 weeks. After the LTE period, people who enter the Continued LTE Period will receive open-label PTC857 for an extra 108 weeks.

The study will be recruiting until March 2024. If you live in Victoria, the trial is recruiting at Calvary Health Care Bethlehem in South Caulfield, and Austin Health in Heidelberg.

### Who is eligible to take part?

There are some specific eligibility requirements for this trial. The best way to learn if you may be eligible for this (or any other) drug trial is to talk with your neurologist and sign up to the **MinDAUS Registry** at [www.mindaus.org/](http://www.mindaus.org/) or by scanning the QR code below. The Registry can send emails if there are trials that you may be potentially eligible to take part in.

You can also view a more detailed description of this study, including eligibility criteria and key exclusion criteria, at <https://clinicaltrials.gov/study/NCT05349721>



# COMING EVENTS

## Our new Equipment Warehouse

Our world-class Equipment Service is the crown jewel in the support we provide to people living with MND.

After years of using a third-party to assist with this service, we are now in a position to bring this fully in-house and operate all aspects within our own team. This means we can deliver this service at the highest quality, every step of the way.

We have leased a warehouse and office space in Ringwood that is currently being fitted out and, from early December, we will be running the MND Victoria Equipment Service fully in-house.

We are excited to have a greater level of control over the quality of this service to ensure a smooth process from start to finish. As this change rolls out, we encourage any and all feedback. **Please contact us at [equipment@mnd.org.au](mailto:equipment@mnd.org.au) to let us know your thoughts and experiences.**



## Kokoda Trail 2024 Challenge Event

Join us for an unforgettable experience from 20 October - 29 October 2024 on the Kokoda Trail, to challenge yourself and make a difference to the lives of those living with MND.



The Kokoda Trail is the most famous track in Papua New Guinea and is renowned as the location of the World War II battle between Japanese and Australian forces in 1942. Joining the South and North coasts of Papua New Guinea, the 96km trail boasts spectacular scenery, untouched villages, and provides a sense of achievement that will stay with you for a lifetime.

MND Victoria's Challenge Events are a great way to have an adventure whilst also supporting our cause. Make

lasting connections with other people who have been touched by MND and raise funds to help those with the disease today, tomorrow and in the future.

**Learn more at [www.mnd.org.au/kokoda2024](http://www.mnd.org.au/kokoda2024) or scan the QR code above.**

**You can also send us an email at [community@mnd.org.au](mailto:community@mnd.org.au) or call 03 9830 2122.**





# Who is MND Victoria?

**MND Victoria was founded in 1981 by a committed group of volunteers who wanted to make a difference to the lives of people living with motor neurone disease. Since then, it's been our mission to provide and promote the best possible care and support for people living with MND.**

Recently, we've been working on a very special "Who is MND Victoria?" video, and we're thrilled to be able to share it with you. This video encapsulates who we are as an organisation and how far we've come since our humble beginnings in 1981. It highlights the importance of the vital work we do each and every day through the various supports we provide.

We're very appreciative of all the support we've received over these many years from donors, volunteers, fundraisers, staff, the community, and those impacted by MND. By supporting us, you're helping the thousands of Victorians affected by the disease to live better, for longer.

We are hopeful that there will come a day when our services are no longer required - but until there's a cure, there's care.



## **MND VICTORIA**

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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.