

# MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria

## Our path towards Reconciliation



# MESSAGE FROM THE CEO



**Welcome to the Summer edition of MND News. The last few months have been quite tumultuous – with rain and floods across many parts of Victoria, and my thoughts are with members of the MND community who have been impacted by these.**

During September, MND Australia and Alex Hawke MP hosted an event at Parliament House in Canberra. The event saw three people impacted by MND speak to the gathered politicians, bureaucrats, ministerial staff, and other guests about their experience of living with MND. MND Australia launched a new video about motor neurone disease and the work of MND Australia and the State MND Associations. The video features Ron, who is living with MND, and Kat, who cares for her husband who is living with MND – both from Victoria. The video can be viewed on MND Australia's YouTube channel at [https://youtu.be/\\_vLUY9TMeoc](https://youtu.be/_vLUY9TMeoc) or by scanning the QR code below/right.

At the event, the Parliamentary Friends of MND was also launched, co-chaired by Alex Hawke MP and Senator Carol Brown – with a broad membership of federal politicians. It is so encouraging to see the support and interest shown by parliamentarians across the parties.

My thanks to all of those who participated in this year's "Shut Up! for MND" Challenge. I had the privilege of speaking with our top 10 fundraisers and personally thanking them for their involvement. The variety of stories I heard – from people working a day in retail, to those sitting outside a shopping centre collecting donations – all without speaking – was inspiring. It is, of course, only a very small taste of what it is like to lose the ability to speak – but it goes a long way towards raising awareness of the impacts that MND has on those with the disease, and those caring for and supporting them.

We held our Annual General Meeting on Monday 24th October. This meeting was attended by many of our members, volunteers, and staff, both in person and via video link. At the meeting, three State Councillors were re-elected, and we thank Jodie Harrison-Fitzgerald, Angeline Kuek, and Maryanne McPhee for their willingness to continue their contribution to State Council. We also heard from our guest speaker, Jenny Dexter, whose husband John died from MND three years ago. Jenny spoke of John's experiences living with MND, her experiences in caring for him, and her recent participation in the MND Victoria Larapinta Challenge. We sincerely thank Jenny for her willingness to share such a personal story with those present.

Our Annual Report is available both on our website and in hard copy from our office. If you would like a copy, please feel free to email me with a request at [kjohnson@mnd.org.au](mailto:kjohnson@mnd.org.au).

As the year draws to a close, I wish you and your loved ones a happy Christmas and a safe New Year.

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

**Kate Johnson**  
**CEO, MND Victoria**



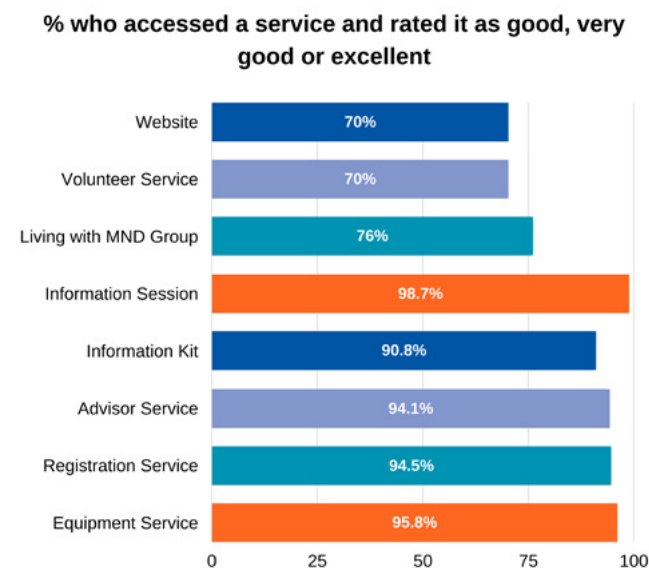
# MND VICTORIA SAYS THANK YOU

## Annual Quality Survey Report

A big thank you to all who returned our Annual Quality Survey this year! Special appreciation goes to those of you who have been registered with us for years and still take the time to provide us with your feedback.

### What you told us

Satisfaction with all MND Victoria services was generally high to very high (see figure 1).



**Figure 1 - Satisfaction with services**

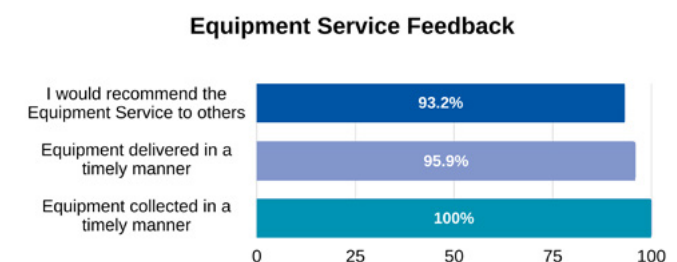
Living with MND groups, Information Sessions, and Volunteer Services were the least used services. Reasons for lower uptake varied. Some people did not know that some services were available or did not realise that they could access services via Zoom. Others would like more opportunities to connect for peer support.

### Support Coordination/ MND Advisor Service

- \* 88.5% were happy with the MND Advisor/Support Coordinator service provided.
- \* 90% were satisfied with how often they received contact from their MND Advisor/Support Coordinator.
- \* 67.3% were unsure whether their Support Coordinator had developed a written care plan with them.

### Equipment Service

66.9% of people who returned surveys used our Equipment Service. Most feedback was overwhelmingly positive (see figure 2)



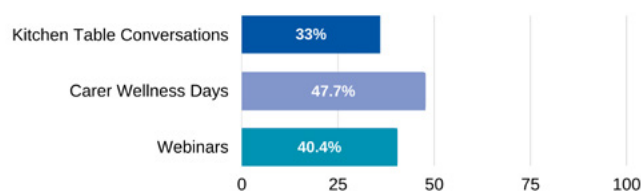
**Figure 2 - Satisfaction with Equipment Service**

- \* 1 person did not have equipment delivered on time and 1 person experienced a delay getting equipment repaired.
- \* 1 person needed more customised equipment than we provide.

## Carer Support Services, Volunteer Services and the MND Victoria Website

We asked whether people knew about our new Carer Support Programs. More than half of respondents did not know about these programs (see figure 3). One third (33.7%) knew about the Carer Support page on the MND Victoria website, where you can find out about upcoming events [www.mnd.org.au/page/114/carers-support](http://www.mnd.org.au/page/114/carers-support)

**Awareness of Carer Support Programs**



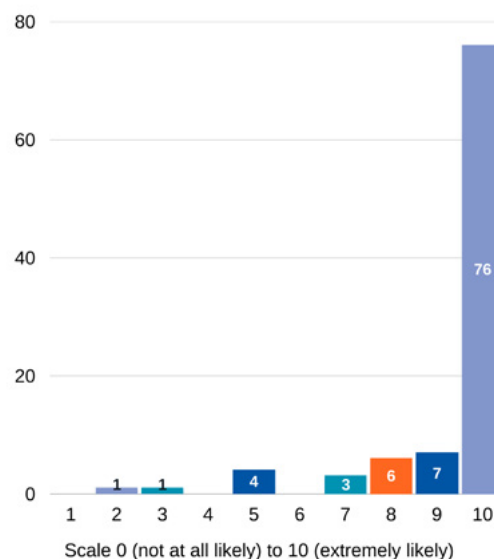
**Figure 3 – Carer Support Program knowledge**

- Some people missed out on online/phone services (volunteer, carer support services) due to perceptions that they are only available face-to-face.
- Most who accessed volunteer services reported benefits. Social Support and Hand and Foot Massage Volunteers were particularly valued.
- Satisfaction with the MND Victoria website and ease of navigation could be improved.

## Overall service feedback

- 77.5% were 10/10 (extremely likely) to recommend MND Victoria to others (see figure 4).
- 90.8% rated the service at 8-10.
- 4 people were neutral (5/10): one of these had recently registered and did not feel able to comment.
- 2 people were not likely to recommend the service to others. They reported difficulties with the quality of hospital care and residential aged care they received, or difficulty accessing a service in the country.

**Should the need arise, how likely is it that you would recommend MND Victoria to someone else?**



**Figure 4 – Rating of service**

We asked about the conduct and manner of MND Victoria staff and volunteers. 57 people entered comments, and these have been summarised in a word cloud (see figure 5). Refer to figure 5.



**Figure 5 – Word cloud summary of feedback**

## What we are doing in response to your feedback

- The “Living with MND” group has been reviewed to provide more positive content, and it will be provided in both face-to-face and online formats next year.
- The “Everything Within” Kits are being redesigned.
- Plans are in place to improve the MND Victoria website.
- MND Advisors/Support Coordinator Team Leaders have contacted some people to find out more about their experience of the service.
- More work will be done to promote events to people who do not access the internet, and to promote volunteer and carer support program services in 2023.
- We are currently looking at how we can provide more peer support opportunities.





## Shut Up! For MND

We would love to say a massive thank you to everyone who supported our educational and awareness raising campaign – the “Shut Up! For MND” Challenge. Over 80 participants took on the challenge of not speaking for 6 or 12 hours on Thursday 29th September (or another date that suited), finding other ways to communicate.

We are excited to announce that over \$50,000 was raised for the direct care and support of Victorians living with MND. These funds will help to ensure that our various programs and initiatives, including equipment, support coordination, carer support, educational seminars and various support programs (such as home modifications and volunteer services), can continue to be provided, and all at no cost to the person with MND.

We would also like to say a very special thank you to our sponsors, Gold 104.3 and KIIS 101.1, whose support was in honour of Susie Harris.

We can't wait to make the “Shut Up! For MND” Challenge even bigger and bolder in 2023!

## Walk to D'Feet MND

We are constantly blown away by the generosity and support of our amazing community. After not being able to host these iconic events for the past few years, we were thrilled to welcome back our Walking Warriors to both the Bendigo “Walk to D'Feet MND” and the Melbourne “Walk to D'Feet MND” in November. We also were delighted to host the inaugural Latrobe Valley “Walk to D'Feet MND” in October.

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



## Home Instead – Melbourne Outer North East

Earlier in the year, “Home Instead - Melbourne Outer North East” very generously donated \$10,000 to MND Victoria. Directors and Franchise Owners Pat and Karen Conte hosted a very special afternoon tea, with very special guests Marlene Coomer and her family. Marlene's partner Brian Mills passed away in March this year after living with MND for two years and nine months, and was cared for by the wonderful caregivers Leonie and Tina. MND Victoria CEO, Kate Johnson, was thrilled to receive the giant cheque at this lovely event, where we heard some great stories of the brilliant work done by the team. We are incredibly thankful to Pat, Karen, and the whole team at “Home Instead - Melbourne Outer North East” for the fantastic work they do in the community, and for their amazing support of MND Victoria.



## Village Glen Walk-a-thon

For the last 8 years, the residents at Village Glen, Rosebud have been hosting a “Walk-a-thon” to raise funds for MND Victoria. The event is always a great success and one of our favourite community events that we look forward to each year. This year was no different, with a big crowd (including lots of four-legged friends) coming and showing their support on the very sunny Sunday 6th November. Over \$11,300 was raised, bringing the combined total over the years to around \$85,000. We would like to say a big thank you to Sue Gabriel and her crew for all of the organising that went into the event, and to all the residents who walked, bought raffle tickets or made the day a success.

# MND RESEARCH



## Calvary Health Care Bethlehem Research Update

Calvary Health Care Bethlehem has a team of 5 research coordinators working with the multidisciplinary team. This article features some of their current research studies which you may be interested in participating in.

### Health Literacy: Please join our survey!

A/Prof Susan Mathers, Director of Neurology at Calvary Health Care Bethlehem, is undertaking a research project titled "Identifying and Responding to the Health Literacy Needs of People living with MND/ALS (Finding clear and Useful Health Information about MND/ALS)".

The project aims to find out how easy or difficult it is for people with MND to find, understand, and make use of information about managing their life with the disease. We want to understand what help, support, and information people with MND and their families need, to make decisions that are best for them.

Calvary Health Care Bethlehem hopes to recruit a broad spectrum of people living with MND, and their family members or carers, across Australia. The research involves completing some short, on-line questionnaires. Your responses are anonymous.

Using the results of the questionnaires, groups of patients, family members, carers and health professionals will then work with an expert team at Swinburne University, led by Prof Richard Osbourne, to develop new ways to meet the information needs of people living with MND, including how health professionals can best respond to these needs.

**For more information, contact Maryanne McPhee on [Maryanne.mcphee@calvarycare.org.au](mailto:Maryanne.mcphee@calvarycare.org.au).**

### LERF – Understanding Lifestyle and Environmental Risk Factors in Amyotrophic Lateral Sclerosis

This study involves completing a one-off questionnaire to help researchers learn more about lifestyle and environmental risk factors for MND.

The online questionnaire includes questions about early life experiences, environmental exposures, adult lifestyle behaviours, cognitive (brain function) status, and information about health and wellbeing, for both people diagnosed with MND and their carers.

**If you are interested in taking part in this one-off questionnaire, contact: [BET-ResearchSPNDS@calvarycare.org.au](mailto:BET-ResearchSPNDS@calvarycare.org.au) or [Ruth.Krasniqi@calvarycare.org.au](mailto:Ruth.Krasniqi@calvarycare.org.au).**

### MiNDAUS Registry

Calvary Health Care Bethlehem, along with other MND Clinics, encourage their patients to join the MiNDAUS Registry. To find out more about MiNDAUS, watch the video on the MND Victoria website at [www.mnd.org.au/page/79/information-and-education-services](http://www.mnd.org.au/page/79/information-and-education-services) or scan the QR code below.

### Are you interested in taking part in MND Research?

If you are interested in taking part in any drug clinical trials for MND, your neurologist is the best person to speak with first.

Signing up to the MiNDAUS Registry gives you the option of receiving an email notifying you of any research studies that you may be eligible to take part in. Visit their website at [www.mindaus.org](http://www.mindaus.org) to join the Registry.

For more general information about research, go to [www.mndaustalia.org.au/research](http://www.mndaustalia.org.au/research)

You can also tune in to the 'MND Research Update Video' with Dr Gethin Thomas on the MND Victoria website - [www.mnd.org.au/page/79/information-and-education-services](http://www.mnd.org.au/page/79/information-and-education-services) or you can scan the QR code on the right.

Calvary Health Care Bethlehem are also running limited access drug research trials. To enquire about taking part in these, email [BET-ResearchSPNDS@calvarycare.org.au](mailto:BET-ResearchSPNDS@calvarycare.org.au).





# GIVING

CHRISTMAS APPEAL 2022

## The *best care* until the world is free of MND

**For most people living with motor neurone disease, the focus is always on appointments and issues around their disability and declining health. We now have the opportunity to help shift that focus - with your help.**

As of November, there are 484 people currently living with MND in Victoria that are requiring the support of MND Victoria. That's 484 people who have a terminal illness but can still get as much out of their lives as possible in the short time they have left.

MND Victoria has been providing vital services to those living with MND since 1981. Over the past 41 years, services have expanded thanks to many wonderful donors and fundraisers who understand how their support and involvement directly helps those living with this horrible disease.

This expansion of services includes the growth and improvement throughout our MND Advisor and Support Coordinator service, our Equipment program and our Information and Education resources. These services are vital in helping those impacted by this devastating disease, because no one should have to travel this journey alone.

Until a cure is found, MND Victoria will continually look to provide services and programs that offer a better quality of life for those living with MND.

That's why we are asking for your generous support this Christmas time.

Last Christmas, MND Victoria launched a new initiative known as "The Bucket List Wish Program". This program was funded entirely by donations through our Appeal this time last year. Through the funds raised, 18 wishes have been

granted for people living with MND. Wishes such as one final holiday with the family, the completion of a large tattoo, tickets and an on-ground experience at an AFL final, a family getaway from the daily struggle of MND to luxurious accommodation on the beach, and many, many more.

Thanks to the support of a fantastic corporate partner and our amazing donors throughout the year, MND Victoria has also been able to offer a program in recent years known as "Take a Break". This is a program that can fund small but useful items, services, experiences, or subscriptions that just make life that little bit easier for someone living with MND. Ultimately, it's about taking a break from MND. It might be tickets to a concert, a gardener to keep on top of someone's pride and joy, a pay tv subscription, it might even be for a handy kitchen tool. There is absolutely no limit on what someone might need to "take a break" – except for the funds available.

These two programs are small but mighty and have an incredible impact. As the number of people living with MND increases, so too does the funding that's needed.

Every day, we continue striving to provide essential and high-quality support to all Victorians living with MND.

But this Christmas we are asking for your help.

Help us grow our new services for people living with MND so they have the opportunity to "take a break" from the daily impact of the disease, whilst we continue to provide the best possible care and support every single day.



Bernard and his wife, Catherine, were thrilled when they were told their wish of spending a few nights together in Portarlington could be made possible by MND Victoria. Whilst Bernard is still able, the couple wanted to create as many memories as possible. Catherine said: "it was the most glamorous accommodation we have ever stayed at." Catherine and Bernard had lots of plans to do things but ended up immersing themselves in the opportunity to be in each other's company in front of the fire with books and magazines.



Margaret has had a long-time wish of spending a few days on a luxury houseboat. She has been living with MND for 12 months and figured it was now or never. She applied for funding through "The Bucket List Wish Program" and within a few weeks, we were able to fulfill this dream for her. Margaret, her family and some friends spent a week on a spectacular houseboat cruising down the Murray River. Margaret said they were able to create memories none of them will ever forget.

**Christmas time can be immensely hard for families going through the MND journey. Your gift might just be that pick me up someone needs at this time of year. Visit [www.mnd.org.au/christmas2022](http://www.mnd.org.au/christmas2022) or scan the QR code below.**

**Every dollar matters and will help improve the quality of life of someone who needs it.**



# LIVING BETTER

## Sleeping Better

Getting a good night's sleep can help to improve your quality of life, provide relief, and make it easier to cope with the many challenges that MND brings.<sup>1</sup>

It is common for MND to affect sleeping, for both the person diagnosed with MND and their carer. Difficulty getting comfortable, muscle weakness, pain/cramps, restless legs, difficulty changing your position in bed, changes to breathing, dry mouth or increased saliva, and stress/distress/anxiety/depression can all take a toll on sleep. If MND is affecting the muscles that control your breathing, carbon dioxide levels can increase in your body and this, in turn, can cause waking throughout the night.

Fortunately, there are things that may help to improve your sleep.

### Who to talk to about sleep problems?

Health professionals including your GP, Neurologist, Physiotherapist, Occupational Therapist and, where relevant, Respiratory (breathing) Specialist, Psychologist/Counsellor, and Palliative Care Physician, can all play a part in working with you to improve your sleep.

### Step 1: Find out the cause/s of sleep problems

As there are different causes of sleep difficulties in MND, an important first step is to understand what is causing the difficulty sleeping. For some people there will be a combination of factors.

This will guide which health professional/s to talk with. It is common for high levels of stress/mental health difficulties to affect sleep for families affected by MND. It is important not to be shy about talking about these difficulties if you think they might be contributing to sleep problems.

### Step 2: Finding solutions to improve your sleep

Talk with your health professional/s about what treatments could help. Table 1 below summarises some common causes of sleep problems and things that can improve your sleep.





Table 1

<b>Difficulty getting comfortable/changing position in bed</b>	Tips and equipment can help you to get comfortable, change your position, and rest your arms and legs in bed at night. Sometimes different supports/equipment can be used over time - it is always worth asking for support if you are uncomfortable in bed.
<b>Changes to breathing at night - frequent waking</b>	There are different causes of disordered breathing at night in MND. Some people experience sleep apnoea. <sup>2</sup> If you have breathing difficulties, non-invasive ventilation (wearing a mask that connects to a machine that helps your lungs to fill at night) can drastically improve your sleep, reduce morning headaches and fatigue, and improve your quality of life. If you notice changes to your breathing, regular check-ups to monitor your lung function, and working out a plan for your situation, are important. Some hospitals can offer a sleep study. Sleep studies involve going into hospital and having specialists study your sleeping to understand the types of changes to your sleep, and to plan treatments to improve your sleep.
<b>Pain</b>	While MND does not cause pain, some of its symptoms can lead to pain. Medications prescribed by your Neurologist/GP/Palliative Care Specialist, and positioning support from a Physiotherapist or Occupational Therapist, can help to manage pain and improve sleep.
<b>Dry mouth or excess saliva</b>	Your Neurologist/Palliative Care Specialist, Speech Pathologist, and sometimes Physio/OT, can try a range of treatments to help manage dry mouth or drooling at night.
<b>Worry/Distress/Anxiety or Depression</b>	There are a range of treatments available including: <ul style="list-style-type: none"> <li>* Relaxation.</li> <li>* Counselling, including strategies to manage troubling thoughts.</li> <li>* Talking with your support network -close friends or family - about your worries and concerns.</li> <li>* Medications.</li> <li>* Seeing a Psychologist or Psychiatrist.</li> </ul>

## What is sleep hygiene?

Sleep hygiene is about forming habits that help to reinforce when it is time to sleep. It is one of many approaches used to help people who have chronic health conditions and/or mental health conditions to sleep better.

Sleep hygiene habits include:

- \* Getting into bed at the same time each night and/or getting up at the same time each morning.
- \* Avoiding looking at mobile devices/computer screens for 1-2 hours before bedtime.
- \* Trying to do something that makes you feel calm before you go to bed at night. A warm bath/shower, listening to music, nature sounds, podcasts, meditation, prayer, listening to relaxation tapes, hugging/relaxing touch, relaxing essential oils, or reading are some things that people use to wind down in the evening.
- \* Make sure the temperature in your bedroom is right for you and try to make your sleeping area a restful place to be.
- \* Try not to get stressed about not sleeping! Avoid clock watching at night, and remember that lying down and meditating/doing gentle breathing exercises in bed is still giving you some rest.
- \* Some people find it helpful to declare an MND-free zone in the evenings – this means time off from talking about MND or stressful worries related to MND after dinner time. You can schedule in time to think about/talk about MND earlier in the day if you need to do this.

1 Boentert, M. 2020. "Sleep and Sleep Disruption in Amyotrophic Lateral Sclerosis." *Curr Neurol Neurosci Rep* 20 (7): 25–25. doi: 10.1007/s11910-020-01047-1.

2 Aiyappan, V. et al. 2020. "Sleep-disordered breathing in patients with motor neurone disease: one size does not fit all." *Neurodegenerative Diseases* 20: 131-138

# EXPLAINING OUR RAP ARTWORK

**MND Victoria's State Council and Staff want to ensure that our Association is welcoming and safe for Aboriginal and Torres Strait Islander people, whether they have MND, have a family member or friend with MND, or want to work at MND Victoria as a staff member or volunteer.**

Across 2022, staff and State Councillors at MND Victoria have worked on the development of our very first Reconciliation Action Plan (RAP). Our Reflect RAP outlines our plans to address and improve our work in relation to First Nations people, in the areas of Relationships, Respect, Opportunities and Governance.

Our Reconciliation Action Plan has been endorsed by Reconciliation Australia, noting that our Reflect RAP enables MND Victoria to deepen our understanding of our sphere of influence and the unique contribution we can make to lead progress across the five dimensions of reconciliation – race relations; equality and equity; institutional integrity; unity; and historical acceptance. Getting these first steps right will ensure the sustainability of future RAPs and reconciliation initiatives and provide meaningful impact toward Australia's reconciliation journey.

We are proud to be joining a network of more than 1,100 corporate, government, and not-for-profit organisations in making a formal commitment to reconciliation through the RAP program.

We commissioned First Nations Artist – Katie Budgen - to create an artwork that represents the MND Community and MND Victoria's RAP journey.

**Katie says of her artwork:** "This artwork represents the strength of those who live with MND and the active steps the organisation is taking towards reconciliation."



She notes that the cornflower (the symbol we use to represent MND) has been reimaged after the Australian straw flower that looks very delicate but has sturdy, colourful leaves that look like flower petals.



The orange connecting meeting places are dispersed through the MND blue background as a representation of the Indigenous perspective being interwoven into the values of the organisation.



The three flowers/meeting places are joined by song lines, and little orange people figures line the path which represents the journey the Association is on towards reconciliation.

A reappearing motif through the painting is the warrior with his spear and shield which represents strength and fight. The single 'people' represent the family and staff who support these fighters.

**We thank Katie for this amazing interpretation of the MND journey.**







# PERSONAL STORY



## Last year *with* Grandma

By Georgia Ross

In February 2020, a fit 73 year old Diann Ross came home from her regular midweek ladies tennis, disappointed in her game and concerned she'd let the team down: "my serve is terrible, I can hardly toss the ball to serve". And so began her journey to understand what was "wrong". With the introduction of COVID and all its confusion about access to doctors, visits and appointments, coupled with some delays, it wasn't until August that Diann's MND diagnosis was formalised. A cruel message delivered as such: "it's just bad luck...". It was shattering advice.

One of Diann's nine grandchildren, Georgia Ross, as a year seven student, completed an English essay based on observations of her Grandma (Gma), including sharing her diagnosis and the last year of her life as she was cared for by her family.

The Ross family share this piece with you in memory of Diann, who passed away on 12 March 2021. The matriarch of the Ross family, a much-loved wife, mother, mother-in-law, grandmother, aunty and friend, who was active, fit, kind, supportive and a wonderful human. We miss her so much and continue to hope and work towards a cure for this insidious disease.

The annoying sound of the phone ringing on the wall startled Grandma, the call that she had been waiting for. Multiple pains and aches over the past few months caused her to go to many doctors and specialists. Pains in her joints that stopped her doing everyday things, aches in her muscles and tendons that made it difficult to do the easiest things. Why was she finding standing up from the couch such a hard and exhausting task? Things like reaching the top shelf were something she could no longer do. She knew there was something very wrong. This phone call could finally give her the answers she had been searching for. No one expected this to happen to Grandma. That day in mid-2020 Grandma was diagnosed with motor neurone disease (MND). MND is a cruel demon that possesses your mind and stops your body from working, gradually getting worse and worse. Grandma was shocked, partly relieved that she knew what was happening to her, but sadness started filling her body.

I remember so vividly when she called my parents and told them. I opened the door to their room, and I could see tears rolling down their faces. I had never seen my dad cry this much in my life. "I hate to ruin your day, but I have MND" my grandma had said to them. I could feel my eyes start to water and my stomach felt sick. My parents and I then told my two siblings, and as soon as we said those 3 letters M N D they burst out into tears. We were already familiar with what MND was because of the AFL and Neale Daniher, so we knew the horrible effects of it.

The next time we saw her, we were all so sad. Grandma and Pa live on a farm in Main Ridge or 'The Farm' as we call it. My cousins and I would always go there every Christmas and Easter, my whole family loves going there, but this time we weren't going there to celebrate anything. My family, my cousins, my aunts, and uncles all going with Grandma on our minds. One of my aunts and her family live in far north Queensland and immediately booked the soonest flights possible to be with Grandma and the rest of the family. It was so special to feel how connected our family was, we were all bonding over wanting the best for Grandma. As



her symptoms were getting worse by the day, we instantly organised plans for a wheelchair, to make the house wheelchair accessible, and a car suitable for a wheelchair. All for Grandma, we wanted her to be as comfortable as possible and not to be put through any pain. We started donating to charities in support of the awful disease and we signed up for events to raise money for it as well.

As the weeks went by, each time I saw grandma, she was in much worse shape than the time before that. People with MND usually live for another 3 years after first experiencing symptoms but, in some people's cases, they can live for up to 10 years. So we still had hope that she would be around for a bit longer. In Grandma's case, her symptoms were progressing fast and the glimmers of hope we had were disappearing. It really is so hard to see someone you love so much basically deteriorate. Our family could not stand to see her in such a state, and we hated more than anything knowing that she would leave us.

Usually, on Christmas, we have a big family feast with all the Christmas foods you could want, and it's all thanks to Grandma, she normally organises everything and cooks all the food, she was the backbone of the family. But this wasn't a normal Christmas. Grandma was stuck in her wheelchair unable to do anything. She couldn't even cut up her food and could barely put her food on her fork and put it in her mouth. We all knew this would be the last Christmas we would have with her, so it was very emotional. My dad, his three sisters and my Pa were the saddest, being Grandma's children and Husband. I can't explain how bad I felt for Pa, you could tell how upset he was, he was usually so talkative and cheerful, but he was silent, you could see the sadness through his eyes. Grandma though, was always in great spirits, she was always so optimistic, and had such a positive view of life.

At the beginning of March 2021, Grandma choked on some water in the middle of the night, Pa called an ambulance because Grandma was coughing heaps too. She was rushed to the hospital where the doctors found out that she had pneumonia. I can't imagine how Pa would've felt in that situation. I don't want to imagine it. We thought that Grandma still had a few more months left in her, but the doctors told us otherwise. My Dad and his sisters got to the hospital ASAP, where they would live for the next week, Grandma's last week. My siblings and I back home had no idea how quickly it all happened, and we weren't ready to say goodbye yet.

I remember when Mum called me while I was at school. Crying, she said to me "George, I'm going to have to come pick you up. Grandma's not doing well". As soon as she called, I knew what was happening. When we got to the hospital, my siblings, my mum, and I were all crying our eyes out. I remember seeing Grandma lying on the hospital bed. Lying there helpless with tubes up her nose to keep her alive. She could hardly even talk to us. She could barely force out a word at a time before she would be out of breath. My siblings and I had never felt this type of pain before. It felt like I was being stabbed in the heart. My head was pounding from crying so much. As we gave Grandma our final hugs and kisses, I remember feeling the saddest I had felt in my life. We had to say goodbye.

Grandma was such an inspirational woman and I aspire to have her attitude and her positive, never give up mentality. She brought my whole family closer together and she will be forever missed.



# BETTER TOGETHER

## Our Incredible Volunteers

MND Victoria is extremely fortunate to have the support of over 100 volunteers who are involved in a variety of roles across the organisation.

To all of our current volunteers, we say a huge “Thank You” - we can only provide the services we do because of you, and we are very appreciative of the opportunity to work alongside you.

We are happy to share the stories of a number of our volunteers, and encourage you to reach out if you would like to access any of our volunteer services, or if you are interested in finding out how you might be able to be involved as a volunteer.



### Peter

My volunteer work with MND Victoria began in 2015 as “the Wednesday morning receptionist” in the Canterbury Road office. This involved answering the phone, processing the mail, handling front desk enquiries, and completing general administrative tasks - it was different every week. I enjoyed working with the business manager and the office staff, and I derived satisfaction from completing these tasks and generally giving back to an organisation that helps so many clients and their families. COVID put a stop to working in the office and my volunteering with MND took another direction.

Currently, I am involved with the Life Story Program which is offered by MNDV. Clients reflect and reminisce about their journey through life, and it is my task to gather and weave all the details to develop their life story. It is a challenge, and one that I do not take lightly, to draw together the anecdotes, special moments, and photos of someone’s life into a cohesive story. And whilst it is the finished product that we work towards, it is sharing time together, genuinely listening, and recording the stories in their voice, which is undoubtedly the most rewarding.

I would actively encourage anybody interested in volunteering with MNDV to talk to Deb Olive - the Volunteers Coordinator, or any of the current volunteers, to find out what it may involve and how much satisfaction can be derived from giving your time, empathy and grateful thanks to this wonderful organisation.



For more information about volunteering with MND Victoria, please call (03) 9830 2122 or email [volunteer@mnd.org.au](mailto:volunteer@mnd.org.au)

For information about volunteer services accessible in your area, please talk with your MND Advisor/Support Coordinator.





## Andrea

In 2018 my dad was diagnosed with MND, and the support given to him and my mum from MND Victoria was invaluable. I experienced first-hand, the amazing work of staff and volunteers in providing care and equipment during a difficult journey. After Dad's passing in 2020, I wanted to pass on the kindness given to my family during our MND journey and to give back as a way of honouring my wonderful dad.

As a volunteer, I am always willing to put my hand up to support and fundraise. I have two main roles as a volunteer. I'm a Bereavement Call volunteer, which involves making a phone call to families about 3 months after their loved one has passed.

My other role, and probably my favourite, is being a Hand and Foot Massage volunteer. In this role, I visit a client once a fortnight to provide a hand and foot massage. My one hour visits with my client and his wife go very fast, as we chat and share stories. I walk away feeling like I have made a small difference for someone during a really challenging time.

To anyone who is thinking of volunteering, I say 'put your hand up'. The staff and volunteers at MND Vic are an amazing group of people to work with. I find that, by volunteering, I get more out of it than I feel that I put in. By volunteering, you're able to make a difference in the lives of people facing the most difficult journey, by making it a little easier.



## Marian

After my husband died with MND, I felt a strong need to give something back to the Association which had done so much to support us. I had already met the staff and several volunteers who'd also been carers for someone with MND, so it felt a safe place to be.

Over my 30+ years, I have been a member of the Board and of a Support Group, co-convened the "Living On" program, been a carer and client telephone support, coordinated the "Walk to D'Feet MND", have done public speaking and manned fundraising and information stalls, to name but a few of my activities. I have found there are many ways to contribute and that, over time, the way you can be involved as a volunteer with MND Victoria can change to meet your availability, interests, and the needs of the organisation.

If you are considering volunteering, know that volunteering is a two-way experience that gives back as much, and maybe more, than one puts in. You may discover skills you never knew you had and there is opportunity to learn new ones. It is a fulfilling experience from which I have greatly benefitted.



## Ron

My wife and I received amazing support from MND Victoria – it enabled me to focus on my wife and to care for her at home, as was her wish. My wife enjoyed visits and massage with MND Victoria volunteers.

Several years later, I realised I wanted to give something back to say "thank you" for all the support we had received. What I did not realise at the time was that volunteering would actually make me feel better – in effect, it spun me around and I have now realised how much I have to give.

My volunteer involvement with MND Victoria has developed over the last few years. I help with the MND News mailout which I love – I enjoy working with our team of volunteers and always feel good afterwards. I also make regular phone calls with a gentleman living with MND. We enjoy talking about our common interests.

This year I put my hand up to collect donations at an Equestrian Event. It was something I had never done before – it was brilliant! I enjoyed it and was able to involve my son as well. Volunteering is now something my whole family is interested in. My family say "Good on you, Grandpa" – at my age it is good to know I can make a difference.

If you are interested in volunteering, "do it". Contact Deb, Coordinator of Volunteer Programs, and she will guide you through the process to find a role that is right for you.



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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.