Winter 2022

MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria

ROLL UP, ROLL UP.

The Great MND Relay is on!

mnd Victoria

Until there's a cure, there's care

MESSAGE FROM THE CEO

During May, we celebrated National Volunteer Week with the theme "Better Together". As life returns to some sense of normal – it has been wonderful to have more opportunities to come together with our community.

We thank all of our volunteers for all that they do for MND Victoria and the MND Community – and for staying engaged with us throughout the pandemic. Without our volunteers we would not be able to do the work we do to support people living with MND – and we are so very grateful for their commitment and support. My particular thanks to Marian Lowe who has volunteered for MND Victoria for 31 years. You will read more about how we celebrated our volunteers later in this edition of the newsletter.

Also during May, we launched our Great MND Relay – with Anthony Callea as the Ambassador for the event. We are very excited about this 41 hour long event and hope to see many of you and your families and friends there if you are able to join us. We are hoping that this will be our most successful event, both in raising awareness of MND Victoria and the services we provide, and in raising the funds we need to keep providing and improving the services, care and support we offer to the MND community. You can read more about the event on the back page of this newsletter.

We have also spent lots of time and consulted with many of our key stakeholders in developing our 2022 – 2025 Strategic Plan to continue delivering on our mission to "provide and promote the best possible care and support for people living with motor neurone disease". When we refer to people living with MND, we include their families, carers, friends and those professionals who provide services and support.

Our 5 strategic objectives are to:

- Ensure the availability of a broad range of high-quality services and supports for people living with MND
- Advocate for the needs of people impacted by MND to be fully and equitably met
- Promote, support and deliver research into care, support, treatment and cure for MND
- Increase awareness and support of MND Victoria
- Underpin our strategy by remaining sustainable.

We look forward to delivering on this strategy and continuing to improve and expand the supports we and others can provide for people living with MND.

Wishing you all a warm and cosy winter.

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

Kate Johnson

CEO, MND Victoria

MND VICTORIA SAYS THANK YOU

NATIONAL 16-22 MAY 2022
VOLUNTEER
Better Together WEEK

NATIONAL VOLUNTEER WEEK 2022
'Better Together'

Volunteers are integral to the MND Community. During National Volunteer Week in May, we recognised and thanked our volunteers, and acknowledged that we are 'Better Together'. Our volunteers bring their skills, experience and understanding to their roles in supporting people living with MND and the work of the organisation. The impact MND Victoria is able to make in the community is greatly enhanced through the work of our volunteers.

To celebrate their involvement, a number of our volunteers and MND Victoria staff visited the Islamic Museum of Australia to explore and learn, and also enjoy a delicious middle eastern lunch.

MND Victoria acknowledges volunteer years of service each National Volunteer Week. This year we are so pleased to recognise the following volunteers with a combined 161 years of service to MND Victoria:

- Marian – 31 years
- Bev – 20 years
- Gary – 15 Years
- Kathleen, John, Maureen, Simon, Janet, Lynette – 10 years
- Carolyn, Jane, Josephine, Wayne, Debra, Jan, Sarah – 5 years.

Over the past year, our volunteers contributed over 1900 hours to the crucial work of MND Victoria. Thank you to every one of our volunteers who assist us in many ways – we really are "Better Together" because of you.

Are you interested in volunteering at MND Victoria?

Volunteers have always been central to MND Victoria and fulfil a range of roles contributing to the vibrant, energetic, and successful Association we are today. Volunteer roles range from providing support for people with MND, to roles that support the staff and programs of the organisation. Our volunteers may work in the community, at our Canterbury office, or across the state in their local areas. We are currently seeking to grow our Hand and Foot Massage Volunteer team and our Life Stories Volunteer team. Our Coordinator Volunteer Programs, Deb, will be happy to talk with you about these and other volunteer programs.

To find out more information about our volunteer programs, call 03 9830 2122 or email: volunteer@mnd.org.au.

South East Melbourne Walk to D'Feet MND

The South East Melbourne Walk to D'Feet MND is always a highlight on our calendar. We love seeing our Walking Warriors join together to walk around the Lakeside Amphitheatre in Pakenham. It truly is a beautiful sight.

We are thrilled to announce that this year, $26,263.50 was raised. This brings the total raised by this event over the past few years to over $100,000!

A very big thank you to Sonya and her team for organising another brilliant event. We can't wait to see everyone there again next year.

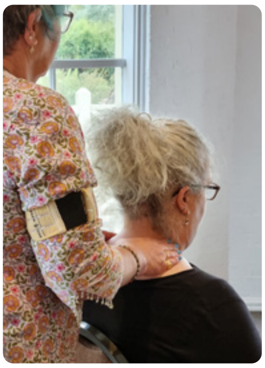
Carers Retreat

Carers provide incredible physical and emotional support to their loved one, and are often doing so at the expense of looking after their own wellbeing. That's why we were very excited to host some Carer Wellness Relaxation Days in Mornington, Ballarat and Kew. Art, mindfulness, yoga and massage were just some of the activities undertaken to give these carers some self-care and relaxation.

These days were an opportunity for carers to learn some tools for looking after themselves while caring for a loved one, and to relax and connect with other carers.

"It's never easy leaving your loved one, enlisting family or paid carers to step in is challenging but, if you can make it happen, the rewards are huge, a bit of time out, the support from other carers and the shared stories are extremely valuable and uplifting." G.T.

We are grateful to have received short term funding from the Victorian Government's Support for Carers Program which made these events possible, and hope to host more of these in the future.



Sunday Sippers for Sue

"Sue Bruerton (Green) was diagnosed with Frontotemporal Dementia combined with Motor Neurone Disease (FTD/MND) in 2020. Along with supporting Sue throughout her illness, we (niece, sister and friends) formed #TeamMNDforSue to raise awareness of the degenerative disease, and to fundraise for MND Victoria who provide amazing support for diagnosed individuals and their families.

Like many things, the pandemic got in the way, and we had to put our main event on hold. During this time Sue's health declined and she sadly passed away in February 2022. The amount of support we received during this unprecedented time is truly appreciated.

"Sunday Sippers for Sue" was held in April 2022 and was an incredibly special day that Sue would have loved. We had live music, colour-in competitions for all age groups, a Mickey Mouse themed photobooth, raffles, paper aeroplane challenge and, of course, lots of delicious food and hot cuppas. The prizes that were donated from our generous community ranged from homemade quilts, home baked hampers, gift cards and fishing gear. The ice-challenge was hilarious. Lots of stories and memories of Sue were shared."

Tonya Bermingham, Joanne Coxall, Tanya Crawford and Lorna Sutcliffe #TeamMNDforSue

MND Victoria would like to say a massive thank you to #TeamMNDforSue for all of their hard work. Despite a number of setbacks, they have raised an incredible $20,823.55!

Reconciliation Action Plan Update

During 2021, MND Victoria formed a working group of staff and members of our State Council to develop our first Reconciliation Action Plan (RAP).

We chose to create a Reflect RAP which focuses on laying the foundations for the organisation's reconciliation journey to contribute to the five dimensions of reconciliation – race relations; equality and equity; institutional integrity; unity; and historical acceptance.

Our RAP has now been formally endorsed by Reconciliation Australia who commented that "This Reflect RAP enables Motor Neurone Disease Victoria to deepen its understanding of its sphere of influence and the unique contribution it can make to lead progress across the five dimensions. Getting these first steps right will ensure the sustainability of future RAPs and reconciliation initiatives and provide meaningful impact towards Australia's reconciliation journey."

Our RAP implementation working group is now progressing the implementation of our RAP by firstly assessing our mandatory and recommended staff and volunteer training to ensure that issues and understanding of First Nations cultures are appropriately covered on a regular basis.

Our RAP will be published on the MND Victoria website once we have sourced appropriate artwork. We welcome any input from the MND Community in Victoria.

MND RESEARCH

New research highlights the importance of non-neuronal cells in MND

By Dr Samantha Barton

In motor neuron disease (MND), it is the nerves that send messages from the brain to muscles that die. These nerves are called motor neurons. The death of these motor neurons is what leads to symptoms like muscle weakness.

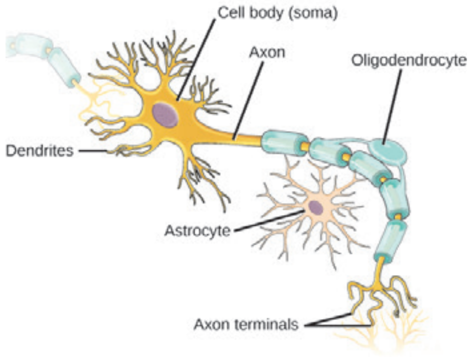
Extensive research has gone into understanding what specifically is going wrong in these motor neurons that causes them to get sick and die. Whilst many pathways of disease have been identified, research has also uncovered that other cell types in the brain and spinal cord contribute to motor neuron death; these cell types are called glia.

This was first discovered through research in mice. Researchers typically use mice that carry a genetic mutation known to cause MND in humans. When this genetic mutation was removed from motor neurons (meaning all cells in the mice carried the MND gene but the motor neurons were otherwise healthy), the onset of disease and the rate of its progression were improved, but the mice were not cured. This suggested that cells other than the motor neurons must be involved in the disease processes that underpin MND. Thus, our research focuses on unravelling precisely how glia contribute to dysfunction and death of motor neurons in MND.

Within our lab, the main type of glia we are interested in are called oligodendrocytes. Oligodendrocytes produce myelin, which is the insulating sheath that all motor neurons are wrapped in. If you consider a power cord for an electrical appliance – myelin is like the rubber coating around the wires, except that myelin not only insulates and conserves the electrical signal, but it can also supply the motor neuron with essential energy sources. In MND, we know the motor neurons that die are covered in myelin and we (and others) have shown that oligodendrocytes themselves are sick and harbour some of the known MND pathologies such as build-up of a protein called TDP-43. So our lab hypothesises that oligodendrocytes, and their myelin, could be dysfunctional in MND and therefore contribute to dysfunction and death of motor neurons.

Dr Barton (middle) and her lab members

Dr Samantha Barton is a senior post-doctoral researcher leading a team of scientists at the Florey Institute of Neuroscience and Mental Health which is aiming to understand the causes of MND. Dr Barton's research has received funding support from MND-RA, FightMND, CASS Foundation, BGRF, the Hayes Foundation and NHMRC.



By CNX OpenStax [CC BY 4.0 (https://creativecommons.org/licenses/by/4.0)], via Wikimedia Commons

To find out about the role of oligodendrocytes in MND, we use a combination of model systems including mouse models, human post-mortem tissue samples and induced pluripotent stem cell (iPSC) models. We have a particular interest in using iPSC – this technique relies on us accessing a small skin biopsy from people living with MND. In the lab, we can then convert these skin cells to iPSC, which means that they are master stem cells capable of becoming any cell type. We then convert these iPSC into oligodendrocytes, motor neurons and also into three-dimensional 'mini-brain' and 'mini-spinal cord' like structures. The beauty of this technique is these cells are genetically identical to the person who donated the original skin sample so we can compare oligodendrocytes from a person living with MND to a person who does not have MND, and identify how they are different, why they are different, and how we can fix them. Indeed, through the use of iPSC, as well as using human post-mortem tissue, we have shown that myelin structure and its composition differs in people with MND, which could have a negative effect on motor neuron health and function. We hope that, through our research, we will continue to identify pathways that could be contributing to MND onset and progression, because we believe that MND treatments will be far more effective if they are able to treat the whole cellular network, including glia, as well as the motor neuron.

LIVING
BETTER

Sexuality and Intimacy in MND

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 becomes 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 maintaining 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 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 if needed. 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...?

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

For more information, visit www.mndaustralia.org.au/mnd-connect/information-resources/sexuality-and-intimacy-in-mnd (or scan the QR code on the right), contact your local MND State Association or call the MND Info Line on 1800 777 175.

PERSONAL STORY

Seas-ing the Day

Chris Symonds' Incredible Para Sailing Career

Chris Symonds truly epitomises the phrase "Never Give Up". An avid sailor from a young age, Chris has not let his diagnosis of Kennedy's Disease* stand in the way of his dreams. Chris is a decorated para sailor and continues to travel all over the world to compete in para sailing competitions. He is also very involved in the MND Community, having been a volunteer on the MND Tasmania Board for a number of years. Below is an interview with Chris about his career and recent success at the Para World Sailing Championships in Italy.

How long have you been sailing for?

"I started sailing when I was nine years of age when my family moved from a farm behind Wynyard to a home 200 meters from the Wynyard Yacht Club."

What inspired you to start sailing?

"I guess the river was my backyard. My parents were farmers. When the farm didn't work out, they came to town and Mum took on a teaching role while Dad worked in a grain store in town. Their friendships with other sailors inspired the whole thing to happen. There was a community project where 12 families got together and built all these boats. In the end, they drew names out of a hat to decide who would get which boat. So that was the start of the journey and the program at Wynyard, and I was part of that some 50-odd years ago, and it's continued on ever since. Sailing has been a big part of my life. I've had some pretty high-flying jobs with roles in management of big companies, international companies, but I've always viewed sailing as a place to just take you away from the world and focus on other things."

Tell me about competing in (and winning) the World Championship in Italy. What was the experience like?

"Wow! To travel in COVID lockdown, compete and win against 70 other yachts from 25 nations was very special. Although it was my third World Championship (I have previously won gold in the Netherlands and in Wisconsin, USA and have been runner up in Kiel, Germany and in Spain), this was special, as I did it with Ela, not alone. Ela is my NDIS support person, coach and respected friend. She's been supporting me for three years now and had never been involved in sailing before she met me. Her planning and preparation are second to none. She helps me with my sailing, making sure I'm all organised and planned, and together, we're a great team."

You've been named Para Sailor of the Year a few times. How does it feel to be recognised on this level?

"I have won the award in three consecutive years now. Awards and wins are nice, not only for me but my team, partners, club, local community, Tasmania, and Australia. For me, ensuring our values are of the highest standard is more important. Values are things we can control, results are not."

What has living with Kennedy's Disease taught you?

"Plan ahead for condition changes, patience, not to get frustrated, use supports and equipment to keep you safe, and a huge respect for others living with MND who have the same symptoms as KD but faster progressing."

Have you learned anything new or gained a new perspective on life?

"'Never give up' is an MND motto that is so true. Don't be afraid to ask for help when needed. Be positive, and ensure that you have positive people around you. Life is short, if you can't make a difference, move on to something else where you can make a difference."

Is there anything else you would like to say?

"I want to thank my wife, Fayellen, who is so supportive of my busy life over 40 years of marriage and raising four very special children. I also want to thank my NDIS support team who assist me to achieve amazing outcomes, not only with my sailing but giving to the community."

* Kennedy's Disease (KD) refers to Spinal and Bulbar Muscular Atrophy (SBMA) and is a rare kind of inherited disease that affects the nerve cells in the human brain. KD and MND share a lot of similar symptoms as they both cause the weakening and wasting of muscles. MND Victoria and MND Tasmania also provide support for people living with KD.

For more information on KD, visit www.mndaustralia.org.au/mnd-connect/information-resources/kennedy-s-disease or scan the QR code on the right.

MND VICTORIA'S

NEVER GIVE UP

NZ TREK

20 23

Join MND Victoria's Never Give Up New Zealand Trek to help provide and promote the best possible care and support for people living with MND.

As part of this incredible adventure, you will discover the history and majesty of New Zealand's South Island, from Christchurch to Queenstown. Traversing the Southern Alps, you will trek through lush alpine meadow and into steep, glaciated valleys. You will gaze upon the turquoise surface of Lake Tekapo and stand in the shadow of awe-inspiring Aoraki, New Zealand's highest mountain.

Best of all, with every step you take, you'll raise vital funds that will continue enabling the best possible care and support to be delivered to the 470 Victorians currently living with MND and those who will be diagnosed in the future.

Highlights

- Discover New Zealand's South Island, from Christchurch to Queenstown
- Experience the beauty of Lake Tekapo and other World Heritage-listed sites
- Stand in the shadow of Aoraki, New Zealand's highest mountain
- Raise vital funds to provide care and support to people living with MND

26-31 March 2023

Moderately challenging (3/5)

Fundraising target:	$3,000
Travel package: *Land only and subject to change*	$2,899
Registration fee: *Non-refundable*	$390

Twin-share in 3-star motels and lodges

Register before 3 July 2022 and get **$100 off** your registration fee

Register now:

events.inspiredadventures.com.au/events/mndvic-southernalps-2023

UPCOMING EVENTS

New Merchandise Alert!

Beanie weather has arrived and we are absolutely thrilled with our revamped "Never Give Up" beanies. They're super comfy, cosy and colourful and, at only $20.00 each, they're the perfect way to keep warm in style this winter.

Get yours now at www.mnd.org.au/beanie or scan the QR code on the right.

We are fundraising with Entertainment

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SAVE THE DATE!

The Melbourne Walk to D'Feet MND is back this November

After 3 long years, we are very excited to welcome back the Melbourne Walk to D'Feet MND for 2022! Due to restrictions, we haven't been able to host this iconic event since 2019, so we're really looking forward to seeing the MND Community at Princes Park, Carlton on Sunday 27th November 2022. More details to follow!

GIVING

Care Appeal

“MND Victoria adds life to days, not days to life.” – A supporter once said this, and we cannot think of a more appropriate comment for the work that our Association does. The vital support that MND Victoria provides for people impacted by MND can only happen because of the generosity of our supporters.

Our organisational mission is: ‘To provide and promote the best possible care and support for people living with MND’. MND Victoria is the only organisation that focuses on providing a comprehensive range of care and support for people currently living with MND to help them to live as well as possible for as long as possible. These services include:

- information
- education for people with MND, their families and the health professionals supporting them
- individual advice and support for people with MND to help them navigate the NDIS and Aged Care systems
- provision of assistive technology devices at no cost to the person with MND, no limit on the number of items provided, or time limit on how long they can be used.

While the breadth and depth of our services has expanded since 1981, delivery of care and support has been, and will remain, our major focus. We are determined to see improvements to the ‘best possible’ part of our mission, and we imagine that you can also see great benefit in that.

This year alone, we’ve been able to pilot our dream-making Bucket List Wish Program and a vitally important Carer Support Program, but our goals and the needs of people living with MND don’t stop there. Through some recent surveys, we’ve identified opportunities to purchase a wider array of vital assistive equipment and communication devices, implement a counselling service, expand our bereavement support service and shorten wait times for services.

The reality is, we can only provide our core services and implement new programs with increased support from our fantastic donors. Your donation, coupled with donations from other passionate supporters, will enable the Association to keep doing more for people who need our help. The only limit to what MND Victoria can do to support people living with MND is the amount of funds available. That’s where your help and generosity come in.

If you are in a position to make a gift, please visit www.mnd.org.au/mndcareappeal or scan the QR code above.

Bucket List Wish Program

MND Victoria has launched The Bucket List Wish Program and fulfilled a wish for Peter.

Peter is an avid surfing fan who attends The Rip Curl Pro Bells Beach event most years.

However, due to the severity of his MND, Peter was unable to physically make it to the event this year. So, we worked alongside Rip Curl to help provide a once in a lifetime experience for Peter. We were able to have the renowned Bells Cup Trophy delivered to Peter’s home, and were also able to gift Peter with a rash vest signed by his favourite surfer, Gabriel Medina.

MND Victoria’s Bucket List Wish Program has been made possible thanks to our generous and kind donors.

THE GREAT MND RELAY

MND Victoria provides support services so that no one has to face this devastating disease alone – and now we need your help to make sure that no one walks alone at "The Great MND Relay".

The Great MND Relay is a 41-hour event, representing the 41 years that MND Victoria has provided care and support for those impacted by MND. To achieve a 41-hour continuous relay, we need our dedicated community to come together, so get your family, friends, club, school or community group on board with you, and pledge the time you'll arrive at The Relay. It's up to you how long you're there!

There'll also be plenty of performances, entertainment, activities, food trucks and more over the 41 hours, so you're sure to have a GREAT time no matter when you attend!

WHEN: 8:00 pm Thursday 23rd June - 1:00 pm Saturday 25th June 2022

WHERE: Harold Stevens Athletics Track,
20 Outlook Road, Coburg North VIC 3058

TICKETS: $10 each, Kids under 5 attend free

There's still time to register. Whether you're there for an hour or setting yourself a monumental challenge, every step you take will be making a positive difference for those in the MND Community.

Take action and sign up today at www.mndrelay.org.au or scan below.

Anthony Callea joins The Great MND Relay

We're so excited to have Anthony Callea as the official ambassador for The Great MND Relay! MND touches the lives of so many people, including Anthony, who lost his dear friend to MND this year. He truly understands the devastation of the disease and the essential support MND Victoria provides everyone living with MND. We are absolutely thrilled to have his support at The Great MND Relay.

Unable to make it to The Great MND Relay event? That's okay!

This June, we invite you to embrace The Great MND Relay's - Your Relay, Your Way.

Take on a physical challenge of your choice over 41 hours! This flexible option is free to register and you can choose when your 41 hour challenge begins during MND Week (Sunday 19th June 2022 - Saturday 25th June 2022).
It's Your Relay and you get to do it Your Way.

THE GREAT MND Relay

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www.mnd.org.au
www.facebook.com/MNDVic
www.instagram.com/mnd_vic
www.linkedin.com/company/mndvic

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.