

Spring 2021

MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria



GIVING'S IN FULL BLOOM



Until there's a cure, there's care

MESSAGE FROM THE CEO



Welcome to our Spring edition of MND News. It is lovely that we are starting to see some sunny days and a bit of warmth as the year marches on.

Our vision at MND Victoria is “working towards a world without MND.” Whilst providing and promoting the best possible care and support to people living with MND is our primary focus as an organisation, we do also make contributions each year to support research into the cause, treatment, and cure of MND.

With the 2020/21 financial year ending, we were pleased to be able to contribute over \$230,000 to research, despite the pandemic restrictions meaning the cancellation or postponement of so many of the events that contribute funds for research.

“Superball XIII” was held as a virtual event last October and raised \$90,000 to provide the Superball XIII Research Grant. We thank the organisers of this annual event for their dedication and flexibility in managing to raise significant funds despite restrictions.

“Rock Off MND” is a yearly rock concert held in Geelong to raise funds for research. There are a number of surrounding events, such as “Tee Off for MND” and “Jen’s Bubbles and Brunch” which also raise funds for this campaign. Again, the concert that was planned for March last year was postponed and ultimately cancelled due to restrictions, however, the organisers still managed to raise over \$60,000 to provide the Jenny Simko MND Research Grant.

We are so grateful to these dedicated fundraisers for their continued support in such difficult times.

Funds raised for research are managed by MND Research Australia and are allocated as part of their annual research grants round. In addition, we were able to support several researchers and allied health professionals to attend the National MND Australia conference on the 3rd of September and to attend other conferences and/or professional development opportunities through our annual Nina Buscombe Awards.

We were relieved to see the scrapping of the planned Independent Assessments in the NDIS. Along with our colleagues across Australia, we advocated to our local Federal MPs, highlighting our concerns regarding Independent Assessments and the likely negative impact of these on people living with MND who are accessing the NDIS. In particular, we thank Dr Helen Haines, Independent MP for Indi, for meeting with us to hear our concerns. We were also able to highlight the inequities between the supports available through My Aged Care in comparison with the NDIS.

Our AGM is planned for Monday 25th October 2021 and will again be held as a virtual event. Given that this is our 40th anniversary year, we will be acknowledging this special milestone, and we have the Reverend Ian Parton as a guest speaker, talking about 30 years of the Barwon Support Group and his experience of MND Victoria. Further details and an invitation to all members and other interested people are included on page 7 of this newsletter.

At the time of writing this, Victoria is once again in lockdown and our thoughts are with everyone in the MND community impacted by restrictions and lockdown. Please be assured that, as always, delivery of the best possible care and support to people living with MND and their families and carers is our highest priority, and we are constantly adjusting and improving to ensure that we can do this regardless of restrictions. Please let us know if there are ways in which we could further improve our support.

Let’s hope Spring brings fewer restrictions and more sunshine.

I hope you enjoy this edition of MND News.

Kate Johnson
CEO, MND Victoria

MND VICTORIA SAYS THANK YOU

Tax Appeal

Last edition, we introduced you to Graham Casson and his beautiful family. Graham was the face of our 2021 Tax Appeal and set the goal of raising \$100,000 by sharing his heart-warming story.

We are very excited to announce that, thanks to a fundraiser held by the Broken Hill Aquatic Stingrays, Graham's story has raised over \$100,000!

Thank you to each and every person who donated – it meant the world to Graham and his family, and to every Victorian who has been impacted by MND. We are also very thankful to Graham's son, Trent, who secured print advertising and feature stories in various major regional newspapers which helped raise awareness of MND Victoria. Graham passed away in July 2021, knowing that his story has made a positive difference.



Volunteer with Us

Volunteers are an integral part of the MND Community. We could not do the work we do without their dedication to help provide people living with MND with the care and support they need to live better for longer.

Volunteer opportunities are available with MND Victoria on the Mornington Peninsula

We are seeking volunteers to build our team supporting people living with MND across the Mornington Peninsula. Volunteer roles are available in our **Life Story, Hand and Foot Massage, Social Visiting, and iPad Buddy teams.**

If you are comfortable using a computer and like to help people tell their stories, maybe **Life Story** volunteering is for you. If you like to sit and share a coffee and a chat, maybe even working on a crossword or a jigsaw together, **Social Visiting** might be your role. Our **iPad Buddies** are confident iPad users who relish the opportunity to help someone else become comfortable using their iPad. And, for those who would like to learn skills in gentle massage, our **Hand and Foot Massage** volunteer role can help people living with MND to relax.

All MND Volunteers are provided with initial training to prepare them for their role and ongoing support, education, and connection with other volunteers.

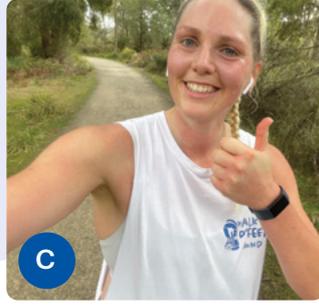
For more information about any of these roles, and to discuss the process to become a volunteer with MND Victoria, email volunteer@mnd.asn.au or call Deb (Coordinator of Volunteer Programs) on 0432 053 287. We look forward to welcoming you into our team.



A



B



C



D

Run Melbourne

“Run Melbourne” was meant to take place on Sunday 25 July 2021 but, due to COVID-19 restrictions, the event was made virtual and ran from Saturday 24 July to Sunday 1 August instead.

Whilst we were sad that “Run Melbourne” couldn’t physically go ahead this year, we are grateful to, and proud of, our 15 Champion Runners. Together, they raised over \$18,500 for the care and support of Victorians living with MND. Here is what a few of our Champions had to say about the experience:

A “I try my best to give back each year and help raise money for MND Victoria. I want to help raise money so that others going through the worst time of their lives can get the same help and care that we did to make that time a tiny bit easier.”
Rebecca Churcher

B “My dad was diagnosed with MND a few years ago and it has been heartbreaking to see what the disease is doing to, and taking away from, him. I wanted to run because even though it’s only a small amount I’ve raised, I feel like every little bit has to help.”
Rebecca Hickey

C “I am beyond proud to have been a Champion Runner, not only did I tick half a marathon off my bucket list but I raised over \$2,000 with the help of many beautiful people for MND Victoria, which truly means the world.”
Jess Walton

D “I decided to become a Champion Runner to demonstrate my support for my dear friend and colleague, Dave Steele, who was cruelly diagnosed with this disease in late 2019. I have seen the impact of the marvellous work the team at MND Vic has had on Dave and his family, and the continuous support they offer in many different aspects of Dave’s life as he lives with this condition.”
Kate Evans



Drink tea for MND

Calling upon our TEA-riffic community! “Drink Tea for MND” is a fun (and delicious!) way to raise awareness and funds to support MND Victoria.

Thank you to everyone who has signed up to host a DT4MND event. Whether it was in person, virtually, or has been postponed to a future date when we are not in lockdown, we are all very appreciative of your support.

DT4MND Week was officially held from 23rd to 29th of August, but the great news is your DT4MND event can be held ANYTIME, ANYWHERE that suits you! You can host your tea your way, on the date of your choice. It could be a morning tea at work, a virtual afternoon tea, a luncheon - the ideas are endless!

For more information, visit www.drinkteaformnd.org or scan the QR code on the right.



PERSONAL STORY

Like all other Australians living with MND, Mel receives services from her local MND Association. Please contact your local State Association for more details on the services they provide.

Mel Dee Dzelde

My MND diagnosis came in January 2021 after already being in a fight for my life for four years. In 2017, I was diagnosed with stage IV rectal cancer, with secondaries in my liver.

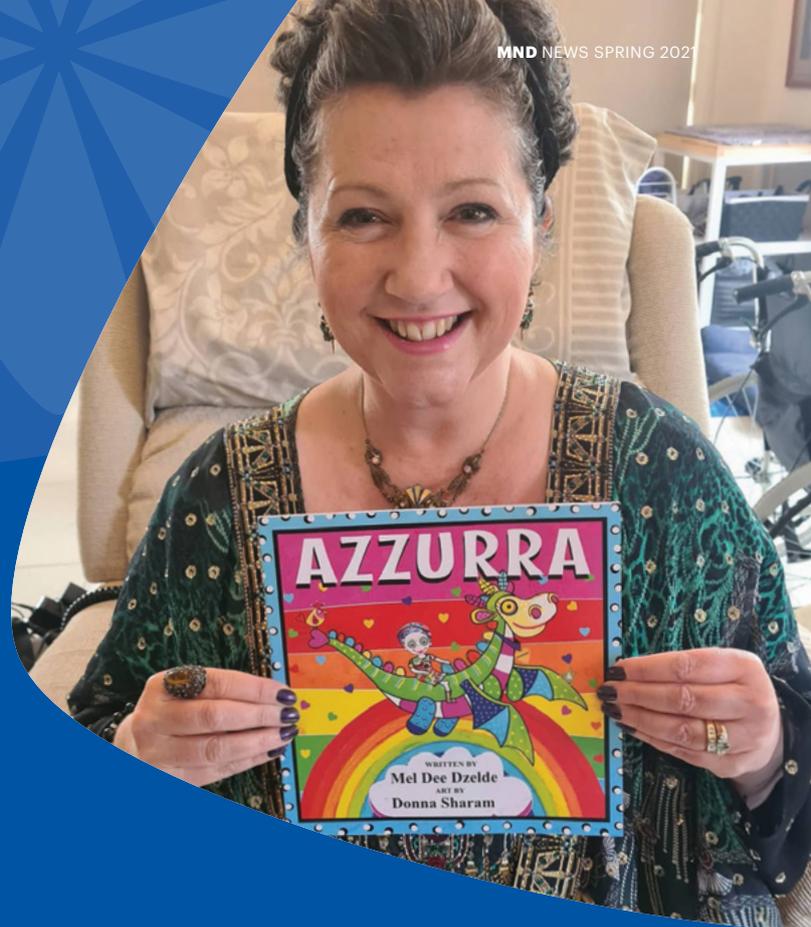
Since my cancer diagnosis, I've had multiple operations, weeks of radiotherapy, and multiple rounds of chemotherapy. 2020 meant a year of doing round after round of chemo and, with each round, I became weaker and less tolerant of the treatment. As I'd done chemo before in previous years, my oncologist wasn't sure why it seemed to hit me harder than before. I had to give up my beloved radio career, and my dropped foot that started in November 2019 was also becoming more noticeable and more of a problem. This sinister symptom, initially thought to be a side-effect of the chemo, was my first sign that MND was about to be added to my list of health challenges.

Like many, it seemed to take ages and multiple visits to doctors and specialists before two neurologists confirmed what felt for me the most unfathomable diagnosis. Even when confirming the news to me, my neurologist said, "I can't believe I have to tell you that you have MND and cancer!" It all felt so unreal.

I remember feeling completely numb at first. I knew that I needed all of my strength to stay strong and fight this new disease, but I was already weakened beyond comprehension.

Fortunately, I have a very strong mind and I'm surrounded by love and support. I quickly snapped back into a way of being that had helped me through four gruelling years of cancer treatments, and got back to the business of healing.

My belief in the power of positivity and keeping my vibration high is how I stay happy and grateful. I honestly wake up every day feeling so blessed for all that I have and for all that I am. Having two terminal illnesses keeps me focused on the now. I don't project and I don't allow others to talk about what my future may hold. I honestly believe that there's not



a soul on this planet who knows what's ahead for me. If I'd listened to my initial prognosis in 2017, I wouldn't be here today.

Surrounding yourself with support is extremely important and that's where MND South Australia have been amazing. Whilst I don't look ahead in a gloomy way, I'm still aware that I need to put things in place to make my life easier for me and my loving husband, Chris. The team at MNDSA have been wonderful in helping me with equipment and advice. Just having a kind understanding voice on the other side of the phone has also been such a relief as the disease has progressed.

MNDSA have also supported me in continuing with my life's dreams. I wrote a children's book last year and have published it this year. It's a bright, beautiful book called 'Azzurra', encouraging children to find their "Inner Dragon" to help them when facing life's challenges.

I'm also very passionate about raising awareness of MND. I was initially shocked at how little most people knew about the disease. Since my diagnosis, I've spoken about the need for more funding and awareness on radio and TV. With my media background, I would like to contribute more in this way.

Having MND isn't something I would ever choose or want, but there are still blessings to be found in every experience, including this one. I'm more grateful for each day. I'm careful to fill my precious time with people and things that I love and which give me joy. Plus, because I believe I have a duty to myself and others to stay positive and not allow fear to change who I am, my time is now so much happier and more on-purpose than it's ever been.

In these COVID times, we've all learnt to pivot. For those of us with a terminal illness - or two - we've been doing this all along. Life is meant to be lived fully and attitude is really the key to making sure that happens.

LIVING BETTER

Caring for your Mental Health

Being diagnosed with motor neurone disease (MND) can be devastating, and managing emotions can become hard

Living with a life limiting illness, and having the daily challenges that come from increasing physical disability, can cause stress and other concerns. Maintaining connections with family and others might get difficult too. Your emotions and moods, general state of mind, and relationships with others, are all important. There are, however, positive ways to deal with emotions and your overall wellbeing.

Doing things each day to look after you can make a positive difference to your mental health and living with MND. Being proactive in exploring MND management options, and looking after your mental health, can have a large impact on your physical health and how you feel each day.

Getting plenty of rest when you can, building on the things which you enjoy, and other strategies, can help make you feel more relaxed and able to deal with MND. Talking with mental health professionals may be a useful source of support as well.

By doing your best to look after yourself, you're likely to feel a greater sense of control, and lift your moods. You're also more likely to enjoy time with others, your interests, and other things important to you.

Who can help?

Not everybody wants to talk about what they are going through. While people living with MND have some things in common, they also have very different experiences of the disease. There is no 'right' way of dealing with MND. Some things you feel and do with MND, however, may be signs that you might benefit from some extra support. These things can include:

- * panic attacks (extreme anxiety and strong physical sensations of fear)
- * persistent irritability
- * problems concentrating
- * being easily distracted
- * persistently avoiding other people
- * angry outbursts
- * difficulty accepting and/or adjusting to the diagnosis and disease related changes
- * persistent sadness
- * persistent feelings of being overwhelmed
- * when feelings interfere with ability to carry out usual activities
- * avoidance of usual activities and connections

These responses are understandable and can be a common reaction to the situation you are experiencing, but the behaviours can have a negative impact on you and those around you. You may find it helps to talk to people who you know and trust about how you feel. It is not always easy to do this, but seeking support is a great first step to feeling better.

If you are finding it hard to talk to people close to you, it may help for you to talk to someone more distant about what's going on, such as:

- * your doctor
- * your MND Association Advisor or Support Coordinator
- * a mental health professional (e.g. counsellor or psychologist)
- * others going through similar experiences (people at support groups for example)

People with MND have individual support needs rather than 'a one size fits all'. Your local MND Association Advisor or Support Coordinator will be able to guide you towards the support you need.

This article has been adapted from the MND Australia webpage 'Caring for your mental health'. To view the entire resource, visit www.mndaustralia.org.au/mnd-connect/living-with-mnd/caring-for-your-mental-health or scan the QR code on the right.





Tips to help care for your mental health

- * **Start slow and small:** when making changes to how you look after your mental health, it can help to change one thing at a time.
- * **Find ways to work around challenges:** living with MND can be a challenge, but you're likely to be already finding ways to adapt and live with the disease, and there are things you can do to manage new or extra challenges if they arise.
- * **Relaxation:** doing things that you enjoy and find relaxing can lift your mood, such as listening to music.
- * **Managing sleep as best you can:** sleeping well is important for managing emotions and wellbeing. However, sleeping with MND can become difficult, so talk to your health care team so that they can support you and work to improve the particular issues that are impacting your sleep.
- * **Stay connected:** try to keep enjoying and maintaining your relationships with your family, friends, and others in your social circle who matter.
- * **Keep active:** with MND, it becomes harder to physically move, but that doesn't mean that you can't find ways of being active that work for you. Don't forget to speak with your OT or physiotherapist if you need some assistance with being active.
- * **Keep learning:** learning new things, or learning how to do usual activities another way, can help you gain confidence and feelings of satisfaction and achievement. Learning may also provide a greater sense of purpose and give you an improved ability to get the most out of life.

Important things to remember

- * Be kind to yourself. Everyone is different and there is no right or wrong way to feel.
- * Feeling overwhelmed is not about being weak, it is about being human.
- * It may take a little while to find a person who you feel comfortable to talk with, but don't give up. It is okay to see different professionals until you find the right person for you. Some psychology service's websites have a section with short biographies of their practitioners which can help guide you in deciding who may be the best person for you to see.
- * Others in your family may be feeling the same way.
- * Others in your family may not understand the changes they see in you, so it may be useful to explain to them what is happening to you.

MND RESEARCH



Exploring the impact of communication and cognition on healthcare involvement and decision making in MND

Communication and cognitive impairments are known to negatively impact health outcomes generally. Also, they are recognised as barriers to shared healthcare decision making. Shared decision making involves patients, their families and healthcare professionals sharing information and knowledge so that decisions and choices match with patients' values and preferences. This process highlights the importance of everyone working together to facilitate tailored management of MND symptoms and to maximise quality of life. People affected by MND (that is, people living with MND as well as family members and carers) face changing needs as the disease progresses and this can impact decision making^[1]. Decision making in MND has been described as an ongoing cycle because people need to react and adapt to ongoing change^[2].

In this study, 19 people living with MND and 15 family members were interviewed one to three times. Participants were asked to describe their experiences of making healthcare decisions. They were also asked how changes in their speech, communication, or thinking skills changed the way they were doing things or changed the way they interacted with healthcare professionals.

The main theme identified in this study was communicating takes effort. This encapsulates the effort required by people living with MND to cope with symptoms or circumnavigate impairments, the effort family members provide in support, and the effort healthcare professionals make to accommodate for changes in communication abilities.

People living with MND described how slurred speech, respiratory weakness, and fatigue makes talking so effortful they sometimes avoid it. This means they ask healthcare professionals fewer questions, provide short answers, or do not fully express their opinions. People reliant on communication aids (e.g. email, writing or eyegaze technology) recognised it was time-consuming which sometimes presented problems in busy clinical environments. People who used communication aids reported frustration if others second-guessed their responses: especially if it was incorrect. People living with MND whose speech was difficult to understand, used the National Relay Service, email, and text messaging to manage healthcare appointments independently.

The support provided by family members was essential for many people living with a communication and/or cognitive

impairment. Examples of practical support for communication tasks included answering the phone, managing medical and clinic appointments, filling out forms, and liaising with community disability support services. People who used communication devices often needed family to set up devices and show staff how to use them. Examples of emotional support were: being present in clinical appointments, providing personally relevant information, and encouraging the implementation or use of high-tech communication devices.

Participants in this study described many ways healthcare professionals adjusted their practice to accommodate a communication impairment. Examples provided were allowing extra time, conducting joint sessions with another clinician, and using email instead of telephone. Without this support, involvement in healthcare appointments would have been reduced. Some participants described occasions where support wasn't provided which negatively impacted their input in decision making.

Being able to explain MND-specific care needs was imperative and it caused anxiety for some participants to have new paid carers or nursing staff unfamiliar with MND. Being able to communicate to facilitate 'difficult conversations' meant that some participants completed medical-legal issues (e.g. documenting Powers of Attorney or Advanced Care Plans) whilst communication skills were intact. Others, however, stated that the onset of communication impairment would be the trigger to start planning.

To summarise, this study shows the considerable effort people living with MND and their carers undertake to maintain or maximise their involvement in healthcare. Much of this effort is largely 'invisible' activity because it occurs outside of medical or healthcare appointments. Despite the effort, healthcare involvement and communication can be compromised. Healthcare professionals and health services can make accommodations or adjustments to minimise any impediment to involvement in healthcare decision-making for people living with MND and their families. These results demonstrate that communication is everyone's business.

Camille Paynter, B.SpPath (Hons)
PhD Candidate, The University of Melbourne
NHMRC/MNDRA Postgraduate Scholarship

References:

- Hogden, A., et al., Development of a model to guide decision making in amyotrophic lateral sclerosis multidisciplinary care. *Health Expectations*, 2015. 18(5): p. 1769-1782.
- King, S.J., M.M. Duke, and B.A. O'Connor, Living with amyotrophic lateral sclerosis/motor neurone disease (ALS/MND): decision-making about 'ongoing change and adaptation'. *Journal of Clinical Nursing*, 2009. 18(5): p. 745-754.

Motor Neurone Disease Association of Victoria has
the pleasure of inviting you to attend the

40th Annual General Meeting

Monday 25th October 2021 at 11 am

The AGM will be held via video link
A link will be sent to those who RSVP.

The AGM will:

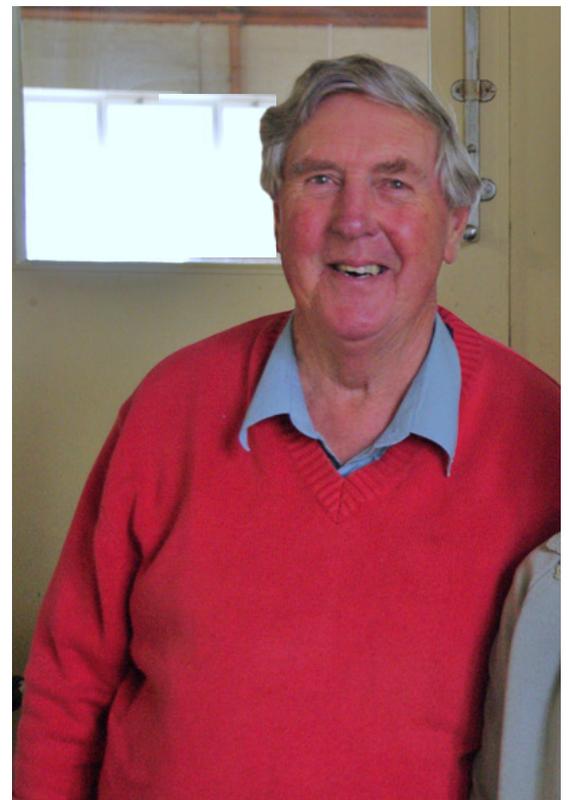
- Confirm the 39th AGM minutes
- Adopt the Treasurer's Report and Financial Statement for 2020/2021
- Appoint the auditor
- Elect State Council members

Our guest speaker will be Reverend Ian Parton,
speaking on 30 years of the Barwon Support
Group and involvement with MND Victoria.

Please **RSVP** by Thursday 21st October
2021 to receive the video link.



**Call for State Council
Nominations**
Scan the QR code for
more information
and the nomination form.



MND Victoria

PO Box 23, Canterbury VIC 3126

Telephone: (03) 9830 2122 Freecall: 1800 777 175

Email: info@mnd.org.au

UPCOMING EVENTS

Cross4ACause – A Cyclocross Fundraising Event

“Cross4ACause” is a new cycling event coming to Regional Victoria on Saturday 16 October and Sunday 17 October 2021 to raise awareness about MND, raise funds for MND Victoria, and to provide an opportunity for the Cyclocross Community to come together and showcase their sport to the wider community.

Cyclocross is a unique sport. Riders race around a course that involves mud, obstacles, hurdles, hills, sand, and more mud. It’s fast-paced and great fun to watch as crashes are almost guaranteed as riders battle for position.

Located at Hammon Park, Creswick, “Cross4ACause” will bring riders from across the country as a portion of the weekend will also be the National Championships.

We do have something for everyone, with kids races, the “dogs of cross” race, tracklocross riding (no brakes, no gears!) as well as the more traditional cyclocross. For those who simply want to watch, there will be food trucks, music, and a hot-air balloon night glow.

Started by the family of Brian Chatham who succumbed to MND in December, “Cross4ACause” wants to highlight the incredible work MND Victoria does daily, and to honour both Brian and his son Brendan, who suddenly passed away not long after Brian’s diagnosis.



The entire Chatham family have been humbled by the support they have received for this event and hope that you can come along to Creswick on October 16 and 17.

Visit <https://entryboss.cc/> to purchase tickets or contact Chris at cross4acause@gmail.com for more information.

Entertainment

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GIVING

Your support matters

COVID-19 has certainly changed so much for so many. For MND Victoria, the pandemic has meant we have found new ways to ensure that we can continue to provide care and support for Victorians living with MND. But it has changed the way we fundraise, with lockdowns impacting so many major and traditional revenue streams. In particular, it has meant the cancellation of the majority of our community-based fundraising events.

Our mission is 'To provide and promote the best possible care and support for people living with MND'. We are driven to ensure that 'best possible' can be even better than it is today, and we know that, with the support of the MND community, we will achieve that.

There are many ways to support us and the work we do. It is quite easy to do, and it is now more important than ever:

- * **Host a fundraiser:** there are many ways to fundraise both in person and virtually. Our Supporter Development and Communications team are here to provide you with all the support and encouragement you need to help reach your goal. Contact them at community@mnd.asn.au or on 1800 777 175 to get started.
- * **Purchase merchandise:** we have several brand-new items in our merchandise store, including our limited edition 40th Anniversary Hoodie. Merchandise is a great way to visually raise awareness of MND Victoria and support us at the same time. View our store at www.mnd.org.au/store
- * **Donate:** Every single contribution made to MND Victoria, regardless of its size, helps make a difference in the lives of people living with MND. Plus, any donation over \$2.00 is tax deductible. Visit www.mnd.org.au/donations or scan the QR code on the right.



Please dig deep so that those who hear the fateful words "You have motor neurone disease" can still enjoy life and remain independent, safe, and engaged with their community for as long as possible.

40 YEARS OF CARE AND SUPPORT



2021 will be a memorable year for so many people but, for us at MND Victoria, it is a very important year.

2021 is the year that we acknowledge 40 years of having a significant impact on the lives of thousands of Victorians affected by motor neurone disease. Since we were founded (originally as the Motor Neurone Society) in 1981, it has been our mission to provide and promote the best possible care and support for people living with MND.

In each newsletter this year, we are looking back on a decade in our history to reflect on the journey that has led us to where we are today. Below are our milestones from 2001 – 2010.



2001 The March of Faces banner project (which is a photographic display of men and women with motor neurone disease), was introduced to Australia by Jackie Williams, an MND Association member.

2002 Mavis Gallienne, who helped to establish MND Victoria, was awarded the Order of Australia for services to the MND community. The Department of Defense approved funding for ALS-specific research and the MND Research Tissue Bank of Victoria became a reality.

2003 The Young People's Group was established for people under the age of 50 living with MND.

2004 The first 'Walk to D'Feet MND' event was held at Princes Park, Melbourne and raised \$8,275 for research. The Australian Motor

Neurone Disease Registry, which is a de-identified disease-based registry that facilitates the collection and storage of Motor Neurone Disease data, was established.

2005 The Bendigo Support Group celebrated 20 years of meeting and supporting people in Bendigo who have been affected by MND.

2006 The first-ever 'MotorOn' event was held by the zo-ee foundation. This event ran each year for ten years and raised over \$600,000 for MND research.

2007 The age restriction for Rilutek™, a brand of riluzole, was lifted to include those diagnosed with MND in the past five years. The Volunteer Hairdressers service started, allowing people living with MND to receive haircuts without having to leave the comfort of their homes.

2008 The Benalla Community began fundraising to create research grants named in honour of Mick Roger, who was diagnosed with MND. Through the "Act to D'Feet MND" events and the "MND Charity Superball", they have raised well over \$1,000,000 which has funded some of the best and brightest researchers in Australia over the past 13 years.

2009 MND Victoria Volunteer, Anne Janssen, was nominated for the Victorian Senior of the Year Award. Anne first became a volunteer in 1995 and continued until 2019.

2010 MND Victoria started our partnership with Vitality Brands, who donate funds to us every year for the "Take-A-Break" program.

Our next newsletter will cover our milestones from 2011 to today.



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