

MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria

**On a roll!
The Great MND Relay
raises \$320,000!**



Until there's a cure, there's care

MESSAGE FROM THE CEO



Welcome to the Spring Edition of MND News.

Winter has certainly not been a quiet time for us at MND Victoria, with many small and larger events raising awareness of MND and MND Victoria, as well as raising much-needed funds to support us in continuing to provide the best possible care and support for people living with MND.

As you will read further on in MND News, The Great MND Relay was an overwhelming success. We were so grateful to have Anthony Callea as the event ambassador, helping us to promote the event and raise awareness of our organisation and the impacts of MND on those living with it. We thank the family and friends of Anthony's friend Greg, who passed away with MND in early 2022, for allowing Anthony, and MND Victoria, to share Greg's story and the impact MND had on him and those around him.

The Relay saw so many people who have been touched by MND come together to ensure that our wheelchair was moving around the athletics track continuously for 41 hours – and achieving 470 laps.

Many thanks to all of those who participated, attended, and contributed to the event. Watch out for next year's event – hopefully bigger and even better.

We have also been so well supported by community events. We have really missed these events across the last couple of years of restrictions – not only the funds they raise but also the sense of community and connection they bring to the broader MND community. Thank you to every community group that has held an event to raise funds and awareness for MND Victoria.

As I write this article, I am sitting on the Larapinta Trail in the Northern Territory – supporting and giving my thanks to our group of Larapinta Trek Challenge participants. I would like to offer my thanks and gratitude to them all for their willingness to take on this physical challenge and for the funds raised through this challenge.

MND Victoria sees an important role for our organisation, both individually and as part of the National Network of MND Associations, in advocating for the best possible support and services for people living with MND. We have supported MND Australia in their advocacy to federal politicians in the lead-up to the Federal election, and more recently in the lead-up to the Federal budget. We are calling for equity of access to support for people over the age of 65 who are diagnosed with MND, who are not eligible for the NDIS – we see this as a critical change needed to ensure that all people diagnosed with MND have equity in the services and supports they can access. In addition, we are advocating for funded access to assistive technology and equipment for people over 65, at least equal to that available through the NDIS.

At a Victorian level, we are advocating for the State government to also act on, and advocate for, appropriate access to disability supports for those people, such as those with MND over 65, who cannot access the NDIS. We are also calling for better access to state-funded health services, including an appropriate level of access to palliative care services.

Keep an eye out for our second Shut Up! For MND campaign – asking people to commit to not speaking for 6 or 12 hours on 22 September – to get a tiny taste of what it is like to lose the ability to speak and to help raise awareness and funds for MND Victoria. Be sure to tell your family, friends, and networks to get involved – or perhaps nominate someone you would like to see Shut Up! for a few hours.

In the lead-up to warmer weather – and hopefully a continuing decline in COVID cases – we look forward to seeing even more community events and further engagement with the MND Community.

Have a lovely Spring.

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

Kate Johnson

CEO, MND Victoria

MND VICTORIA SAYS THANK YOU

The Great MND Relay

The Great MND Relay ran for 41 hours in Coburg North from 8:00 pm Thursday 23rd June to 1:00 pm Saturday 25th June. Our dedicated community came and worked together, achieving a 41-hour continuous relay. There were also plenty of performances, entertainment, activities, food trucks and more, over the 41 hours, so there was always something fun to do no matter what time of day (or night!) you attended.

Regardless of what the weather threw at us, there was always someone walking the track, showing just how committed and determined the MND community is. Together, we managed to achieve our collective goal of walking 470 laps in 41 hours, covering the wheelchair baton

in 470 cornflowers to represent every Victorian currently living with MND. The final lap, led by The Great MND Relay Ambassador Anthony Callea, was an extraordinary moment for the hundreds of people who completed it together.

We are very humbled to announce that The Great MND Relay has raised over \$320,000!! This huge amount of money will enable MND Victoria to continue to provide the best possible care and support for families impacted by motor neurone disease.

The Great MND Relay is now our most successful fundraising event in our 41-year history, and that's all because of the support of our wonderful community. Thank you to our participants, Champions, volunteers, performers, and sponsors for being part of something truly special.





Community Fundraising

We have had several incredible community fundraisers lately that have helped raise awareness and funds. We have been thoroughly impressed by the passion, creativity, and generosity of all those involved in the various events! Here's a wrap-up of some of them.

Barellan Central School

"We walked around our local town in blue in the morning as a whole school, to raise awareness. During recess, we sold merchandise, blue cupcakes, and blue cookies with MND engraved in the icing. During this time, students paid \$2 per water balloon to throw at a nominated slider in the afternoon. In the afternoon, some staff and student leaders dressed in costume and slid down a large slippery tarp while students threw water bombs at us. We raised \$1,087. It was a great day!" – S.F.

Alamanda College

"We thoroughly enjoyed supporting MND Victoria's Blue Cornflower Day. As a school community, we raised over \$1,400. This was a cause near and dear to some of our staff members, with an Assistant Principal losing a sibling, so the Year 5 & 6 Mini School really got behind the day." – E.S.

Red Cliffs East Primary School

"Red Cliffs East Primary School is a small rural school near Mildura with approximately 130 students, but it also has the biggest supportive extended school community, so when one of our families told us that they had a family member who had been diagnosed with MND and they would like the school to help raise awareness of MND and some money for MND Victoria, the school was only too happy to help.

With the permission of the School Principal, Craig Warn, and the support of a number of families, a fundraising Community Breakfast/Blue Day was organised. The total amount raised by the School Community was \$4,000. This amount was raised from the Blue Breakfast, raffles (with prizes donated from local businesses), guessing the number of blue lollies in a jar, the sale of some MND merchandise, general donations from our school community, and RCEPS rounding up the total amount to \$4,000.

The students, staff and community of Red Cliffs East Primary School are very proud to have been able to support the MND Awareness Day and hope that our contribution to MND Victoria helps. Thank you for the support you gave us when organising our Community Breakfast Day." – B.D.



Reconciliation Action Plan (RAP) Update

The Association continuously strives to better our understanding and take active steps towards reconciliation. Our RAP implementation working group is currently putting the finishing touches on our Reflect RAP which will be shared in the near future. We look forward to sharing it with you alongside the beautiful artwork which local Indigenous artist Katie Budgen, a proud Kamilaroi woman, has created.

A review of our induction programs is underway to include a greater understanding of First Nations cultures, and of how we, as an organisation, can provide the best possible care and support for all.



Warrnambool Fun Run

“On Saturday 16th July, King’s College Warrnambool, Warrnambool Presbyterian Church, and Warrnambool Surf Life Saving Club joined together to put on a Fun Run to raise money for MND.

It was exciting to see over 180 people keen to take part in the event and that it was made up of a mix of babies in prams, kids, teenagers, parents, adults, grandparents, and even some dogs! Over 2, 5 and 10kms they ran and walked with a friendly and encouraging attitude shown by all.

Thank you so much to our staff who got up early on a cold Saturday morning to serve and participate in this event, thank you to those who supported the cause by buying a beanie or socks or made a donation, and we are thankful to God that we could be out in His creation and share time together with others again. We raised \$7,000 to send to MND Victoria. Thank you so much for your support.” – C.W.

Larapinta Trek Challenge Event

In August, a group of 16 individuals set off to hike the Larapinta Trail in the Northern Territory as part of our latest challenge event. Over the seven days, these legends explored the scenic landscapes of the Australian Outback along the red dirt tracks, immersing themselves in the rich history of Australia’s First Peoples and camping under the stars.

In the lead-up to this amazing experience, each participant worked super hard to raise vital funds to provide care and support for people living with MND.

We are so thankful to each and every one of them - to date, they’ve raised over \$90,000 (and counting)! Thank you, Jenny, Sarah, Renee, Hamish, Bree, David, Chris, Pamela, Sian, Sharyn, Grant, Luke, Ashleigh, Rachel, Anne, and Tin – you’re all superstars!



Western Rams Football Sporting Club

“On the 25th of June, the Western Rams hosted our first MND day to raise funds for MND Victoria. The day was a huge success, raising \$13,441 and having an all-around good day with players past and present taking the slide to freeze MND for club life member, Ron Lalli-Cafini.

It was a very special occasion for the club, wearing a special jumper to honour Ron. Also, the Reserves won their first game in 1512 days.

On behalf of the Western Rams, we would like to thank MND Victoria for all the fantastic work they do for all people with MND.” – S.L.C.

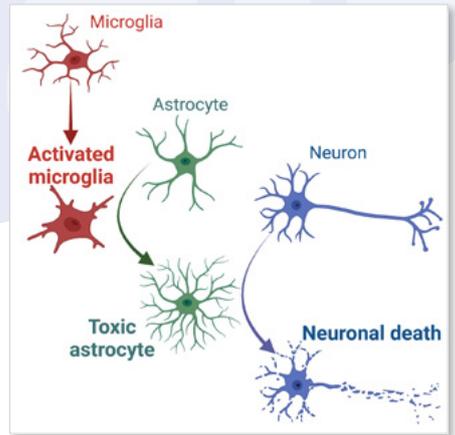


Fundraise for MND Victoria

Are you interested in becoming a community fundraiser for MND Victoria? You could host an event, get active, set a challenge, celebrate an occasion, have a bake sale...the ideas are endless!

When you sign up to fundraise for us, you will receive your own online fundraising page to help spread the word about your activity and to receive donations. You will also have access to support from our team as well as a number of resources to make it a fun experience! Get in touch with us by emailing community@mnd.org.au or calling 03 9830 2122 to chat today.

MND RESEARCH



A schematic diagram of Dr Liddell's research

When normally benevolent cells become lethal in MND

By Dr Jeffrey Liddell

Motor neurone disease (MND) occurs when the nerves that control movement and muscles – known as motor neurones – deteriorate and die. While MND involves the failure of motor neurones, the causes of this failure are not known. Many potential mechanisms have been identified, and increasing evidence indicates that other cells in the brain and spinal cord called glia may play an important role in causing the death of motor neurones in MND.

What are glia?

For a long time, glia were thought of as passive cells that simply support neurones. However, it is now recognised that glia have many effects on the way neurones function.

There are 3 types of glia: microglia, oligodendrocytes, and astrocytes.

Microglia protect the nervous system in the brain and spinal cord by removing damaged neurones and other harmful substances. They are the immune cells of the brain.

Oligodendrocytes produce myelin, which is the fatty insulation around the connections between neurones that is essential for proper communication.

Astrocytes help to repair damage to neurones, provide nutrients to neurones, regulate communication between neurones, and help to protect the brain from potential toxins in the blood.

In MND, it has been shown that astrocytes can lose their normal supportive functions and become toxic to motor neurones. Astrocytes appear to produce toxic factors that kill motor neurones. We don't know why this occurs and what the toxic factors are.

What makes astrocytes give off toxic factors that lead to the death of motor neurones?

Recently, it was discovered that microglia can provoke this toxic behaviour of astrocytes. In MND we believe we have discovered a trigger for this: a process known as ferroptosis. **Ferroptosis is a type of programmed cell death in response to adverse iron-dependent or iron-related processes in the cell.** We find that microglia grown in a dish respond to ferroptosis, sending signals

that provoke astrocytes to release toxic factors that kill neurones. Furthermore, we find evidence of both ferroptosis and neurotoxic astrocytes in people with MND and MND model mice.

Through the generous support of the MNDRA, we are now studying the impact of ferroptosis on microglia grown in a dish. We are investigating the signals they release that provoke astrocytes, and trying to find the neurotoxic factors given off by astrocytes that kill motor neurones in MND.

This deadly behaviour of microglia and astrocytes appears to be occurring in MND. Being able to more accurately model it in a dish gives us better opportunity to learn how and why glia become neurotoxic. This is really exciting because it will then guide the development of effective disease-modifying treatments for MND that prevent motor neurone death by targeting glia.

Dr Jeffrey Liddell is a mid-career neurobiologist at the University of Melbourne. Gaining his PhD from Monash University in 2011, his expertise is in glial cell biology, examining how these normally supportive brain cells can become corrupted and contribute to the death of neurones in neurodegenerative diseases. His work is supported by the NHMRC, CASS foundation, University of Melbourne, and Motor Neurone Disease Research Australia. When not in the lab, he enjoys long-distance running, netball and playing with his kids.



GIVING

Bucket List Wish Program

MND Victoria's Bucket List Wish Program has been granting wishes and helping create special moments for those with MND, and their loved ones.

Margaret's Luxury Houseboat Wish

Recently, Margaret wished to stay in a Luxury Houseboat with her loved ones, and we helped make it come true with the assistance of the team at Echuca Luxury Houseboats.

"Thank you to MND Victoria for allowing me this fantastic trip, everything from start to finish fulfilled my wish list expectations, dreams, and memories I will never forget.

My family and friends who accompanied me all expressed the knowledge of the ever-closer bonds which now exist between us as something they have all felt and will last forever. The fun we all had with jokes, loud music, which I especially enjoy, together with singing and watching the others dance, made this a memorable occasion which we will all cherish." - Margaret



Bernie's Lavish Getaway Wish

Recently, Bernie wished to have a lavish getaway with his partner, and we helped make it come true.

"I think it was the most glamorous accommodation we have ever stayed at. We had great plans to do lots of exploring, however, we ended lazing our days away in front of a cozy fire, with books and magazines - such luxury! Jack Rabbit was yet another highlight. It was a beautiful day, overlooking the bay as we sipped our wine while watching the activity on the water. We did indeed have a fabulous time with lovely memories. MND Victoria, we thank you for providing such an opportunity for people and their families facing the challenges of MND." - Bernie

Thank you to Jack Rabbit, a local winery on the Bellarine Peninsula, for providing a lovely dining experience as part of this wish.

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

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.

Thank you to everyone who donated to our recent Care Appeal. In the end, a tremendous \$87,270 was raised, which will aid us in our mission 'to provide and promote the best possible care and support for people living with MND.'

LIVING BETTER

Fatigue and MND

Fatigue/extreme tiredness is a common part of MND that affects quality of life. Sometimes it is difficult for others to understand your fatigue - it is an invisible symptom, but one that can have a big impact.

What is fatigue?

Fatigue can be described as extreme tiredness or weariness or a feeling of lack of energy that can affect your motivation and make it hard to function.

Experiences of fatigue in MND differ between people. Some people talk of a feeling of 'whole body tiredness', while others describe 'extreme tiredness in specific muscles'. For some, muscle fatigue is partially/wholly relieved by taking regular, short rests. For others, it takes longer to recover after using muscles. Some people find that fatigue can make it hard to concentrate.

Experiences of fatigue also change as the symptoms of MND progress.

What causes fatigue in MND?

There is no single, known cause for fatigue in MND. A number of MND symptoms can contribute to feeling fatigued. These include muscle weakness, immobility (difficulty moving), weakened breathing, sleep difficulties, metabolic changes, and reduced nutrition/food intake.

Other causes of fatigue include other health conditions, specific medications, depression, lifestyle factors, and stress/anxiety.

Understanding the cause/s of the fatigue

It can be helpful to understand what is contributing to your fatigue, particularly if you are experiencing a lot of fatigue relative to the amount of muscle weakness that you are encountering.

While it is usually not possible to completely relieve fatigue, there may be things that can be done to reduce your fatigue levels. Although there is not a lot of scientific evidence about how to manage fatigue in MND, the evidence supports managing any reversible factors that might be contributing to your fatigue.

Depending on your situation, it may help to use this fatigue checklist:

- * Check with your neurologist/GP if you are on any medications (for MND and/or other health conditions) that can make fatigue worse. Sometimes the dose can be changed or an alternative medication can be used.
- * Talk with your neurologist/GP about any difficulties in sleeping that you are having, or about other symptoms that may be affecting your sleep e.g. cramping, breathing difficulties.
- * Think about whether stress/worry or feelings of anxiety/depression might be increasing your fatigue.
- * Consider your diet and whether you might not be getting enough nutrition.
- * Take note if you wake up with a headache or notice difficulties with breathing.
- * If you experience fatigue in particular muscle groups, it can help to take note of where you feel fatigued, what tasks are the most tiring, and how long it takes to recover.





Managing fatigue

Everyone is unique and will have their own ways of managing and coping with fatigue.

Step 1:

The first step is to think about whether any of the above reversible factors might be making your fatigue worse and to talk with your doctor/s about it.

- * There are medications that can help to treat some of these causes of fatigue.
- * Your doctor might refer you to a respiratory (breathing) specialist for a review of your breathing, a dietitian to look at your nutritional intake, or a psychologist to support you to manage the stressful, emotional impacts of MND.

Step 2:

It may be helpful to talk with an Occupational Therapist about energy conservation strategies:

- * Energy conservation is a way of adapting how you carry out your day-to-day activities, so that you use less energy.
- * An Occupational Therapist can work with you to reduce the amount of energy needed to do the things that are most important to you. Sometimes this involves using special equipment/technology, doing something in a different way, using larger muscle groups, or pacing your activities during the day and the week.
- * Sometimes accepting help with tasks that are less important to you can free up energy for things that are more meaningful.

An Occupational Therapist can work with you to focus on what matters most to you.

Step 3:

Fatigue in specific muscle groups

Physiotherapists and Occupational Therapists may be able to assist if you are experiencing fatigue in specific muscle groups. Doing a task differently, planning when and how you do some tasks, reviewing your seating/positioning, or using equipment/technology can help to reduce the load on particular muscles in your body.

Other things to consider:

The evidence about specific types of prescribed exercises and fatigue in MND is not clear yet, but some people tell us that they find appropriate exercise prescribed by a neurological Physiotherapist or specialist Exercise Physiologist helpful.

There is evidence to support meditation/relaxation techniques improving people's ability to manage fatigue related to high levels of stress/anxiety associated with chronic health conditions.

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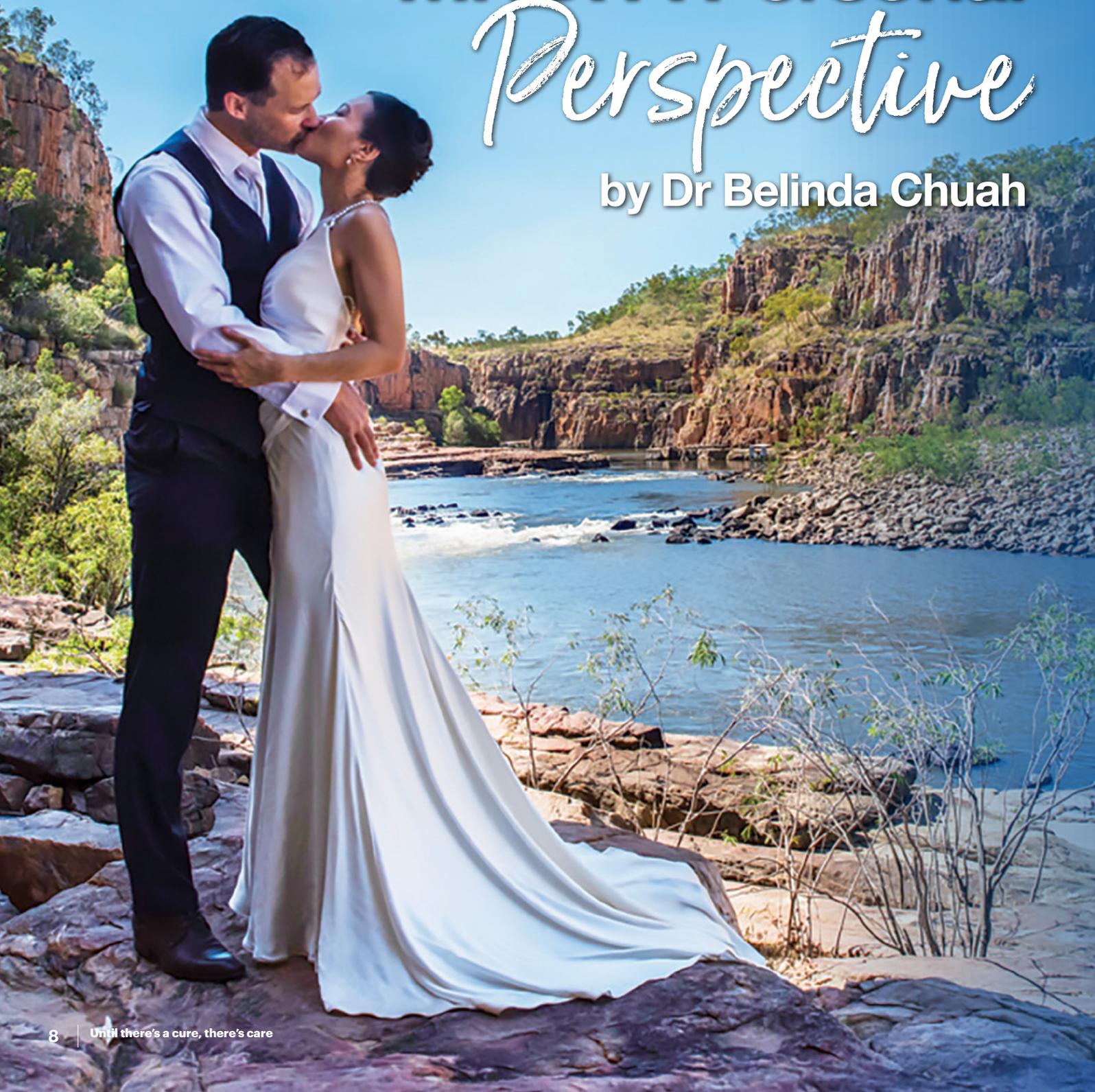
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Find out more about Sleep and MND here by visiting www.mndaustralia.org.au/articles/sleep-and-mnd or scan the QR code on the right.



PERSONAL STORY

MND. A Personal *Perspective* by Dr Belinda Chuah





My name is Belinda, I am 43 years old, the proud mother of Judd and loving wife of Andrew Pirola. I write to share my personal story about motor neurone disease (MND).

It is four weeks since my life changed completely. On 4th May 2022, I was unexpectedly diagnosed with ALS (amyotrophic lateral sclerosis), a form of motor neurone disease (MND). MND is a neurological disease that destroys motor neurones in the brain and eventually leads to paralysis in the body. In MND, no two people are the same. Where the weakness first starts, how the weakness progresses, and the rate at which the weakness progresses, is different from person to person.

While some people can live a long time with MND, the average life expectancy is 27 months. MND is fatal. It has no cure, no known cause, and no effective treatment. Some forms of MND tend to run in families, however, over 90% of patients have no family history at all. I have no family history of neurological disorders and have always been a fit, healthy, and active mum.

No matter how old or how fit a person is, this disease does not discriminate. It is a crippling illness that results in profound muscle weakness which, in my case, initially started in my hands and has spread to my arms. The condition will progress to the extent that I can't walk or use my arms, and eventually it will take away my ability to talk, swallow and breathe. MND has been nicknamed "The Beast", due to its insidious and relentless nature.

My symptoms first began in mid-2021 when I noticed my right hand occasionally locking in strange positions which I had to shake out. Over time, I noticed that everyday tasks were becoming harder due to loss of grip strength (e.g. opening jars, cutting food, carrying my old dog up the stairs). However, life was hectic and full. I was a working mum and busy organising my belated wedding celebration with Andrew, delayed due to COVID. Eventually I noticed that lifting my arms was becoming a struggle and I needed to ask Andrew or Judd to assist me to put on my jackets. Even tasks such as brushing my hair were becoming tiring.

I then noticed the same trajectory of weakness starting in my left hand. While we were fairly sure it was something simple and fixable, like repetitive strain injury (RSI) or carpal-tunnel syndrome, Andrew, who is neuropsychiatrist, was concerned enough to find a good neurologist to run some tests.

It was a complete and utter shock to us both, the day that the neurologist, after completing a series of nerve conduction tests and Electromyography (EMG), turned to face us and uttered the three letters that would change our lives forever: MND.

The moment ran like this:

After pulling out the needle from the last muscle test, the neurologist sat down next to me (Andrew on my other side) and said, 'It is not carpal tunnel'. I replied, 'well that's not good' to which she responded, 'yes I too was hoping it would be carpal tunnel'.

She then gave a sigh in a dark, depressing tone and dropped her head.

It was at this moment I knew that bad news was coming and, in an attempt, to ease her burden of delivery I responded, "It is bad, isn't it?"

"Yes," she said. "It is very bad [pause]; you have MND - motor neurone disease."

She then explained the diagnosis of "ALS" (amyotrophic lateral sclerosis), which is a type of MND. She explained that there is no cure, a very short life-expectancy, and that the future involved profound disability.

In disbelief, I asked, "How will I die? What will the end look like?"

She replied, "Your body will become progressively weaker over time, from the outside towards the centre, impacting on swallowing and speech and eventually your lungs will no longer be able to support your breathing."

This was followed by: "I am writing you a referral to a specialist support and palliative care service."

There are no words to explain how to comprehend this news. In the same moment I was hearing the neurologist urging me to travel to whatever destination I had always dreamt of, and to create my bucket list, because "Your time is now; there is no tomorrow."

No amount of psychological training and years of experience could have prepared me to look my 11-year-old son in the eyes and tell him that “Mum is very sick.”

And then to have him ask, “But, you will be okay, right?”

And to have to reply, “No, I’m sorry Judd. Mum isn’t going to be okay. Mum can’t get better from this.”

“What do you mean, Mum?” Tears well up in his eyes and he reaches for me with his soft little hand to hold mine.

A parent is supposed to be able to tell their children that everything will be okay, everything can be fixed. I wanted to protect him but was forced to reply:

“I’m so sorry, Judd, but Mum is dying.”

Then, a guttural whisper between tear-filled eyes, “No, Mum.”

The weeks that follow, the phase in which we currently remain, are a blur, and an impossible-to-process overload of emotions. Grief. Loss. Existential terror. Andrew and I support one another and Judd and provide as much of a happy home and normality as can be done, while having to deliver the news and manage the shock and grief of friends and family. How do you tell your Mum and Dad that you are dying, knowing the utter grief they will experience from the incomprehensible reverse natural order of death?

There is practical future planning such as wills, power of attorneys, making plans to move to a wheelchair accessible home, as well as medical appointments and allied health specialists coming on board. Amongst this, I have had the amazing support of MND Victoria who are the only not-for-profit organisation providing direct care and support to Victorians living with motor neurone disease.

The one fundamental issue that I have found the most challenging in dealing with MND is the fact that, whilst the time I have available is finite, the length of time I have left is ultimately unknown. No doctor can advise or predict the progression rate of decline. I do not know how much quality or independent time I have. Twelve months? Twenty-four months? Five years, or beyond? Will I still be able to walk in three months’ time? Or will I have one more year of ambulation freedom? How much time do I have left for the ability to speak, to express to Judd all my hopes and dreams for him? If I book opera tickets for January 2023, do I book a wheelchair seat, or will I still be walking?

The happy, joyful moments are now tainted by grief. Will this be the last time I can play basketball with Judd? Is this the last time I will be able to dance with Andrew? I experience incredibly deep sadness about all the things I’ll miss out on: Judd’s graduation; holding my potential grandchildren of Judd and my two stepchildren; enjoying

years of love and the rewards of retirement and celebration of life into twilight years with Andrew; the privilege of caring for my parents into their old age as a thank you for the wonderful life they have given me. And the worry about how my son will manage without me to guide him.

I catch myself staring at my beautiful young son who has filled my life with such meaning, purpose and the deepest experience of joy and love, trying to imagine what his face will look like as a young man. Will he know that I will be proud of the man he will become no matter what mistakes and falls he makes along the way. That I hope my death will not be a shadow over his life in which he creates an unattainable yard stick ‘Have I done well enough for my Mum, would Mum be proud of me?’ Instead, I hope I will represent a shining light through his life to provide nurturance and an enduring sense of unconditional love as he develops into his own independent strong being. I would be cheering him on to make great life choices, but to know that ultimately any stumbles along his journey are his to make and grow from – that he is accountable to himself rather than carrying a heavy ghost of me on his back perpetually judging him. I wish I could be there to hold his hand and lift him up when the inevitable adversities of life knock him down. But I know he will have the strength to rise back up because I can see that he has great character already, with Andrew as his guide, alongside our support crew to wrap their arms around him on my behalf.

There is the terror about what is yet-to-come, and about leaving behind a trail of palpable grief and pain by my passing as a mother, wife, daughter, sister, and friend. There is also the task of redefining myself and my identity: coming to terms with the ending of my fulfilling and rewarding 16-year career as a psychologist. I must try to re-invent myself as someone with an active brain yet limited moving body parts. I am aware of losing the pleasure and satisfaction of my care-giver role to my son and husband (driving, cooking meals, washing clothes).

I am being stripped of everything I have control over, and slowly being left with just the essence of Me.

As a fellow MND battler has described, it feels as if we are running two parallel races at the same time. One is the task orientated race—an attempt to control and to put things in place for the future of my family as best I can. The other race is mindful living – ‘Today is my best me’. I am determined to live my best life and to make the most of life each day because each tomorrow will be a little harder as I grow weaker, and so I am called to live fully today. I am planning fun times with friends and family and soaking up meaning and joy in my life. Life is all the more precious for its brevity.

We are holding each other tight as we ride the waves of despair and terror that is the storm of MND. However, throughout this difficult journey, we also bear witness to the great depth of human compassion and kindness. We have been uplifted by the love, care and support of what I call the “layers of my onion”—my family, friends and the wider community around us.

I have the most amazing, caring husband cradling me in his heart and arms. I feel so tremendously blessed to have found a depth of love, connection and understanding with Andrew that transcends the concept of love that I had imagined only existed in dreams. He is walking this journey with me hand in hand. I have a gorgeous, thoughtful son, so funny, compassionate, and warm. Each holding my hand through each step of the way and over each hurdle. I have witnessed, with admiration, my 11-year-old quietly (without any awareness that anyone is watching), lift himself up with such astounding natural strength and unbeknownst inner resilience, to face a new world carrying a weight on his shoulders with such grace and courage. Without prompts, he carries my shopping bags and holds my hand as I walk up and down stairs in case of an unexpected fall. I have been blessed with unexpected glimpses into my son’s beautiful nature. For example, four days post diagnosis, I went to use his iPad and saw his google search history. The previous searches were all game or sport related (‘AFL fixtures and results’, etc). These changed abruptly with the more recent heart wrenching search terms like, ‘how to best spend the last 1 to 2 years of your life’.

I have loving family, friends, and a great bunch of work colleagues. We have seen an unwavering offer of support and compassion from not only friends and family, but from people I have only just met. There has been the development of invaluable friendships that might otherwise not have been born or solidified without this situation, such as the support and camaraderie of other mothers within Judd’s wonderful school community. The show of support and countless messages of encouragement have hoisted us up, lifted our spirits and given us the strength to face this dreadful disease head-on. Whilst this disease is horrible, it has elicited in others the best aspects of human nature.

Unfortunately, a cure won’t be found in my lifetime, but I am grateful for the support of MND Victoria who provide vital care, support, education and equipment to families such as ourselves. We have been tremendously impressed by the kindness and professionalism provided to us by MND Victoria and it has been an invaluable comfort to have their care and support during this chapter of our lives.

Thanks for taking the time to learn about our journey, and about MND.



UPCOMING EVENTS

Shut Up! For MND

Are you ready to Shut Up! For MND? This unique and bold way to help Victorians impacted by MND is back for 2022.

What: We are challenging YOU to go 6 or 12 hours without speaking, and nominate others who you think should Shut Up! for a great cause.

When: Thursday 29th September 2022 (or another date of your choice).

Who: You, your workplace, your pals, or anyone you would like to nominate to join you in Shutting Up!

Why: All money raised through "The Shut Up! For MND Challenge" directly supports people living with motor neurone disease by funding the direct care, support and vital assistive equipment required to help them live better for longer.



It's FREE to sign up and once you register, you get your own personal fundraising page to start making a difference. Join now at www.shutupformnd.org.au or scan the QR code on the right.



The MND Community inspires us every day, and we can't wait to see the support and generosity from so many once again.

'Never Give Up' New Zealand Trek

Are you ready to say "kia ora" to New Zealand's stunning Southern Alps? Join us for the adventure-of-a-lifetime on our 'Never Give Up' NZ Trek!

Over six days, you'll trek from Christchurch to Queenstown, through lush alpine meadows and remote forests, into steep, glaciated valleys and in the shadow of New Zealand's highest mountains.

Best of all, with every step you take, you'll raise vital funds that will continue to enable 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.

Places on this incredible and meaningful adventure are limited. Don't miss out! More details are available at <https://events.inspiredadventures.com.au/events/mndvic-southernalps-2023> or scan the QR code on the right.



MND CRLI

MND Australia, in partnership with GenieUS, is launching the first Australian MND Clinical Research Learning Institute® (CRLI). The MND CRLI is a two-day program that educates attendees on the research process and development of new treatments. The object of the workshop is to empower attendees to be strong advocates and contribute their lived experience voices to the field of MND.

This two-day program will take place on 11-12 November via Zoom and spaces are limited. People living with MND, current and former caregivers, and family members are encouraged to apply. For more information and to apply, please visit www.mndaustralia.org.au/CRLI or scan the QR code above.



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

41st Annual General Meeting

Monday 24th October 2022 at 11 am

The AGM will be held at 265 Canterbury Road,
Canterbury, and via video link.
A link will be sent to those who RSVP.

The AGM will:

- Confirm the 40th AGM minutes
- Adopt the Treasurer's Report and Financial Statement for 2021/2022
- Appoint the auditor
- Elect State Council members

Our guest speaker will be Jenny Dexter, speaking on her experience of her husband's journey with MND, her experience as a carer, and why her involvement in our recent Larapinta Challenge Event was so meaningful and important for her.



Please **RSVP** by Wednesday 19th October 2022.



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

WALK TO D'FEET MND IS BACK!

It's time to get your walking shoes ready! "Walk to D'Feet MND" are cherished events that provide opportunities for our community to come together and show support for people impacted by MND.

We are very excited for the three upcoming "Walk to D'Feet MND" events being held at various locations across Victoria in the next few months. We look forward to seeing our Walking Warriors at these events!

TICKET PRICES

Adults: \$40.00

Child (under 18): \$20.00

Family of 4*: \$100.00

*1 adult and 3 children, or 2 adults and 2 children

Every registration includes a free "Walk to D'Feet MND" T-Shirt.



Walk to D'Feet MND Latrobe Valley



When: Sunday 2nd October 2022
10:30 am – 5:00 pm

Where: Victory Park, Traralgon VIC 3844

The Latrobe Valley Walk has two distance options - a 0.4km route and a 1.2km circuit, both of which are wheelchair and pram friendly. Limited on-site disabled parking is available for people with MND, and there is plenty of street parking available nearby.

Register at www.mnd.org.au/events/61/latrobe-valley-walk-2022 or scan the QR code above.

Walk to D'Feet MND Bendigo



When: Sunday 20th November 2022,
10:30 am – 12:30 pm

Where: Lake Weeroona Park, Bendigo VIC 3550

The Bendigo Walk is wheelchair and pram friendly. Complete 2 laps of the lake or 2.8km. Disabled parking is available for people with MND.

Register at www.mnd.org.au/events/74/bendigo-walk-2022 or scan the QR code above.

Walk to D'Feet MND Melbourne



When: Sunday 27th November 2022,
9:30 am – 12:00 pm

Where: Princes Park, Carlton North VIC 3054

The Melbourne Walk is an easy 3.5km flat walk around Princes Park, wheelchair and pram friendly. Disabled parking is available for people with MND.

Register at www.mnd.org.au/events/73/melbourne-walk-2022 or scan the QR code above.



MND VICTORIA

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