Spring 2022

MNDnews

The newsletter of the Motor Neurone Disease Association of Tasmania

Stick Fishing to Stick it to MND

mnd Tasmania

Until there's a cure, there's care

MESSAGE FROM THE PRESIDENT

Welcome to our Spring edition of the newsletter. This time of year brings renewal and the biggest event on our calendar – the Walk to D'Feet MND! We cover the event in more detail in the following pages but be sure to mark out the 16th of October on your calendar to join us once again for a fun day at the Queen's Domain.

We have the usual great prizes up for grabs, and we are using our own website to manage team fundraising and donations this year which should be much easier for you. Get in touch if you'd like to be involved.

We have a new member on our fundraising team that we will introduce to you shortly. In the meantime, keep an eye out for some exciting new events.

We have been fortunate enough to continue our partnership with Southern Cross Austereo (SCA) who are supporting us with another year of radio advertising and interviews so that the public can learn more about the people involved in the battle against MND. Thank you again to SCA for your generosity. Keep an eye out for our new television commercial too!

Tracey Dickson (Board Member of MND Tasmania and MND Australia, and Professor at the Menzies Institute) will be attending a meeting with Federal MPs and Senators at Parliament House in Canberra in September. Other State-based Associations and MND Australia will be there too. It's a great chance to meet with Government to educate them about MND and the needs of our members. We'll be sure to keep you posted on how the event goes.

We love to hear from our members, so please don't hesitate to get in touch. Please write and share your stories, opinions, questions, or any thoughts about this newsletter. Write to me at info@mndatas.asn.au and see our contact details on the back page.

Kate Todd
President

MND TASMANIA SAYS THANK YOU

Evandale Primary School Ice Bucket Challenge

We are so grateful that eight SLC members and Mrs Gadsby (Principal) nominated themselves to do the Ice Bucket Challenge on their last day of the term - Friday 8 July 2022.

For every $20 raised, one SLC member had a bucket of icy cold water tipped onto their heads! They even organised anonymous bids for those that wanted to compete to tip a bucket of water onto someone's head. The Evandale Primary School community also raised funds from students on their 'Wear PJs to School' day. We were very excited to use the new MND Tasmania website to help fundraise for the event.

Overall, an incredible $1,605 was raised, smashing the original target of $180. We thank you all for your wonderful effort and for donating to MND Tasmania!

Stick Fishing Competition

Shane Ling, one of MND Tasmania's biggest supporters over the years, runs the Stick Competition every year in memory of his fishing partner and good friend, Gary Alexander, who used to run the competition. Gary passed away with MND a few years ago, and Shane was with him every step of the way, taking Gary fishing on his boat for as long as was possible.

In the beginning, the Stick Competition was very small, with only a dozen or so people competing for a few small prizes. After Gary was diagnosed, Shane and the group decided to ramp up their efforts and have grown the competition into the successful event that it is today.

Every year they raise thousands of dollars for MND Tasmania, and we are very grateful for their efforts, and for the continuous support we have received every year!

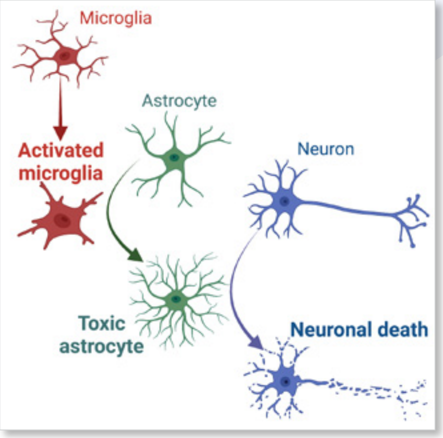
Acknowledging Peter MacFie

We mentioned Peter MacFie, who passed away with MND, in our previous newsletter. Recently his brother, Robert, let us know of a recording of a lovely performance made in 2006 by Peter at Dr Kate McPherson's 50th birthday celebrations. Finding this video was bittersweet as Kate also had MND, passing away in 2007.

'Let It Be Me' features Peter MacFie - guitar and vocals, Louise Oxley – vocals, and Ian Beecroft 'Croft' - flute and vocals. Thank you for sharing this with us, Robert!

Link to performance: www.youtube.com/watch?v=iRMH4AtGj44 or scan the QR code on the right.

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.

MND RESEARCH

The Symposium that connected MND Researchers with people living with MND!

by Lyzette Matthews

On the 28th – 30th of April, FightMND and MND Research Australia hosted the inaugural Australian and New Zealand MND Research Symposium in Brisbane, Australia. Attending this conference was a unique opportunity for me to gain insight into what is likely to become the forefront of MND research, and to hear first-hand from Australian and New Zealand researchers about a broad spectrum of research topics, with updates on current preclinical, clinical, and current treatments.

As a new PhD student focusing on preclinical MND research, hearing directly from those living with MND, and how grateful and supportive they are of us as researchers, was an incredibly eye-opening and heart-warming experience. As my lab's work is involved in the 'behind the scenes' research, we do not get much interaction with those with a lived experience of MND, so being able to put our research into a wider context with the work from other researchers across Australia and New Zealand was extremely insightful in identifying how on-track we are in finding a potential cure. Whilst preclinical and clinical research is extremely important, ensuring that MND patients are comfortable and well supported in the final stages of this unforgivable and fatal disease is an obvious priority. Learning about the current physical treatments available for those living with MND, and what is being done to improve their quality of life as a 'right now plan', was also an avenue of research I was particularly interested in.

Amongst all of this, the greatest takeaway from this experience came not only from the opportunity to attend, but to present a poster of my honours' work and, in doing so, I made several new connections (and potential future collaborations) with researchers from across Australia and New Zealand – those with whom I am now connected on Twitter! Lastly, a key presence during the symposium was Claire Reilly, a research advisor for MND New Zealand and also a MND patient. She made a significantly large impact due to her consistent advocacy for creating a 'trans-Tasman research bridge' between Australia and New Zealand. Hopefully, with the continued support from FightMND and MND Research AUS and NZ, events such as this will help to establish future collaborations and ground-breaking research. I would like to thank and acknowledge MND Tasmania for funding my travel.

Everyone at MND Tasmania is passionate about MND research. One of the most difficult things about MND is that there is no known cause, treatment, or cure, so research into these areas is essential.

Lyzette Matthews is a PhD Candidate at the UTAS Wicking Dementia Research and Education Centre, and below is her testimony after attending the AUS & NZ MND Research Symposium through the support provided by MND Tasmania.

UPCOMING EVENTS

Walk to D'Feet MND is back!

We are currently planning our Walk to D'Feet MND 2022 and it is shaping up to be one of our best yet! Walk a lap of the track or run the full 5km. All funds raised will stay in Tasmania to care for and support those currently living with MND/KD.

When: Sunday 16th October 2022 | 10:00 am - 1:00 pm

Where: Upper Domain Rd, Queens Domain, Hobart, Tasmania

Register at: www.mndatas.asn.au/events/4/walk-to-dfeet-mnd or scan the QR code on the right.

Registrations are now open on our website! And we are hoping that now that we have our very own site, registrations will be much easier than in previous years. Sign-up and give us some feedback on what you think of the new event platform!

Have a look at the wonderful list of raffle prizes below!

We would love to thank our amazing supporters that help us make this our biggest fundraiser.

Stay & Play

One night's accommodation in a recently refurbished Harbour view room at Hobart's Wrest Point Casino, including breakfast for two and a $200 voucher for Point Revolving Restaurant. Plus a Pennicott Wilderness Journey voucher for two adults, and three Bottles of Bream Creek Wine. ***Total value over $1,000***

Local Loot

Farmgate Hamper plus six Bottles of Glaetzer-Dixon red wine. ***Total value over $800***

Voucher Bonanza

Anytime Fitness 6-month membership, plus a $100 Shambles voucher and a $100 Hill Street voucher. T***otal value approximately $800***

- Two pairs of **Blundstone Boots** plus a **Family pass to ZooDoo**. ***Total value over $600***
- One night's accommodation at the **Woolstore**, including breakfast for two and parking. ***Total value approximately $550***
- Two pairs of **Blundstone Boots**. ***Total value approximately $500***
- **Tupperware pack** plus a $250 Harvey Norman voucher. ***Total value approximately $420***
- **Elite Appliance** Smeg Breakfast Pack. ***Total value approximately $299***
- **Fuller Bookshop** $50 voucher plus Daci & Daci voucher. ***Total value approximately $100***
- **State Theatre** tickets x 2 plus Daci & Daci voucher. ***Total value approximately $100***

UPCOMING EVENTS

MND Support Groups

The MND Support Groups in Tasmania are independently run by community members for community members. We appreciate their willingness to devote their time and volunteer for such a worthy cause.

North West MND Support Group

The NWSG in Ulverstone invites all MND Tasmania members and supporters to its meetings.

WHEN: At 11 am on the first Wednesday in the month, except January

WHERE: Ulverstone Returned Servicemen's Club Back Room, 21 King Edward Street, Ulverstone

CONTACT: Junene Stephens is the secretary and can be contacted on 0428 252 763 or email: jstephens@berendsen.net.au

Northern MND Support Group

This is an informal catch-up style group, where members come together to talk all things MND and Kennedy's Disease, as well as share experiences and helpful tips. The group have currently ceased in-person meetings, and are instead communicating via a private Facebook group. **You can request to join at www.facebook.com/groups/337315731509176 or scan the QR code on the right.**

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 Tasmania.

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!

Please register online at www.drinkteaformnd.org or scan the QR code on the right.

Raise awareness and funds for Motor Neurone Disease while catching up with friends...

UPCOMING EVENTS

MND Tas Commercial

Have you watched our new commercial? It is a powerful message, and we sincerely thank all involved in the making of it! Your kindness and bravery are always inspirational!

Check out the video at https://youtu.be/lWa41I18wgI or scan the QR code above.

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.**

Have you been diagnosed with MND?

We provide useful and informative information, assisting with equipment needs, raising the profile of MND in the community and raising funds for research into MND.

MND Tas Website

We hope that you have visited our new website and that you are loving it as much as we are! It not only has a fresher look and feel but it also makes your experience while using it much easier. It is an information hub for members as well as a supporter hub with specific information and resources for Health Professionals.

You can find us at www.mndatas.asn.au

Please let us know your feedback and suggestions by sending us an email at info@mndatas.asn.au

GIVING

Bucket List Wish Campaign Appeal

MND Tasmania has focused on care and support programs to improve the lives of thousands of Tasmanian families impacted by MND for the past 36 years. But there is one thing we are yet to tick off our list ... our new BUCKET LIST WISH PROGRAM.

Living with motor neurone disease is incredibly hard for those diagnosed, and for their loved ones. This new initiative and pool of funds will be able to provide experiences, gifts or services to help make a wish come true, and give families a chance to create memories that they can cherish together during an incredibly difficult time.

About the Bucket List Wish Program

The Bucket List Wish Program provides the opportunity for those diagnosed with motor neurone disease to have a wish granted. Every wish is unique – it could range from sky diving to a family weekend away, to trying a new hobby or watching your favourite football team play. There are some wishes that may not cost anything, such as meeting your favourite celebrity.

This is where we need YOUR help. The more we raise, the more wishes we can grant.

We kindly ask you to consider a donation to MND Tasmania. Your gift will help to make a wish come true. Help us to add another layer of support to the services that we have been providing since 1986.

Visit www.mndatas.asn.au/bucketlistwish or scan the QR code on the right.

Thank you to those who have donated so far to our Bucket List Wish Appeal. All proceeds raised fund a wish for someone living with MND.

Thank you for your support!

MND Tasmania is a volunteer organisation receiving no government funding. We are dependent on the generosity of our community and would like to acknowledge and sincerely thank our donors.

We are grateful for the support we received from Bridgette O'Neil (Civilscape Contracting Tasmania), Birralee and Districts Pony Club, and the continued support we receive from Kevin Burgess. We have also received donations in memory of Stephanie Hart, Bill Dermody, and David Greenwood.

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.

References

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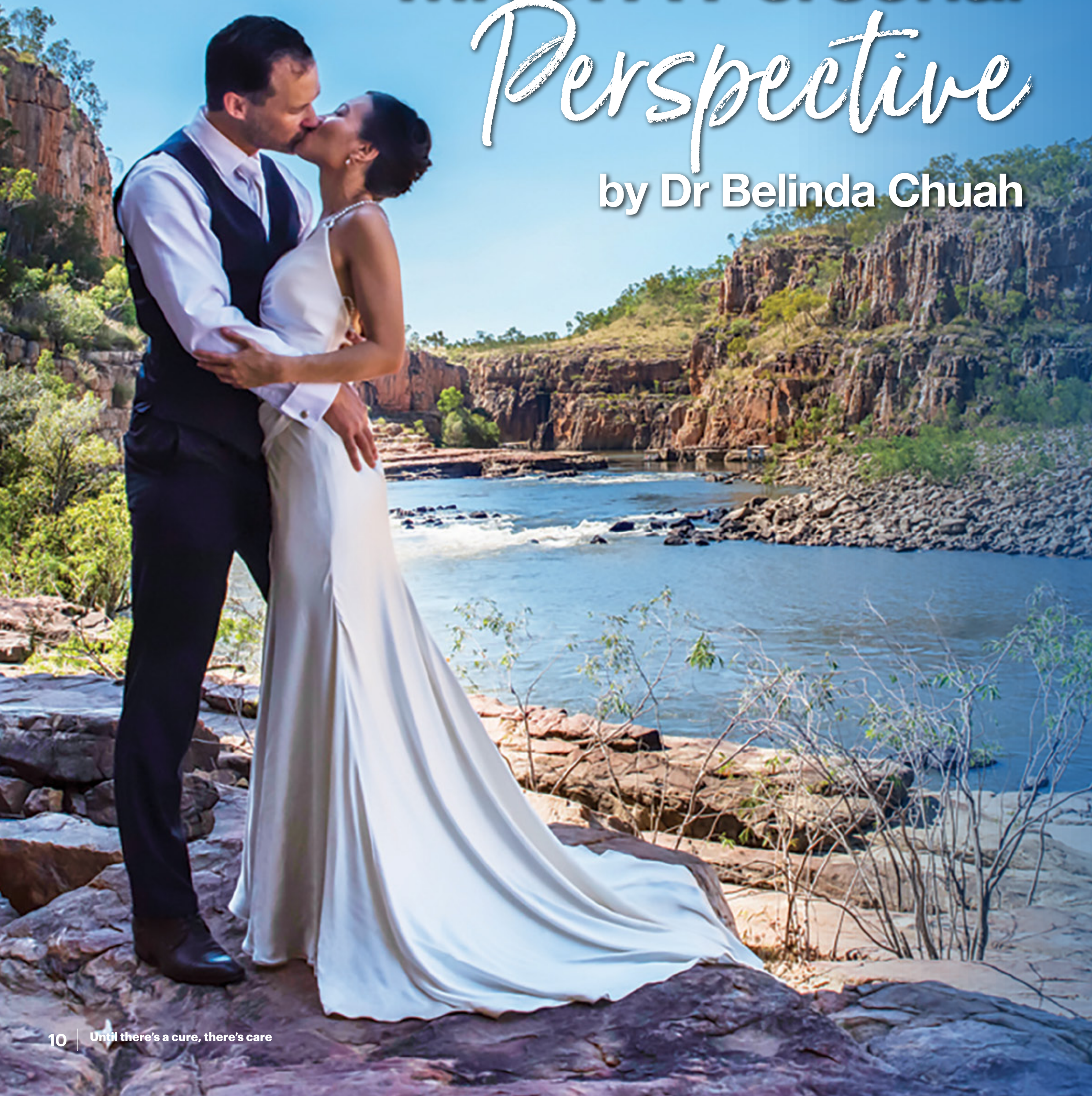
Find out more about Sleep and MND here by visiting www.mndaustralia.org.au/articles/sleep-and-mnd or scan the QR code on the right.

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 carpel tunnel'. I replied, 'well that's not good' to which she responded, 'yes I too was hoping it would be carpel 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.

MND ADVISORS AND NDIS SUPPORT COORDINATORS

Client Numbers

We are currently supporting 42 registered members:

North West Region Tasmania	8
North Region Tasmania	18
Southern Tasmania	16
TOTAL	42

CURENTLY SUPPORTING

42

REGISTERED MEMBERS

DELIVERED

750

HOURS OF SERVICE

in the last quarter

MND Advisors and NDIS Support Co-ordinators

Northern Tasmania: Emma Forsyth (Mon-Thur):
p: 0456 182 551 or e: eforsyth@mnd.org.au

Southern Tasmania: Jenny Fuller (Tue, Wed, Fri):
p: 0412 599 365 or e: jfuller@mnd.org.au

Team leader: Kim Hamilton (Tue - Fri):
p: 0422 149 445 or e: khamilton@mnd.org.au

FREECALL 1800 777 175

This number is at the MND Victoria office (Monday - Friday, 9 am - 5 pm). To assist the volunteer receptionist, please say that you are calling MND Tasmania. If you wish to speak to a Board member or an MND Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.

Right: Emma Forsyth
Below: Jenny Fuller

MND Tasmanian Board Members:

MND Tasmania has a volunteer Board and no paid staff.

President: Kate Todd

Senior Vice President and Fundraising: Michelle Macpherson

Vice President & Public Officer: Chris Symonds

Secretary: Lucy Polizzi

Treasurer: Julie Driessen

Member Support: Elisa Howlett

Ordinary Directors: Tracey Dickson, Steve Issac

Ex-officio Support: Libby Cohen

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.

MND TASMANIA

PO Box 379, Sandy Bay,
TAS 7006 Australia

Freecall: 1800 777 175

Charity ABN: 21877144292

✉ info@mndatas.asn.au
www.mndatas.asn.au
f www.facebook.com/MNDTas