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# MND News

Summer 2024

Magazine of the Motor Neurone Disease New Zealand Charitable Trust



## Living well with MND

“I found that focusing on what truly matters helps.”



## Message from our Chief Executive

Kia ora koutou,

A strong theme that I feel really comes through this edition is the importance of taking care of both mental and physical health, for living well with motor neurone disease (MND). I feel a strong sense of pride when I read all of the contributions every edition, but this month in particular there is a real strength that comes through from every one of our contributors. The common thread about taking care of your mental wellbeing is so important, and you can read more about some practical tips to do this throughout this season's magazine.

As we head towards the festive season, it is a timely reminder to hold your loved ones close and for those living with MND, to make the most of what you can do.

This edition, we also hear from MND NZ Research Advisor Dr Natalie Gauld, who recently travelled to Australia for an international MND research symposium. While Natalie has returned home brimming with ideas about new international research, and with good connections for bringing clinical trials to New Zealand, she does remind us that this is a complex disease with a cure unlikely soon. Natalie also provides a very helpful assessment of some of 2024's global MND research developments.

For us, this demonstrates why our work to support you, the MND community, matters as much as ever. We are a small organisation, supporting a small community with big challenges. We do this through the support of our donors and sponsors, and we are privileged to be connected to people right across the continuum of the MND community through service, advocacy, and research. Thank you for all your support throughout 2024, we couldn't do what we do every day without your efforts.

This month we also hear from Kiwi Jon Beardmore who is on a round-the-world mission to reconnect the world, and at the same time raise funds and awareness of MND in memory of his Dad, Eric, who died in 2022 after living with MND for eight years. While donations make a difference, we know that not everyone is in a position to donate financial support. Jon's fascinating story shows there are other ways to help, and raising awareness is one of those ways.

We are also preparing for the annual **Walk to defeat MND** which will be taking place on Saturday 22 February in Auckland, Wellington, and Christchurch. This incredible day of solidarity, support, and remembrance is an opportunity for our community to come out in the boldest cornflower blue (the colour of MND) in support for those living with MND.

Thank you for being with us, and I wish you and your whānau a safe festive season.

Ngā mihi nui

Mark Leggett



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Cover: Ella Kahu, who hasn't let her MND diagnosis stop her travelling, has found ways to cope, and make sure she can still make the most of every day.

## A special thank you

Our heartfelt appreciation goes out to the below for their kind support in making the MND News Summer 2024 issue a reality.

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*If you're moving, please let us know your new address so that you don't miss the next issue of MND News.*

## Disclaimer

This magazine provides information only. Content should not be taken as a recommendation for any individual, or as an endorsement by MND NZ. We strongly advise you discuss options with those who know you best before making any changes to your routines.

## This edition we're inspired by:



### Tony Treloar

**Tony** took on the challenge of the Auckland Marathon, joining 'Team MND' after reading about others' efforts in the Winter magazine. Having MND, completing

5kms would be like running two marathons. You can see an inspiring video of Tony crossing the 5km finish line with the support of his son, Josh, on the Auckland Marathon Facebook page.

### Brent Thompson

**Brent** has been living with MND for 11 years but has kept his passion for flying alive. With the help of his technical friends and wife Jess, Brent has been able to develop all sorts of technical advancements to allow him to continue doing what he loves. Read Brent's story on our website.



### Pamela Glading

**Pamela** has been living with MND for 17 years, but says that every day is a blessing. She shared chapter 5 of her memoirs, *A Thousand Cycles Of The Moon*, with us and you can read her story on the next page.



# Adjusting to life with MND: Pamela's story

Pamela Glading, former National Director, UNICEF New Zealand, Yoga Tutor and an extensive traveller, has sent us Section Five of her Memoirs, *A Thousand Cycles Of The Moon*, in which you can read the ways she has adjusted to living with motor neurone disease (MND) and how much she appreciates the ongoing support from Motor Neurone Disease NZ.

We have elaborated on this chapter, highlighting some of the ways she's adjusted and continues to live a happy life but albeit in a slightly different way.



Wellington's Pamela Glading has lived with MND for 17 years, and while she has now largely lost her mobility, her outlook on life, and her positivity and appreciation for the beauty that surrounds her is stronger than ever.

She says that her approach to living well with MND has come down to never dwelling on what is to come, or asking 'Why me?'; "There seems to me to be no value in feeling angry or asking 'Why me?' There is no answer."

Instead, she stays focused on the positive. She has surrounded herself with positive, supportive, compatible, empathetic, cheerful people who bring her much love and laughter. "I have amazing family, friends, support workers, medical professionals and an adorable cat whose company, assistance and humour lift my spirits every day."

She also takes the time to cherish her precious memories of a life well lived. "I heartily enjoy my memories and focus on the many wonderful things I can still do. I am enormously grateful to be having an extremely interesting, varied, rewarding life, full of opportunity, excitement and a great deal of joy. I am enormously grateful to live in a comfortable country with excellent medical care and support."

For Pamela, there are good days and bad days, and she has learnt to manage her limited energy and confine stress. "Almost 17 years later, although I am mostly bed bound, can still only safely walk very short distances, need to carefully manage my energy, have good days and not such good days, I am very grateful I am still here. My initial rapid progression of MND has dramatically slowed and I am still thoroughly enjoying life."

"I have never felt sorry for myself and find it is far more healthy to be accepting, optimistic and confident that one's life is taking the course it is meant to."

Pamela says she counts her blessings and focuses on the things she can still do – from spending time with her family and friends, watching the ever-changing garden outside her large bedroom windows, with trees, flowers, and birds that differ every day, through to reading, writing, music, and watching ballet, theatre, dancing, films and concerts from her 'large, comfortable bed'.

"With a smartphone, smart TV and Chromecast, I enjoy the rapidly advancing technology which keeps me in touch, every day, with current events and friends all over the world. I have special correspondents whose frequent, lively, stimulating and amusing interaction I treasure. I have been brushing up my French using an excellent language app and have committed to daily lessons. Every day, I am very busy, enjoy the humour which surrounds us all – and there is never enough time in the day."

Pamela's whole outlook is grounded in the philosophy of yoga, and while her physical practise is now limited, she continues to focus on techniques such as effective breathing and mindfulness, which she says has helped her enormously.

"Anger and self-pity can be enormously unhealthy and destructive, as is a feeling that one needs to "fight" something they cannot control which can cause self-defeating and harmful stress. It is far more healthy to face the challenges head on, accept the reality of the situation, find out all there is to know about the possibilities and likely developments, and calmly do everything possible to help yourself and your loved ones."

"In the last 17-years I have learned a great deal about myself and others, and have travelled into another of life's dimensions. It is extremely interesting to learn how adaptable we can be and how much joy there is without constantly rushing about. I have learned to discipline myself not to ever dwell on the things I can no longer do or change. Instead, I invest my time and energy in finding great pleasure in the things I can do. I feel very grateful for the time I have to deepen my relationships with my loved ones and to watch my grandchildren grow."

"I have discovered that physical constraints can enhance opportunities for the spirit to soar. I am learning and experiencing so much more about patience, the value of humour and humility. I have the time and opportunity to more deeply explore my special relationships and interests. I treasure each day which brings opportunities to learn, love and laugh."

■ To purchase a copy of Pamela's memoirs, *A Thousand Cycles Of The Moon*: <https://www.copypress.co.nz/shop/a-thousand-cycles-of-the-moon/>

# Taking care of your wellbeing

**Living with motor neurone disease (MND) can bring many challenges, not just physically but also emotionally. It's natural to feel overwhelmed, stressed, or anxious at times, and taking care of your mental wellbeing is essential for living well with MND.**

## **Acknowledge Your Feelings**

When dealing with a life-limiting illness, it's common to experience a range of emotions, including sadness, anger, and fear. These feelings are normal and acknowledging them can help you process and manage them more effectively. Try to express your feelings openly with someone you trust – whether that's a friend, family member, or health professional. Many people find that talking about their emotions helps lift some of the mental weight.

## **Build a Support Network**

Connecting with others can be a great source of strength. Your support network might include your family, friends, or others living with MND who understand what you're going through. Sharing experiences with others who have MND can be comforting, as it reminds you that you're not alone. You may also want to reach out to local support groups or online communities for additional support and understanding. MND NZ can help connect you with a group or individual in your area.

## **Stay Connected**

Open communication with your healthcare team is vital. They can help you manage both the physical and emotional aspects of MND. If you're struggling with your mental health, let them know. They can guide you towards resources like counselling or support groups and may be able to suggest other techniques or therapies to help you manage stress, anxiety, or low mood.

## **Practice Self-Compassion**

Be kind to yourself and allow yourself time to adjust to new changes as they come. Don't be too hard on yourself if some days feel harder than others. Practicing mindfulness or relaxation exercises, such as deep breathing or meditation, can help you stay focused on the present moment, reducing feelings of stress or worry about the future. For some inspiration, you can read about how Pamela is doing this on the left.

## **Celebrate Small Wins**

Setting achievable goals can give you a sense of purpose and accomplishment. These goals don't

need to be big—something as simple as reading a book, listening to your favourite music, or spending time with loved ones can bring positivity into your day. Celebrating small successes helps build resilience, reminding you of the things you can enjoy and achieve.

## **Seek Professional Help If Needed**

If you feel persistently low, anxious, or have trouble coping, reaching out for professional mental health support can make a difference. Talking with a mental health professional like a psychologist or counsellor can provide you with tools to manage difficult emotions and offer a safe space to talk through your concerns. Remember, seeking help is a sign of strength, not weakness.

Caring for your mental health is an ongoing journey. With the right support and strategies, you can navigate the challenges of MND and focus on what matters most – living a life filled with meaning, connections, and support.



# Life after diagnosis: Rosemarie's story



On the 4th of January 2024, the lives of the Johnson family were changed forever. After experiencing a slew of symptoms, Rosemarie was eventually diagnosed with ALS, a common variant of motor neurone disease (MND). For many, living with MND comes with many challenges and Rosemarie's experience brings to light the behavioural changes, frustrations, and limitations that follow a MND diagnosis.

This is a story of agency and conviction, but mostly of hope. Rosemarie's story has been shortened for clarity and length. Warning: this story discusses assisted dying.

Looking forward to retirement, Rosemarie's 70th birthday was on the horizon. She aspired to re-enrol in university to tackle her lifelong dream: a PhD in either Sociology or Anthropology. However by January 2024 after meeting with multiple specialists, her life, in her words "came crashing down".

After months of perplexing symptoms, Rosemarie found it extremely hard to perform even the simplest of tasks. She was losing focus, brain fog, and found generally very easy tasks like brushing her teeth or making a cuppa became difficult. She found herself in pain, dealing with lower back issues, and her right hand was unable to grip that very cuppa she had spent so much time making.

Rosemarie visited her doctor who, after a quick assessment, assured her these symptoms were treatable and easily explained. However, it should be known Rosemarie never took one answer as gospel, so she pushed for a second opinion with a secondary GP in the same practice. After the secondary GP also dismissed her concerns, Rosemarie successfully pressed them for a specialist referral. The specialist immediately recognised the gravity of the situation, insisting that Rosemarie see a neurologist. Later that month, her diagnosis had a name, it was motor neurone disease (MND).

Like many others in the same boat, the diagnosis came as a devastating blow, not just for her but also for her husband and her two daughters. Despite their own research, MND mimicked many other neurological and muscular conditions. Following the diagnosis, Rosemarie and her family monitored her symptoms closely. However, within four-months of

her diagnosis she was provided a range of mobility solutions to help her navigate (quite literally) the rapid decline of her movement.

Fit for Sir Stephen Hawking himself, Rosemarie received a bespoke motorised wheelchair that she could operate with her head movement, as her hands and fingers lost their function. Following this, the family sought funding for full-time at-home care and eventually employed a nurse to assist with Rosemarie's decline in the day; later that care would extend to the night.

While she was told a blood test could reveal a hereditary link, Rosemarie swore off getting this to avoid her daughters carrying the weight of this worry. However, not one to sit around, Rosemarie's love of learning propelled her to understand all the complexities of MND. With her custom wheelchair in tow, Rosemarie attended her first fundraising event organised by Motor Neurone Disease NZ: Cuppa Tea for MND, in Auckland. She met several others with varying degrees and forms of MND – from bulbar palsy to ALS. This visit gave her a real sense of perspective about how this disease affects people in different ways.

Feeding into her existing knowledge about her worsening condition, she watched documentaries and kept track of any scientific advancements about MND. If not in time to help her, then maybe to help those in the future who would need a breakthrough. She made it her mission.

It had now been a few months of living with MND, and Rosemarie observed that she was now more practical and pragmatic than ever. Her inhibitions

# Surveys to be launched in the new year

vanished, she was headstrong. MND had not rid her of her ability to be a social butterfly, in fact, quite the opposite. While MND had taken so much away already, including her mobility, it had given her a chance to say what she wanted to, and to use her voice when it counted the most.

As she hoped for more answers, she was told this condition boasted a linear decline. At this turning point, Rosemarie made a case for assisted dying and jumped (metaphorically of course) through the assessment hoops. Shortly after making this tough decision, Rosemarie and her husband were struck with Covid-19. Having dodged it for almost four years, with the added lack of mobility and consistent pain of MND, Rosemarie's recovery was tough. But upon her recuperation, and as weak as she was, she made the brave decision to bring her special date forward – one day after the anniversary of India's Independence, an event that resonated deeply with her.

But her story doesn't end there. A big believer in giving back to science, Rosemarie insisted on donating her organs to those in need. Contacting NZ Blood Service and Organ Donation New Zealand (ODNZ), she again jumped through the necessary hoops to ensure this would be done. Finally, she arranged for her brain tissue to be taken for research purposes to the University of Auckland. She remained hopeful her brain cells may provide some clues about MND and a possible cure in the future. Her vision was to leave a lasting legacy, and in particular, give back to the countless organisations in New Zealand that helped her through it.

On her chosen date of August 16th, 2024, Rosemarie took her final breath. While her 70th was on the horizon, the sun set on Rosemarie's life just shy of 69 years old. Her star however, shines just as bright.

■ Story as told by Rosemarie Johnson (BA, MA(Econ), GDip (Banking), GDip (Social Anthropology)).

Rosemarie's story highlights the different ways people can choose their response to topics such as assisted dying, genetic testing, and organ donation. MND NZ encourages all people with MND to be informed and empowered in their decision-making. We admire the bravery with which Rosemarie faced a fast progression with MND, and her desire to share her story.

**M**otor Neurone Disease NZ will be launching two new surveys early next year, so that we can improve our knowledge of the impacts, experiences and needs of people with MND in NZ.

The survey findings will be key in understanding what is working well and what is not, what is happening in different districts, and how New Zealanders with MND are affected by it, including their needs and management.

The summarised findings will:

- Help us better understand MND in New Zealand
- Help Motor Neurone Disease New Zealand advocate for the MND community
- Help people working with MND patients understand their needs better
- Encourage more research on MND in New Zealand

Internally, we have nearly completed the development of the two surveys – one for people with MND, and another for families and carers, and we expect them to be out in early 2025, depending on the ethics review process.

The patient survey is longer because MND is complex and there has been very little research like this in New Zealand before. The family carer survey is smaller, but equally important as we seek to better understand the impact of MND across New Zealand. As health research funded by the Health Research Council, these surveys require preparation input, and ethics review.

We thank all who have provided input into the surveys already – your time and views have been very valuable.

The survey information will be kept confidential, and only seen by the research team, with no names collected.

This research is led by Dr Natalie Gauld, Research Advisor and Best Practice Advocate, MND NZ, supported by other health researchers, neurologists and other health professionals. We look forward to getting these surveys out early 2025 and getting a better understanding of the impacts, experiences and needs of MND in New Zealand.

# Update on ALS studies



The past 12 months have held a lot of promise for research into ALS (the most common form of motor neurone disease), with results due from a couple of very promising studies. Here, Dr Natalie Gauld, Research Advisor at Motor Neurone Disease NZ, shares an update on these studies.

## AMX-0035, or Relyvrio

This year, we expected results from a large study of 664 patients, looking at the impacts of AMX-0035, also known as Relyvrio. AMX-0035 contains two drugs: sodium phenylbutyrate and taurursodiol (also called Tauroursodeoxycholic acid or TUDCA, a dietary supplement). An earlier small study showed good results, and on this basis the product was allowed conditional approval in the US and Canada while awaiting the large study to come through. The European Medicines Agency was less convinced, so it remains unregistered there. In March 2024, the large study results came through showing no benefit of AMX-0035 on ALS. My huge disappointment at not getting on this study in 2022, after I was diagnosed, has now been replaced by a big disappointment that this promising medicine has failed to deliver for our community. Unfortunately, this is very typical in ALS, and drugs that look promising in animal studies or early human studies often do not prove to be beneficial in the larger studies.

## TUDCA and Edaravone studies

A second study that also looked promising was for TUDCA alone (one of the two ingredients in AMX-0035). But it was no surprises after the failure of AMX-0035 that TUDCA alone also failed to show benefit in the 300-person European trial.

A further study of interest was for Edaravone, a drug available in the US for ALS, but turned down in Europe. Edaravone has been tough to administer, requiring patients to travel to clinics for a daily intravenous infusion into the bloodstream for 10-14 days, before having 14 days off, then repeat. This drug is also extremely expensive. Development of a liquid version swallowed or given through a PEG

(feeding tube) would have reduced patient burden, but study results in 2024 found it was not effective.

On a brighter note, tofersen, for SOD1 gene mutation ALS, was approved in Europe this year, following approval in the US in 2023. Also in 2024, a study was published following 26 patients in Germany whose average progression rate slowed from 0.41/month before starting the treatment to 0.11/month afterwards.

MND NZ recommends that people with ALS are offered genetic testing. If they have the SOD1 gene mutation there may be the opportunity to access tofersen under a compassionate access programme.

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**“Lighthouse II study has finished recruitment worldwide. This study of 3 antiviral treatments includes 20 patients from New Zealand.”**

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Lighthouse II study has finished recruitment worldwide. This study of 3 antiviral treatments combined (Triumeq, usually used for HIV) includes 20 patients from New Zealand, and is supported financially by MND NZ. We look forward to seeing the results of this trial in due course.

It is worth remembering that getting medicines approved in Europe is a good sign that the drug has proven the benefits are greater than the risks. Usually, drugs still need to be approved in New Zealand and funded by Pharmac to be free for people with ALS here. Tofersen is not yet approved here, nor funded, but may be available free from the company through compassionate access. Edaravone is not approved or funded in NZ, and we are unaware of any compassionate access scheme.



# MND Research Symposium

The 2024 Australia and New Zealand MND Research Symposium in Melbourne brought together MND researchers to share latest findings and insights on this complex disease, with the hope of uncovering solutions for people with MND. Dr Natalie Gauld, Research Advisor at Motor Neurone Disease NZ, shares her summary of the symposium.

Notable presenters included Professor Kevin Talbot from Oxford, Dame Pamela Shaw from Sheffield, Professor Ammar Al-Chalabi from King's College London, and Professor Jeffrey Rothstein from Johns Hopkins. The symposium's timing coincided with an MND global roundtable, which meant Melbourne hosted an unprecedented number of international MND experts presenting on clinical trials, genetic studies and potential new treatments.

## A Complex Disease with No Cure in Sight

A consistent message throughout the symposium was that while there has been progress in understanding MND and trials, a cure is still a distant goal. Experts do not anticipate a cure within the next 20–50 years. More than 170 potential treatments have been tested in clinical trials without a cure or significant change to patient outcomes. However, ongoing research into genetic and environmental factors may shed more light on the disease and help target new treatments.

ALS (the most common form of MND) is highly complex with many unknowns about the genetics and environmental factors and the pathway to getting the disease. Research on environmental factors is very challenging because there are so many things in our environment that we may not be asking about, and it is expected that multiple different factors are involved for each person with MND. The disease varies considerably between people and treatment responses can take time, with some trials not running long enough to demonstrate effectiveness.

The blood-brain barrier, which protects the brain from toxins, is another significant challenge for treatment. This barrier prevents many drugs from reaching the brain, making it harder to develop



Panel discussion taking place at the symposium

effective treatments that reach where they're needed.

## Antisense Therapy and Tofersen's Success

Presenters spoke of the breakthrough success of Tofersen, a therapy targeting the SOD-1 gene mutation found in around 2% of sporadic ALS cases and 12% of familial ALS cases. For people with this mutation, Tofersen has shown significant potential, reducing the rate of clinical decline and improving respiratory function, quality of life, and survival rates when started early.

Following Tofersen's success, other antisense therapies are being trialed in other gene mutations. Unfortunately, not all trials have been successful; for example, studies of WVE-004 and BIIB078 in C9orf72 gene expansion and ION541 which targeted ATXN2 repeat expansions did not show benefit.

## Combination Therapy and New Approaches

Research is increasingly pointing to a combination, or "cocktail," approach to treating ALS. The complex pathways involved suggest that tackling different areas with multiple drugs may be more effective than a single-drug treatment. For example, a study presented at the symposium tested 107 previously trialled compounds on motor neurone cells derived from people with ALS. The combination of riluzole, memantine, and another unnamed compound

produced better results than any of the three drugs alone, demonstrating how combination therapy may offer new possibilities.

Most MND research remains preclinical, involving studies with cell models and animal trials to understand drug effects before human testing. However, researchers are continuously evaluating potential drug targets, such as hypermetabolism – a common issue in MND where muscle cells consume more oxygen than normal. The symposium included promising findings on trimetazidine, an angina drug tested on mice to reduce muscle hypermetabolism, as well as Ambroxol, a cough medicine that restores lipid metabolism and is expected to enter Phase II trials soon in Australia.

### **Gene and Environmental Factors in MND**

One well-accepted model for ALS involves six steps, each influenced by genetic and environmental factors. This is why ALS risk increases with age. The genetic component of ALS varies widely, with some genes having high penetrance – meaning most people with the gene will develop the disease – while others have lower penetrance, so carriers may not develop ALS. Twin studies presented at the symposium showed that MND often affects only one twin in non-identical pairs, supporting the role of both genes and environment.

Retroviral sequences, or ancient viral DNA fragments inherited in human DNA, were also discussed. Present in the blood of 59% of people with ALS (compared to 5% in the general population), these retrovirus pieces may contribute to MND. Antiviral drugs, including those in the Lighthouse trial, are being trialled in ALS patients.

### **Care Inequities and Clinical Insights**

Care disparities for people with MND were studied, finding variation in access to feeding tubes and Bipap machines in rural versus metro areas. We will be looking for regional variation also in our upcoming MND patient survey in New Zealand, which you can read about on page 7.

There was also a session on speech language therapy, highlighting the need for more training and resources to support MND patients.

### **Exercise and Physical Function**

A study showed that individually tailored exercise could help slow muscle decline in people with MND. The study found high adherence and satisfaction among participants, suggesting that some prescribed exercise may hold potential for maintaining muscle function and overall well-being.

Overall, the symposium showcased the latest MND research, highlighting both progress and the substantial challenges ahead. The complex nature of the disease and its many unknowns underscore the importance of international collaboration and continued investment in research.

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**“ Some people with no known family history can still occasionally have changed genes that can then be passed on.”**

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### **Genetics**

Dr Emma Scotter presented the findings of her research into the genetics of MND in New Zealand. This provides a very useful view of how some people with no known family history can still occasionally have changed genes that can then be passed on.

A total of 184 people were tested – 149 with diagnosed MND and 35 without MND who are at risk of familial MND (known family history). Of 149 people with MND, 128 people had sporadic MND (no known family history) and 21 had familial MND. Of the 128 with sporadic MND, four people (3%) had the C9orf72 repeat expansion, two people (1.6%) had the SOD1 gene variant, and 14 (15%) carried variants of unknown significance.

This research is very complex with different variations of gene mutations, for example, SOD1 has different variants, allowing traceability between families internationally. Additionally, some people with gene variants known to cause MND have other MND-associated gene variants. Further research around the world will keep building our knowledge about genes. I am very appreciative of the work of Emma Scotter, her team, and others involved in this research for helping us better understand the genetics of MND in NZ and build knowledge internationally of genetic aspects to this disease.

A take home from this research is that some people with MND even without family history will have the SOD1 gene mutation and therefore could be eligible for tofersen treatment. Any New Zealander with MND should be able to have genetic testing if desired, talk to your neurologist or family doctor.

# Living well with MND: Travel

Ella Kahu noticed something wasn't quite right while on a year-long trip in a caravan across Australia. Despite being right-handed, she felt her left hand was much stronger, however she brushed it off assuming it was nothing serious. She thought, who wants to worry about their health while on holiday? Months later, when they got to Melbourne, she casually tested her grip strength at a wellness expo and was shocked enough with the differences in her grip strength to seek medical advice back in New Zealand. This is Ella's story of coming to terms with her diagnosis and learning to travel with MND.



In early 2022, I was living a dream. My husband and I took a year off work to travel across Australia in a caravan, enjoying the freedom of exploring new places and making memories. It was during this trip that I first noticed something odd. My right hand felt weaker. But I brushed it off, assuming it was nothing serious. After all, who wants to worry about their health while on holiday?

Months later, while visiting Melbourne, I casually tested my grip strength at a wellness expo. To my surprise, my right hand was half as strong as my left – and I am right handed. This nagged at me enough to seek advice back in New Zealand. My GP initially suggested it might be a pinched nerve, while an x-ray showed arthritis in my neck, a typical sign of aging. My GP also referred me to a neurosurgeon. It took a couple of months to get that appointment but then things started happening quickly – an MRI, uncomfortable nerve tests, and an appointment with a neurologist. Though I still clung to the hope of a straightforward explanation, MND was beginning to loom in my mind.

## Making Every Moment Count

On April 11, 2023, my fears were confirmed and I was diagnosed with ALS. Over the next 20 months, MND's relentless progression has left me with a non-functioning right arm, a weakening left hand, weak legs, "foot drop" in my right leg, frequent falls, and slurred speech. Some days, it feels like MND has robbed me of a part of myself. But I'm determined to treasure the time I have and make every moment count.

For my husband and me, the diagnosis set a new pace to our travels. We knew we had limited time to do the things we loved. Since then, we've travelled across Europe and the UK for three incredible months, explored Antarctica (a trip that was equal parts awe and nerves), and spent precious holidays with family. We even invested in a three-wheel off-road bike to help me stay active, connected, and immersed in nature.

MND complicates travel in ways I never anticipated. Falls are more frequent, and the accessibility of accommodations is now a key concern. I can no longer plan far in advance, uncertain what I'll be capable of in a few months. Flying is manageable thanks to airport wheelchairs, but every journey is a logistical challenge. We have just come back from Australia, as it is the only place where I can still get travel insurance for MND. We also spent three months travelling the South Island in our caravan. Each trip is harder, and reminds me that my traveling days are limited, so I cherish each experience that much more.

## Support and Strength in the Journey

I've been fortunate to have a strong support network. The hospital connected me with a team of healthcare professionals, and the care I've received has been excellent. I have appreciated the support and information provided by support advisor Moira, through MND NZ. Dealing with a terminal illness is emotionally gruelling, and while my family's love has been invaluable, I believe that counselling and mental health services should be integral parts of MND support alongside the physical supports such as physio and OT.



# Join the MND Registry

**There is still a lot we don't know about MND, including its causes and why it affects people in different ways.**

The New Zealand MND Registry was started in 2017 to collect data and health information from people with MND in New Zealand.

Over time the Registry has become a rich repository of data that supports our goal of bringing treatment studies to NZ, supporting policy decisions, improving quality of life, discovering effective therapies, and finding a cure.

We are pleased to see a recent increase in people joining the Registry, with data from 462 individuals now stored securely. The Registry allows us to see changes over time in patient outcomes, variation by region, and answer so many other research questions to advance our understanding of this complex disease and its best management.

The Registry is based at the University of Otago, and is voluntary, anonymous, and highly secure. Having your information added to the Registry is a significant contribution that you and your family can make to the collective understanding of MND. People with a family member with genetic MND can also join.

The Registry is run by Dr Sarah Buchanan from the Neurology Department at Dunedin Hospital and the University of Otago.

## How to Join

Contact [mndregistry@otago.ac.nz](mailto:mndregistry@otago.ac.nz) or call 0800 MND REG (0800 663 734). You can also enrol online: [mnd.org.nz/research/mnd-registry](http://mnd.org.nz/research/mnd-registry). If you don't know if you are on the Registry, please get in touch.

- ▶ My husband, children, and friends have been with me every step of the way, and I can't imagine going through this journey alone.

## Advice for Those Facing a Diagnosis

If you've just been diagnosed with MND, I want to share some words that helped me: "Just keep breathing." The diagnosis is overwhelming, no matter how prepared you think you are. It takes time to process and accept the reality of what lies ahead. I found that focusing on what truly matters helps. For me, that meant prioritising "family, friends, and fun."



Making memories, capturing moments, and living in the present became my new goals.

My advice is to do what feels right for you. Be open about your needs, record videos of yourself talking to preserve a part of you for loved ones, and consider voice banking so that if you do lose your voice the assisted communication tools will be able to use your voice rather than a generic digital voice. Most importantly, remember that every day is a gift. My body might not be what it used to, but I strive to make the most of what I can do now, finding positivity where I can and planning for a future that, while uncertain, still holds moments of joy.

## Final Thoughts

Living with MND is incredibly hard. But I hold onto this thought: my body is as good as it's going to be today, so I need to make the most of it. I try not to dwell too much on what's to come while also making plans that allow me to embrace each day fully.

MND may be relentless, but I'm still here, finding strength in my family, my memories, and the connections I hold dear. For anyone facing this disease, know that while it may feel insurmountable, there is support, strength, and moments of joy to carry us through.

# Walk to Defeat MND 2025



**Mark your calendars and join us for this incredible day of solidarity, support, and remembrance on Saturday, 22 February!**

In Auckland, Wellington, and Christchurch, we'll come together in our brightest, boldest blue – the colour of the cornflower, the international symbol

of MND. Whether you're walking in memory of a loved one, to show support for someone currently living with MND, or simply to show you care, this event brings our community together to make a difference.

## Walk Locations

Join us at one of our three main locations:

- **Auckland** – Silo Park
- **Wellington** – Frank Kitts Park
- **Christchurch** – Hagley Park South

Head to [www.mndwalk.org.nz](http://www.mndwalk.org.nz) for more information.

## Community Walks

Can't make it to an official location? You can organise your own community walk! Community walks allow everyone to join in, regardless of where they live, creating a nationwide network of supporters standing in solidarity against MND. Whether you're personally affected by MND or just want to help, it's a great way to connect and show support for our community. Download an organiser kit from [mndwalk.org.nz](http://mndwalk.org.nz) and reach out if you'd like any further guidance.



## Volunteer with Us

We couldn't make Walk to Defeat MND happen each year without the amazing efforts of our volunteers. If you'd like to lend a hand, we'd love your support with planning, set-up, and on-the-day assistance at each location. Volunteering at Walk to Defeat MND is a rewarding way to get involved and make a tangible impact on a day that's all about unity and support.

To join us as a volunteer, host your own community walk, or for more information in general, please reach out to Rob at [rob.bloch@mnd.org.nz](mailto:rob.bloch@mnd.org.nz).



# On a mission: the Galapagos Postman and MND

New Zealander Jon Beardmore is on a mission to reconnect the world, and at the same time raise funds and awareness of motor neurone disease (MND) in memory of his Dad, Eric, who died in 2022 after living with MND for eight years.



While on a trip to the Galapagos Islands in 2023, Jon spotted an ancient postbox on Isla Floreana. Since 1793, sailors and whalers on multi-year trips would pass by the island and leave letters for their loved ones in a barrel, the idea being that other sailors who were on the way home, would collect these to take on their journey.

Today, the postbox is still standing, and visitors to the Galapagos are encouraged to leave a letter, and at the same time, take one with them if there is one addressed to someone in their home country.



Jon has taken this one step further, launching 'The Galapagos Postman Challenge', taking 50 letters and spending a year travelling the world to hand deliver them.

At the time of writing, he is in Nagoya, Japan, and has just delivered letter number 40 – although the adventure is constant, and you can find out where he is now via his online tracking map, or social media handles, listed below.

Along the way, Jon aims to raise awareness, and funds for local MND charities through his media appearances, via his social media, and by talking about MND with those he meets. He has raised over \$10,000 so far. Where he can, he also takes the time to meet with local MND organisations to learn more about how MND affects people in the countries he visits.

"The Galapagos Postman Challenge is about reconnecting people via the written word in the form of letters and hand delivering them to provide a personal touch," says Jon. "It's also to highlight the loss of mobility and freedom of movement that my father and other people with MND lose. Something we shouldn't take for granted."

Jon, who originally comes from Taranaki, will be in New Zealand over the Christmas period to deliver letters in Whangārei and Christchurch, before continuing on his journey, finishing in March 2025 – a year after he started.

Keep an eye out for the Galapagos Postman – it might just be your door he's knocking on!

## Keep up with his journey

The Galapagos Postman tracking map: <https://z6z.co/galapagos-postman/>

Instagram: [instagram.com/bigoadventures](https://www.instagram.com/bigoadventures)

Facebook: [facebook.com/BigOAdventures/](https://www.facebook.com/BigOAdventures/)

Support Jon's fundraising: <https://mnd.org.nz/galapagos24>



# Here to help

Meeting the needs of people living with MND and their families and carers is a vital part of MND NZ's mission. Our team of MND Support Advisors located around New Zealand provide information, support and advocacy for clients, carers, whānau and the health professionals working with people with MND.

Support Services Manager Toni Foster, who is based in Auckland, shares her thoughts on the diverse role of the MND NZ support service.



## Building Relationships

The role of a support advisor is to provide individual support to everyone diagnosed with MND if they want it. We feel privileged to be allowed to share this journey, and to be invited into the lives of people with MND. It is up to the person themselves to decide what our support looks like with regards to frequency and type of contact – face to face, email, text, video or phone call – and this may change throughout their journey. We are also able to continue to provide support for family and whānau for as long as they would like us to be involved, and we can also help to link them with bereavement services.

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**We want our clients, carers and their families to know we are just a phone call or email away.**

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Support advisors can also help with guidance about support groups, so individuals can decide for themselves if this is something that they would like to be part of. Some people may prefer to meet with another person with MND on an individual basis, in which case the support advisor may be able to facilitate contact with someone who is in a similar situation.

## Support Through Empowerment

We want to empower our clients, family, carers and whānau with information to help them navigate their way through the health care system and support them through their journey.

Each person comes to us with different needs, desires and wants. Some people want to know everything about the disease and others do not. We are sensitive to the individual; no-one has the same experience or the same needs.

We have written information and resources that we can share with clients, their family and whānau, and also information for health professionals. We also have information on our website and links to other helpful websites. Our aim is to provide people with

information that will enable them to make informed decisions throughout the journey.

Some health care professionals might not have prior experience with MND. Support advisors provide written resources, support via technology and can meet with health professionals to assist in providing the best possible care for their clients and the specific needs of living well with MND.

## Advocacy

Support advisors are experienced professionals, with connections to multiple services which can help people at the various stages of MND.

We are not part of Health New Zealand – Te Whatu Ora, but work alongside each region and have built good working relationships with local health teams. We can help navigate the system, and we understand how it all works, or who to contact with queries.

## Support Service Contacts

Our charity was built on the ethos of helping people affected by MND – it's the cornerstone of all that we do. If you or a loved one has MND, we're here for you.

**Toni Foster:** Support Services Manager  
Phone: 021 230 3038 Email: [toni.foster@mnd.org.nz](mailto:toni.foster@mnd.org.nz)

**Sally King:** Northland, North Auckland & Waitemata  
Phone: 027 202 8166 Email: [sally.king@mnd.org.nz](mailto:sally.king@mnd.org.nz)

**Rachel Woodworth:** Auckland, Counties Manukau  
Phone: 021 036 0218 Email: [rachel.woodworth@mnd.org.nz](mailto:rachel.woodworth@mnd.org.nz)

**Jeanette Tioke:** Bay of Plenty, Lakes, Hawkes Bay, Tairāwhiti  
Phone: 029 777 5588 Email: [jeanette.tioke@mnd.org.nz](mailto:jeanette.tioke@mnd.org.nz)

**Megan Rademeyer:** Waikato, Taranaki, Whanganui (North)  
Phone: 029 773 6662 Email: [megan.rademeyer@mnd.org.nz](mailto:megan.rademeyer@mnd.org.nz)

**Moira Young:** Capital & Coast, Hutt, Wairarapa, Mid Central, Whanganui (South)  
Phone: 021 0278 4494 Email: [moira.young@mnd.org.nz](mailto:moira.young@mnd.org.nz)

**Jasmine Chua:** Upper South Island  
Phone: 029 777 9944 Email: [jasmine.chua@mnd.org.nz](mailto:jasmine.chua@mnd.org.nz)

**Sarah Mathieson:** Lower South Island  
Phone: 027 298 1189 Email: [sarah.mathieson@mnd.org.nz](mailto:sarah.mathieson@mnd.org.nz)

# Thank you

Motor Neurone Disease NZ is the only charity focused on improving quality of life, funding research and campaigning for people affected by motor neurone disease (MND) in New Zealand but relies on donations to do so.

Your donation, big or small, will help grow the support, information, and advocacy we can provide for those affected by MND today, as well as funding research for a brighter future.

## Ways to support

### Online

You can donate via our website at [www.mnd.org.nz/donate](http://www.mnd.org.nz/donate)  
Or simply scan this QR code with your phone to go directly to the donation page.



### Internet Banking

03-1508-0132199-000

Please enter details as follows when making payment.

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Code: Donor ID (if known)

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