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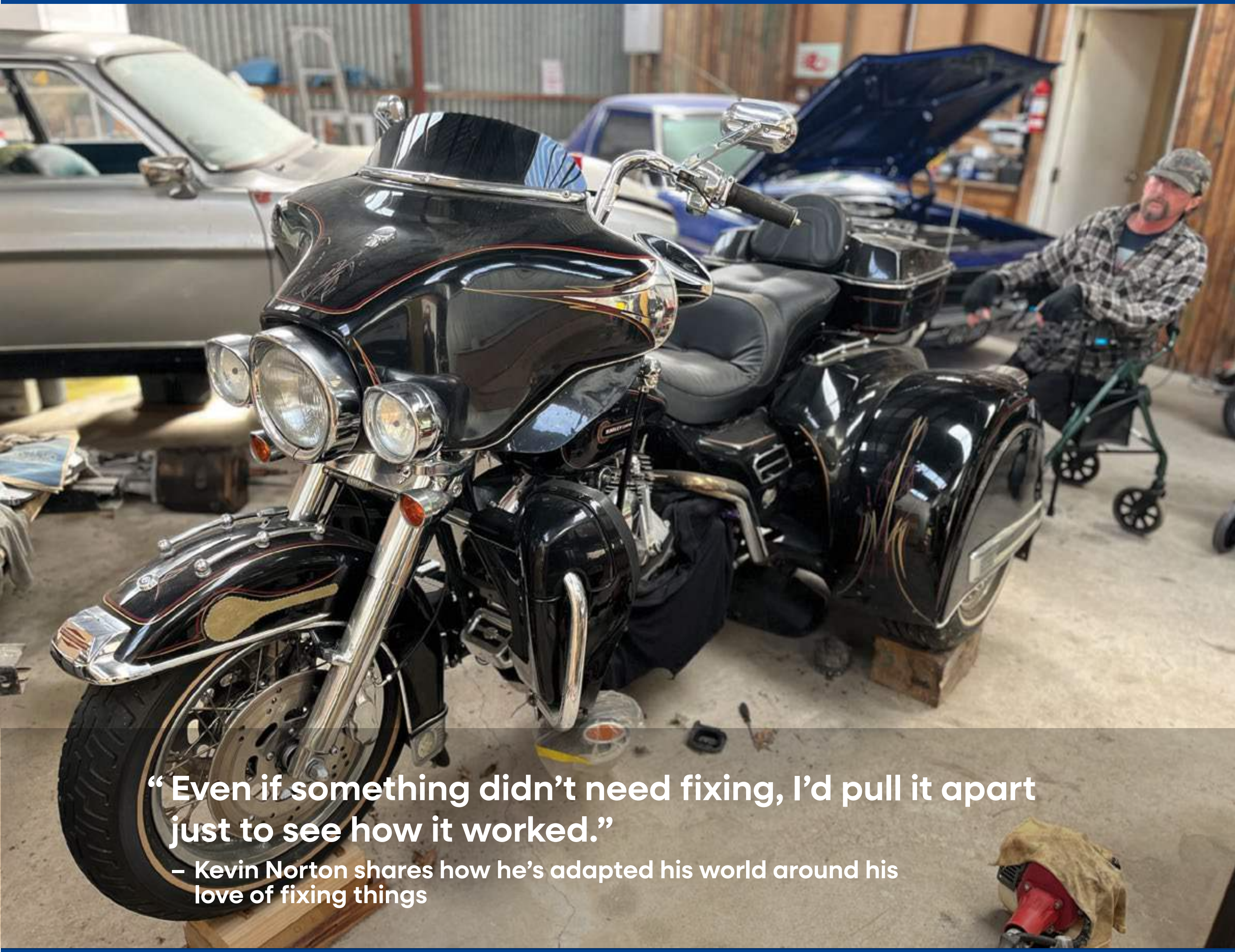
Motor Neurone
Disease NZ

In this issue

MND News

Summer 2025

Magazine of the Motor Neurone Disease New Zealand Charitable Trust



“Even if something didn’t need fixing, I’d pull it apart just to see how it worked.”

– Kevin Norton shares how he’s adapted his world around his love of fixing things

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www.mnd.org.nz

Message from our Chief Executive

Kia ora koutou

With snow flurries recently falling here in Canterbury, introducing a summer magazine seemed to be at odds with the season. However, what a difference a week makes – temperatures are now heading for the mid-20s!

Summer can bring an increase in social events and the often-frantic lead up to the holiday season. Taking care of our physical and mental health during this time can be about finding the quiet spaces and the value of our connections – not always easy to do when we're swept up in the busyness.

Inspirational engagement makes time count
The passing of seasons is also nature's gentle reminder to keep doing what we do here at MND NZ, make time count for people affected by MND and their whānau. This edition is brimming with stories about how our amazing community is making their precious time count.

You can read about the passing of the wheel between Mike Brown and Paul Caldwell, a story of movement, generosity and the road that connects the two men and their whānau. And Kevin Norton shares how he has adapted his world around his love of fixing things – proving that purpose and independence don't stop with a diagnosis.

Stories from the frontline of support and education at MND NZ include a fascinating profile of Jane Kay and her newly created role of MND Educator. Jasmine Chua reveals thought-provoking insights into her world as MND Regional Support Advisor in the Upper South Island.

Impactful research
We outline the framework around our new research strategy and share an important update about the effectiveness of riluzole, the only medicine funded for the treatment of MND (ALS variant) in Aotearoa New Zealand.

Connected community
You'll also find a compendium of practical tips and tricks for living with MND to help with personal care, dressing, around the home and more. A great example of community-led solutions – created by our community, for our community. We want to keep the momentum going on this one, so please send us your contributions so this resource can continue to help others.

Grateful thanks
I would like to personally thank everyone in our community who has recently supported MND NZ with awareness and fundraising events. Every contribution, big or small, helps us make time count for more people living with MND.

Thank you for taking time to read this edition, best wishes to you and your whānau for a safe festive season filled with meaningful connection.

Ngā mihi nui

Mark Leggett

Contents

Cover: Kevin Norton fixes his Harley Davidson.

A special thank you

Our heartfelt appreciation goes out to the people below for their support in making the MND News Summer 2025 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.

2026 Event updates

Trek for MND: Abel Tasman Adventure 2026

We're thrilled to launch the Trek for MND: Abel Tasman Adventure – five days, 55 km of golden beaches, native forest and rugged coastline to raise vital funds for Motor Neurone Disease NZ. Every kilometre you hike helps people living with MND and their whānau.

When: 02–06 October 2026

Find out more and register:
mnd.org.nz/abeltasman

Walk to Defeat MND: New date

The buzz of the crowd, quiet moments of remembrance, the hug of a stranger who gets it. Events are positive, powerful, colourful, and life-affirming. In 2026, our annual Walk to Defeat MND day of solidarity, support and remembrance moves from February to November.

When: Saturday 07 November 2026

Find out more and register or volunteer:
mndwalk.org.nz

2026 New Zealand Masters Games: Official charity partner

We're proud to share that Motor Neurone Disease NZ has once again been named the official charity partner for the 2026 New Zealand Masters Games in Ōtepoti Dunedin. Participants in the 2026 Games will be invited to make a voluntary $5 donation to MND NZ when registering.

When: Saturday 31 January to Sunday 08 February 2026

Find out more and register:
nzmg.com

Jane Kay: Educating with heart

Jane Kay sharing a moment with her dog during a car trip.

After years of supporting people with motor neurone disease (MND) and their whānau, Jane Kay has returned to Motor Neurone Disease NZ in a new role – one that draws on her lifelong passion for teaching, understanding, and human connection.

For Jane, education has always been more than a career – it's a calling. Her journey from classrooms in South Africa to community education in Aotearoa has been guided by empathy, resilience, and the belief that learning can bring both comfort and strength.

"I was born and bred in South Africa and qualified as a teacher. My husband and I had two beautiful daughters.

"Our second daughter, Kirstin, was born with the cord around her neck which necessitated numerous therapies from a very early age. This led me to train further in special-needs teaching." Caring for her late husband's parents, both of whom developed dementia, deepened her empathy and her desire to understand.

"As I did not understand dementia, I made many mistakes and deeply regretted these after they died, and I had time to study this."

When Jane and her younger daughter emigrated to New Zealand in 2006, that drive to learn and support others continued to shape her path. "I was employed as the Dementia Educator at Alzheimers Waikato. I later became both Manager and Educator."

Finding her place

Jane's first connection with MND NZ came through a friend who had lived experience of the disease. "I had a dear friend who had had personal experience with MND and spoke so highly of the organisation. I had left Alzheimers Waikato when the MND role was advertised and wanted to get back to working with people in the community and have the opportunity to make their lives easier in some small way."

As a Support Advisor, she discovered the emotional richness of the MND community. "After working as an MND Support Advisor, I came to think that the main cause of MND is the 'beautiful person gene'. It was an inspirational experience, and the blessings outweighed the sadness that does go hand in hand. I learnt so much from the health professionals involved and was blown away by their dedication. I am passionate about the cause and simply feel at home in this environment."

A new chapter

When the new MND Educator role was created, Jane immediately recognised it as a perfect fit. "I am an educator at heart. When working with young children my greatest buzz was to see their eyes sparkle as they 'got it' when I found a new way to explore something with them. I also loved my adult-education experience in the past and I am excited to be back with an organisation that I love, and in a role that spins my wheels."

Toni Foster, Support Service Manager, says the position marks an important step for MND NZ and the wider community. "This role will enable Motor Neurone Disease NZ to extend our reach into the community and provide the opportunity for the MND community to engage with our service and with one another in a different way," says Toni. "It will also allow us to develop education sessions for health professionals, raising awareness of and knowledge about MND among clinicians to improve care for our community."

Jane agrees that the strength of the role lies in real-world understanding. "Having worked closely with the clients and their whānau, and with the multidisciplinary teams (MDTs) from the four DHBs I was involved with, I have a good grasp of what it is that will be helpful to the MND community. I have been at the rock face, felt it all deeply, so I won't be educating from an academic perspective nor an 'ivory tower'."

Educating for change

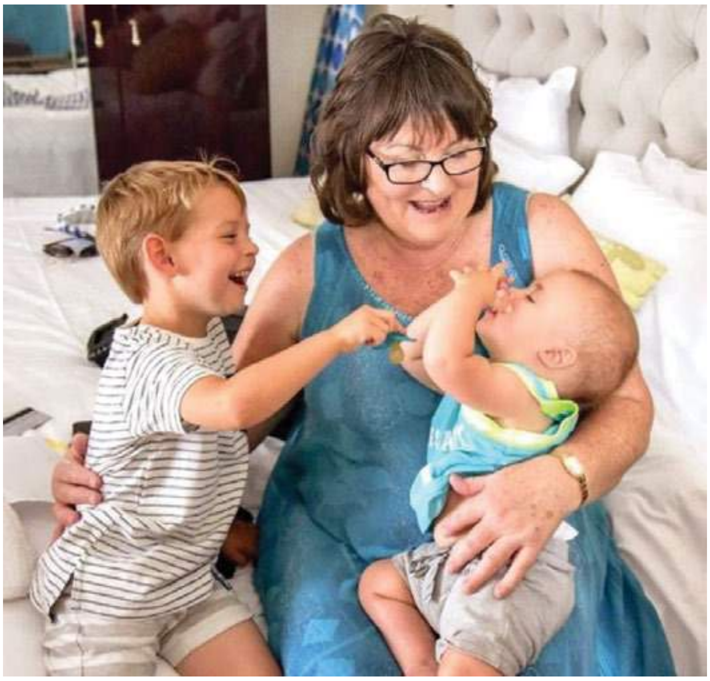
“I am hoping that I will not only give people with MND a better understanding of their situation, but also reassurance of the support that is out there for them and so ease their path alongside our Support Advisors.”

Her focus is already clear. “My priority is preparing the content of online sessions for newly diagnosed people. I am committed to working closely with the Support Advisors to ensure that my role complements theirs and is a help to them. I will then work on establishing connections with specialists in the field who are willing to present on their area of expertise in our *Living with MND* online programme. Alongside this, I will be beginning to prepare information sheets and start a blog on the website.”

> *“I have been at the rock face, felt it all deeply, so I won’t be educating from an academic perspective nor an ivory tower.”*

Toni says Jane’s warmth and experience make her the ideal person to lead this work. “Jane is a warm and empathetic person who is able to form connections with people from diverse backgrounds and put people at ease,” Toni says.

“She is respectful of the role of others in MND NZ and works in a collegial way to achieve the best possible outcomes for the MND community. Her experience as a Support Advisor will be invaluable in this role as she already understands what sort of information is shared with the MND community and will be able to build on this.”



Jane Kay with her grandchildren – making memories and sharing laughter.

Connecting people to the right support

The Educator role has a clear purpose: to ensure information, resources and expertise reach the people who need them most. Jane will work directly with health professionals, caregivers and whānau – bridging understanding between clinical care and lived experience.

Her remit includes developing online and in-person learning for newly diagnosed clients, expanding education for health professionals and service providers, and keeping MND NZ’s educational materials and website content up to date. She will also maintain networks across the health and community sectors to strengthen collaboration and share best practice.

Through this work, MND NZ aims to ensure that the right information and support reach the right people at the right time – helping people live with dignity, confidence and connection.

As always, this work does not happen in isolation – we sincerely thank our generous fundraisers and donors. Your contribution makes this life-changing support possible.

Looking ahead

“It is a great joy and blessing for me to be given this role,” Jane says. “I still have so much to learn, and I am grateful to the support I have from our Head Office, from the Support Advisors, and I am open to any suggestions and advice from them, as well as from people living with MND and health professionals in the field.”

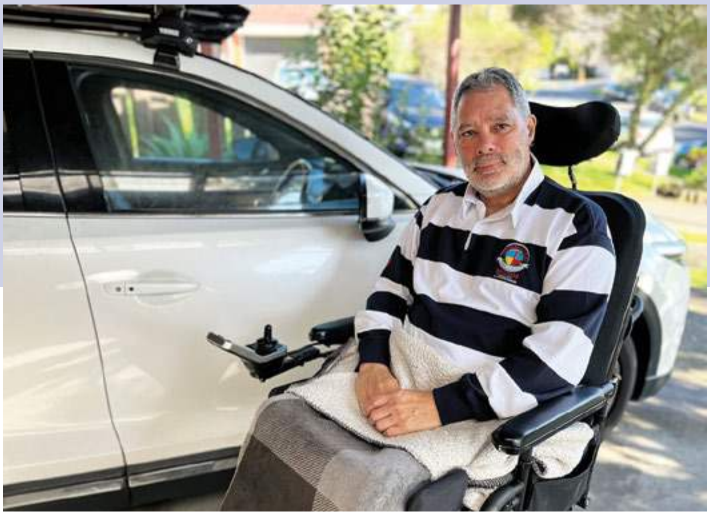
Outside work, Jane finds balance in simple pleasures.

“My faith, family, friends, animals, books and nature. A perfect day is being curled up with a dog or two, and a cat, a good book, a good cuppa and looking out on beautiful scenery. And then a catch-up with someone special at some stage of the day or evening.”

As she steps into her new chapter, Jane brings not only experience and knowledge, but a generous heart – and the conviction that understanding can make life with MND a little clearer, a little kinder, and a little lighter for everyone it touches.

Passing the wheel: A story of mobility and friendship

A car built for independence has become something far greater – a link between two men, two families, and two lives shaped by motor neurone disease (MND). This is the story of movement, generosity and the road that connects them.



Mike Brown at home with the modified vehicle that helped him stay independent after his MND diagnosis.

When Mike Brown first shared his story on the MND NZ website, he described his modified Mazda CX-9 as more than a vehicle. It was a lifeline. A way to keep moving, to stay connected to the world beyond his front gate.

Now, that same car has become something even greater: a link between two men, two families, and two chapters of the same journey. The Mazda that once carried Mike along Auckland's roads is now parked in a Dunedin driveway, ready to start a new chapter with Paul Caldwell. A husband, father, and musician facing his own life with MND.

A connection sparked by story

When Paul first came across Mike's article, he hadn't been looking for a car. The way Mike spoke about staying ahead of the curve, about preparing early and holding on to independence resonated. And the Mazda needed a new owner. "I was inspired by what he said about staying ahead of the game and being proactive," Paul says. "I knew my driving days might be numbered, so the timing felt amazing."

For Mike, the decision to sell was loaded with emotion. The car had been his bridge to independence, and he didn't want it stripped of its modifications or sold to someone who wouldn't understand their value. "My biggest concern was for the equipment to be stripped off the vehicle and someone missing out on the benefit of independence when they didn't need to," he says.

Paul and Gail Caldwell with their dog Rue beside their adapted vehicle.

"I'm thankful the earlier article resonated enough with Paul and his whānau for them to reach out, enquire, and come to Auckland to trial and purchase." From that moment, the wheels of connection were set in motion.

The road north

To collect the car, Paul and his wife Gail travelled the length of the country. They booked one-way flights from Dunedin to Auckland, committed to bringing the Mazda home. "It took a wee bit of planning," Paul says. "Our son picked us up from the airport and dropped us straight to Mike. We stayed overnight in Auckland and then drove the car home."

What might have been a quick hand-over became something more meaningful. The two families spent hours talking before and after the test drive, sharing stories, laughter, and life experience. When Mike realised the next morning that he'd forgotten to hand over the spare key and wheelchair-box remote, it became a welcome excuse to meet again. "We ended up having lunch together," Paul recalls. "It was just a lovely time, sharing about each other's lives and families."

For both men, that simple journey north turned into a shared moment of kinship; two people at different stages of MND, steering through the same landscape with the same determination.

A friendship on wheels

What began as a practical transaction soon became a friendship grounded in understanding. "Through this sale I've gained a rather unique friendship with Paul, his wife Gail and their immediate whānau," Mike says. "It feels like we've known each other for years."

They still talk regularly, about mobility, about family, and about what it means to adapt as life changes shape. Paul says Mike's support has been generous but never overwhelming. "Mike's sensitive to where I'm at," he says. "He doesn't want to overload me with information. Every conversation he'll say, 'I don't want to give you too much because it can be difficult.'"

For both men, those calls have become a steady rhythm. A reminder that sometimes the most meaningful journeys are the ones you don't take alone.

Keeping independence alive

Paul was diagnosed with MND in April 2024, a year after his first symptoms. Like Mike, he faced the loss of mobility with a mix of realism and resolve. The modified Mazda – fitted with hand controls and a roof-mounted wheelchair carrier – arrived at exactly the right time.

"It's been amazing," Paul says. "I wouldn't be driving a standard vehicle now. With the modifications I can still visit people, pop to the shop or go downtown by myself. It's hard getting in and out, but I can still do it, and that takes pressure off Gail."

> *"Having a friend who truly understands what you're going through is quite beautiful really."*
>
> **– Paul Caldwell**

The car has also kept family life in motion.

"Our two youngest have just finished school," Paul says. "Being able to take them in the mornings or pick them up. It's those little things that matter. We've done a few trips, even a concert in Christchurch. Just being able to all travel together again, that's been really special."

For Paul, the Mazda isn't just a means of transport. It's a companion that carries both his family and a piece of Mike's determination. Proof that the drive to keep moving can be shared.

Grounded by faith

Living with MND has taught Paul to look inward as well as forward.

"I'm a Christian," he says. "My faith in God is what gives me hope and strength. Every day is a new challenge, but I believe Jesus died for me. That gives me hope for the future."

Paul and Gail's church community at Caversham Baptist has surrounded them with practical and spiritual support. Every Thursday evening around 30 people gather for prayer, songs and reflection. "It's been incredibly powerful," Paul says. "Just people gathering around us, sharing hope and faith. It's beautiful."

Lessons in generosity

Paul is quick to credit Mike for his openness and generosity.

"He calls himself a private man," Paul says, "but with me he's shared encouragement and little tips and tricks for managing day-to-day things. Having a friend who truly understands what you're going through is quite beautiful really."

For Mike, the feeling is mutual. The sale became more than a transaction; it was a moment of passing something forward.

"We are not alone, nor are we unique," he says. "Share your experience – a challenge shared is a challenge halved. Challenge the norm. While MND may be definitive, I don't allow it to define me. And ask questions.

"You'll never know everything but know and prepare as best you can. As the saying goes, 'measure twice and then once more before you cut.'"

A shared road

The Mazda CX-9 that once gave Mike freedom in Auckland now carries Paul and his family through the hills of Dunedin. For Mike, letting go of the car was an act of generosity. For Paul, taking the wheel was an act of faith. Together they've shown that independence can be shared, and that sometimes, a car can be far more than metal and wheels.

It can be a bridge between people, between experiences, and between what was and what still lies ahead. In their hands, it has become exactly what Mike always hoped it would be: a vehicle not just for mobility, but for connection, friendship and community. Proof that even as the road changes, the journey continues.

Foundations of hope: Dr Natalie Gauld on the new MND NZ research strategy

Dr Natalie Gauld

Motor Neurone Disease NZ's Research Strategy 2025–2028 sets a clear direction for the years ahead – building on strong foundations and aiming for tangible change. In this Q&A, Dr Natalie Gauld ONZM PhD FPS, Research Advisor and Best Practice Advocate, discusses what the strategy means for people living with MND, the power of collaboration, and her hopes for research and care in New Zealand.

Building on solid foundations

What prompted the update to MND NZ's research strategy and why was now the right time to refresh it? The first research strategy was written in 2019. Research is important to MND NZ and to our community, so we needed to review it and look at how we could best build on the excellent work Dr Claire Reilly and others did with that first strategy.

In simple terms, what does this new strategy set out to achieve for people living with MND in Aotearoa? We want to see advances in management of MND in NZ, we want to encourage clinical trials to come here, and we want to encourage work towards better treatment and a cure. We've put in place different funding paths to help achieve these goals and have set clear targets.

Care first, progress always

The strategy focuses on four goals – improving care, progressing toward better treatments, ensuring access to clinical trials, and building collaboration. How do these goals work together to make real-world impact? They are complementary rather than fitting together. The first three benefit our community in different ways, but collaboration is needed in all research to maximise its effect and timeliness. For example, with collaboration between health professionals working at the coalface and academics with the research skills, we can get meaningful insights into how care can be improved. Collaboration in building on work others are doing, having input from different clever minds to make research better, and sharing results of research quickly will accelerate finding disease mechanisms and better treatments. Real-world impact will happen for our community earliest from improving care while we wait for a treatment.

Why begin with improving care? What kinds of research can most immediately help people and whānau living with MND today? We know from the MND Insight Research that there are many concerns our community is facing. Sharing this information will help people with MND and their whānau today, but it also highlights the areas where we need more research to further improve care.

Sometimes the research is already being done, but busy health professionals don't always have the time or support to formally publish their findings. When research is written up and published in a peer-reviewed journal, it becomes visible to other researchers and clinicians, gains credibility, and can influence how care is delivered. We've introduced new assistance to help get these papers published more quickly, and we look forward to this helping create practical improvements for our community.

> *"Real-world impact will happen earliest from improving care while we wait for a treatment."*

Turning insight into action

The MND Insight Research gathered a huge amount of information from people with MND and their families. How has that evidence shaped the direction of this new strategy? We know from the MND Insight Research that 75 percent of the research respondents with MND would like the opportunity to be part of a clinical trial. This encouraged us to include the target of two clinical trials by the end of 2026 – a stretch goal when we've had only one clinical trial broadly available to people with MND before in New Zealand, which started in 2022.

Many people with MND say they'd like the chance to join a clinical trial. What does it take to make New Zealand truly "trial-ready", and what's changing on that front? This came through clearly in the MND Insight Research, and we've been using the figure of 75 percent wanting the opportunity to be in a clinical trial to show sponsors, clinical-trial facilities and others that we're serious about wanting to have trials here.

The work done bringing the Lighthouse II trial to NZ in 2022 helped pave the way for more trials, but pressure in the health system makes it harder. So, we've looked at a different model where a research facility runs a trial to reduce the burden on neurologists and health districts. This looks promising as a good next step.

To get research here, we already have the MND Registry, set up in 2017 and funded by MND NZ, which helps inform our community about research they may be eligible for. We need to have a sponsor willing to offer research in NZ because clinical trials are very expensive, and we need neurologists to support the research, and facilities to conduct it to high standards. Then we need people with MND informed about it and willing to be involved. I've worked in a clinical-trials facility in the past, which helps me understand how it works and what we need to encourage it. We've reached out to two clinical-trial units about bringing MND research here. We've spoken to neurologists about being involved in trials and we've been talking to sponsors, contract-research organisations and trial investigators from Australia to stimulate interest.

We're making progress and hope to achieve our goal of two clinical trials by the end of 2026. We'll keep our community informed on this – it takes time.

The power of collaboration

The New Zealand MND Registry has become a cornerstone of research here. How does it help both researchers and the people who choose to enrol? As a person with MND with a research background, I enrolled immediately with the MND Registry, and I was very happy it was available to encourage and support research. This Registry connects people with MND with researchers but also provides anonymised data for research about MND in NZ. It's a rich source of information to help our understanding of MND in NZ and changes over time.

MND NZ has supported the Registry since it started in 2017 and has recently committed to funding it for a further three years. We greatly appreciate the work done to create this Registry, particularly the work of Dr Reilly, a person with MND who led fundraising initiatives for MND research through MND NZ and was a key person behind the Registry.

> *"I don't expect a cure in my lifetime, but I'd love to see progress toward better treatments and a cure for people diagnosed in the future."*

It's very easy to join. See mnd.org.nz/research/mnd-registry for more details. If you're not sure whether you're already on the Registry, just email mndregistry@otago.ac.nz or call 0800 MND REG (0800 663 734).

Collaboration and connection

Collaboration is a strong theme in the strategy. What will that look like in practice over the next few years – for researchers, clinicians, and allied-health professionals?

I've worked on many research projects, and collaboration is key because it builds on work others have done and brings in different expertise and thinking to make the research well thought-out, high quality, relevant and able to inform change. We want to see collaboration in the research we support and are encouraging it in different ways.

For the MND Insight Research, collaboration with neurologists, academics, a statistician and allied health have been key in the design, along with extensive consultation with the community to make the research the best we can. I also reached out to a UK academic about building on her work on behaviour change in MND, adding robustness to the work, and she'll contribute to one of the research papers.

A vision grounded in care

From your perspective as Research Advisor and Best Practice Advocate, where do you see the biggest opportunities for research to improve quality of life and care right now? The immediate opportunities for change lie in our new initiative to encourage health professionals who work with people with MND – and who are passionate about improving care – to partner with researchers. The resulting research is most likely to make a real difference for our community and will have the fastest impact.

Personal insight and purpose

You've seen MND from many perspectives – researcher, advocate, and person living with it. How does that shape your hopes for where research can take us next? I want research to deliver for our community. I want others to have the opportunity to join a clinical trial. I want to see meaningful change in access to the health services they need. I want to see the pre-clinical research – for example, at Dr Emma Scotter's lab of 10 MND researchers – continue to thrive with international connections and collaborations. I want to see more academics and health professionals researching MND and becoming experts in the area. I want more neurologists to have a special interest in MND.

I don't expect a cure in my lifetime with MND, but I'd love to see more progress toward better treatments and a cure for people diagnosed in the future. I want survival to be extended and care and equipment to be available when needed for our community, based on better use of the tools we already have. Our Insight Research shows some important areas MND NZ advocacy can work to change.

Together, research, advocacy from MND NZ, and the support of experts can drive the changes that will improve the lives of people with MND.

Looking ahead

Looking ahead to 2028, what would success look like – for MND NZ and for the people and families this work is ultimately for? I'm excited about looking ahead and what we can achieve. MND NZ had an excellent research strategy led by Dr Claire Reilly QSM, and I appreciated her feedback on the new strategy that builds so much on this work. I want to acknowledge Dr Reilly for all her work in this space. Everything she did, while living with MND herself, I greatly admire and appreciate, and we've built on her very solid foundation.

I also appreciate the work of Dr Alan Stanley, our Board member, for leading the Lighthouse II study, and the investigators around the country who supported it.

I'd love to see an MND Symposium, like the 2019 symposium led by Dr Reilly, that informs the MND community, informs health professionals, aids collaborations and excites the workforce about improving MND care. I'd love to see multiple clinical trials available throughout New Zealand, many publications about MND research from NZ researchers, and increased research funding for MND.

I'd like to see the MND Registry include 90 percent of people with MND in NZ, so we get the best possible picture of what's happening for our community.

I'd like to see researchers and health professionals reaching out to MND NZ for feedback on research ideas, and collaboration around the country and internationally to maximise the quality and benefits of the research.

■ You can read **MND NZ's Research Strategy 2025–2028** at mnd.org.nz/research2025

Riluzole update

We've recently updated our website and information sheet to reflect the latest research findings on the effectiveness of riluzole.

Riluzole (brand name Rilutek) is the only medicine funded for the treatment of MND (ALS variant) in New Zealand. Riluzole 50 mg tablets are taken twice a day with a glass of water.

How effective is riluzole?

While two early trials showed that riluzole led to a median increased survival of 2–3 months compared to a placebo, these trials had limitations. The trials were relatively short, included people who started riluzole a long time after their MND diagnosis, and the survival information excluded results from people who were still alive when the trial finished1.

So real life studies have been used since then to get a better understanding of how much survival increases with riluzole use when it is started soon after diagnosis and used for a longer time. These studies vary in how much longer people lived on taking riluzole compared with not taking it. Most of these have shown on average 7–11 months longer survival, depending on the study. Results will vary in different people. Starting riluzole early and continuing long-term is recommended for best effect.

Riluzole does not stop progression completely – increasing muscle weakness and loss of ability will still continue. A person taking riluzole, will not usually be able to tell whether it is working or not working for them.

Read more about riluzole or download our information sheet at mnd.org.nz/Riluzole

Jasmine Chua: the art and heart of care

For Support Advisor Jasmine Chua, caring for people with motor neurone disease (MND) is both an art and a privilege. Shaped by her West Coast roots and Chinese heritage, she brings wisdom, humour, and heart to every visit – helping people make time count, one moment at a time.

When Jasmine drives over Lewis Pass, something lifts. The air sharpens, the light changes, and a sense of home settles in. That unmistakable pull of the West Coast that has shaped who she is and how she cares.

Jasmine's roots run deep in both place and culture. Her late mother was a strong, stoic West Coaster: practical, resilient and resourceful. Jasmine's heritage is both West Coast and Chinese. A mix that shaped her worldview and resilience. She says the sea has always been her way of putting things in perspective. The ruggedness and tempestuousness of the West Coast are a balm and a salve. A reminder of what really matters.

"Challenge, in Chinese, is opportunity," she says. "Whereas often in the West it has negative connotations. In the Asian culture, challenge is to be embraced. That's something that informs my decisions, such as the one I made when I joined MND NZ."

The art behind the science

From an early age, Jasmine was drawn to both creativity and care. She studied dance and music throughout school, seeing them as expressions of empathy and connection. "Art and creativity have always been important to me," she says. "When I eventually studied medicine, I realised communication, education and helping people through life crises are an art. The rest is science."

Jasmine Chua with her three-year-old border collie, Theo, beside the Tasman Sea.

She was just 23 when she began practising medicine, a young doctor on a paediatric oncology ward supporting families facing the unimaginable. "One of my first challenges was when the parents of a dying child asked for my advice," she recalls. "I wasn't a parent myself. It was incredibly sobering. I learned very early that if your heart isn't in it, you shouldn't do it."

That conviction has guided every turn since. Her career has never followed a straight line – "more A to Z than A to B," as she puts it – spanning psychiatry, medical education in North America and Europe, and teaching medicine to the armed forces back home. Each chapter, she says, added another colour to her tapestry.

Alongside her professional experience came deeply personal lessons. Jasmine survived cancer at 21, an experience that deepened her empathy and understanding of loss. Later, she helped care for her mother through Alzheimer's and her father through Parkinson's. "The neurodegenerative nature of those diseases wasn't new to me," she says. "The whole

"It is a gift to be able to provide some solace."

“Somewhere there’ll be a lightness along the weight of this journey.”

awfulness of terminal illness, it’s something you don’t forget.”

Finding her place with MND NZ

When Jasmine saw the Support Advisor role advertised, it felt like all the threads of her life converging. “I was looking for a role that had education, health and community at its heart,” she says. “Something where I could use everything I’d learned and give back.”

She joined MND NZ to cover the Upper South Island and Canterbury regions, which hadn’t had a dedicated advisor for some time, and initially took on the entire Te Waipounamu (South Island). “It was a huge area, but it didn’t phase me. I came in green, but looking at all the threads in my tapestry, I realised there were colours that matched the charity. And here I am.”

Travelling between regions, she says, has reminded her of the diversity and resilience of people across Aotearoa. “Every community is different, every whānau has its own rhythm. The role keeps me grounded and humbled. There’s something deeply human about being invited into people’s homes at such a vulnerable time.”

Nearly two years on, Jasmine sees herself as a glue that helps hold the connections together. The link between families, health professionals and the wider MND community. “I value the team dynamic,” she says. “I couldn’t function without it. It’s about making sure nothing, no one, falls through the cracks.”

Presence, humour and balance

Her approach blends clinical insight with intuition and warmth. “Yes, MND is a medical diagnosis,” she says, “but how are people doing psychologically, emotionally, as a family unit? Because our roles aren’t clinical, we can look at the whole picture – the spouse, the carer, the family.”

Humour is one of her most trusted tools. “It’s a risk to use it, because it can fall flat, but humour can lift people. It can be a tool for resilience. One of the first people I met with MND could barely speak, but the spark of humour in their eyes was inspiring. It reminded me that people can still be true to themselves.”

Equally, she values the quiet moments. Sitting in silence, sharing sorrow or simply letting someone breathe. “It is a gift to be able to provide some solace. It’s not all about the busyness of doing,” she says. “Sometimes helping means giving space. It’s a fine balance.”

She knows the emotional toll of this work and has learned to refill her own bucket. “You can’t give from an empty bucket,” she says. “We encourage our clients and their families to fill theirs. To embrace bucket lists and big-ticket things because time counts. But we need to fill ours too.”

The small things that matter

One story that stands out for Jasmine involves a client who needed a walking frame not provided through standard funding. “MND NZ helped with financial assistance,” she says. “The frame suited her perfectly, light, easy to use and it made such a difference. When I saw her later, her eyes lit up telling me about it.”

Those moments, she says, are what this work is about. “Whether it’s a walking frame or a leg brace, they’re not little things. All the little things add up to something big.”

Making time count

For Jasmine, “making time count” isn’t about doing more. It’s about being more. “The unknown, the limbo stage, is the hardest psychological space,” she says. “So, making time count means being in the moment. There will always be something – a humorous text, a Spring flower, a small joy – if we look. Somewhere there’ll be a lightness along the weight of this journey.”

Life, she agrees, can be layered: complex, revealing and sometimes tearful, yet full of growth and meaning. “If a person is diagnosed later in life, hopefully they’ve already started to peel and appreciate those layers,” she says. “But if it happens earlier, the learning becomes so concentrated. Hopefully we can help a little with that layering.”

Having peeled enough layers of life to know what matters most, Jasmine brings wisdom that’s hard-won but lightly carried. “A good day,” she says, “is one where I hope I’ve made a positive difference in someone’s life. Maybe their voice lifts when we talk, or they send a smiley emoji after a visit, or they give me a hug goodbye. It’s all worthwhile when your work can be uplifting.

“What’s uplifting about it?” she ponders. “The people. That’s what this is all about.”

MND community: tips and tricks

A collection of shared know-how from people living with MND.

Every day, people living with motor neurone disease come up with smart, practical ways to adapt. Over time, these insights are often passed quietly from one person to another – shared in conversation, offered with care, or demonstrated by example.

In this feature, drawn from clients and carers across Aotearoa, we've gathered a selection of everyday solutions that have made a real difference. They're simple, honest, and shared anonymously – not as expert advice, but in the spirit of helping others find their own way.

From getting dressed to staying dry, brushing teeth to making memories, these are the tools and tricks that may help.

Personal care

- Using an electric toothbrush means the person can lower their head to the brush, rather than lift an arm. And later on, it makes brushing easier for caregivers too.
- An electric shaver helps with daily grooming and keeping tidy when movement becomes more limited.
- A small clip attached to a shirt front holds a feeding tube upright, helping prevent leaks if the tube was knocked.
- A portable travel bidet for use by partner/carer of the person with MND. Can be used at home and travelling.
- Homeopathic and/or baking soda toothpaste doesn't have the strong odour of everyday toothpaste. Particularly for those with bulbar presentation of MND and sensitivity to strong odours that can set off a gag reflex.

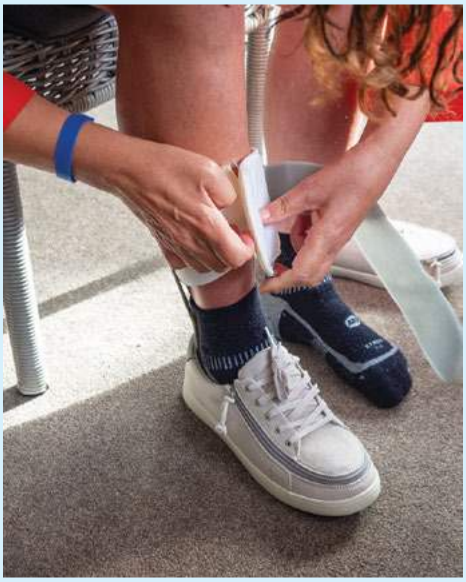
***Note:** These suggestions come from the lived experience of people with MND and their carers. They reflect personal preferences and may not be right for everyone.*

In bed

- A fitted sheet with a satin insert makes it easier to turn over in bed, with less friction and effort.
- Pet cooling mats to cool down burning feet/heels in bed.

Dressing

- Cut-away pants with full leg zips make toileting easier when using a wheelchair.
- Tops and t-shirts:
  - — Button-down t-shirts and zip-front cardigans are easier to manage when arms and shoulders weakened.
  - — T-shirts with buttons at the collar are also easier to get on and off.
  - — T-shirts with front zips (two-way zips) for ease of access for PEG feeding and dressing.
  - — For tops with zips, put a key ring loop through the bottom of the zip. A finger hooked into the circle will make it easier to pull the zip up or down independently.
- Billy shoes with side zips are lightweight, fit over an ankle-foot orthosis (AFO) brace and accommodate swelling better than flat canvas shoes.



Around the home

- Strips of Velcro (hook side) wrapped around a round doorknob gives extra grip for opening doors.
- A PVC poncho with side snaps help keep both the wearer and parts of their wheelchair dry in the rain. Luggage straps can be used to tuck in the loose corners.

Mealtimes

- Silicone or stainless-steel straws offer a practical, dignified alternative to sippy cups when out for coffee.

In the car

- A vehicle assist handle helps with getting out of the car.

Looking back, moving forward

- Keeping a daily log/journal/diary
- *"My one regret is that when my darling Don was suffering from this wicked disease, we never went through all our family photos and trips together. To those who know what's coming – please take that time. The memories are beautiful."*
- *"Every journey is different. Don't think too far ahead all the time, enjoy the here and now."*

Product links

Most of the items mentioned above can be found online, here are a few suggestions from our community:

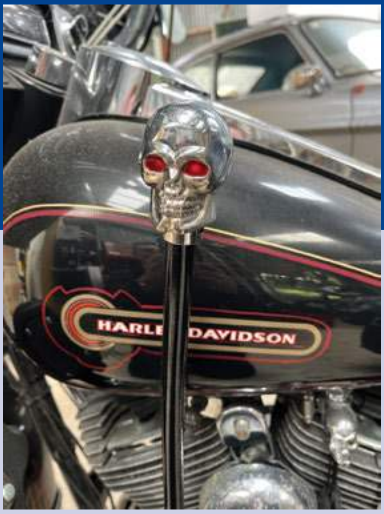
- Cut-away pants and button-collar t-shirts – aliexpress.com
- Billy zip shoes – shop.orthotichouse.co.nz and billyfootwear.com
- Pet cooling mats – animates.co.nz

Got something to add?

Have you found a clever trick, tool, or adjustment that makes life with MND a little easier? We'd love to include more tips and tricks in future editions.

Talk to your Support Advisor or email us at community@mnd.org.nz to share your tip.

Kevin Norton’s story of tools, tenacity and time



Behind a set of double doors on a quiet West Auckland street sits a place that hums with quiet energy. From the outside, it’s a shed. But to Kevin Norton, it’s home. A sanctuary. A life lived among machines. Now living with motor neurone disease (MND), Kevin has adapted his world around what he loves – proving that purpose and independence don’t stop with a diagnosis.

The shed is enormous. Around 22 metres long, eight wide, and tall enough to have once housed a 40-foot motorsailer. Today, it holds something far rarer: the independent life of a man with a passion for mechanics and a determination to keep moving. “It’s my own space,” Kevin says. “I live here. I work here. I don’t have to go anywhere. It’s just a good place to be.”

At one end is a warm living area with a wood-burning stove. In winter, it’s toasty, in summer, it’s sweltering. The rest of the space is alive with projects – vehicles in various states of repair, rust removal rigs, a repurposed hospital trolley, and his prized Holden Ute. “Hopefully, the Harley will take that title one day,” he adds, gesturing to the three-wheeled motorcycle.

There’s no set routine. “I just come out of my room and see where I go,” he shrugs.

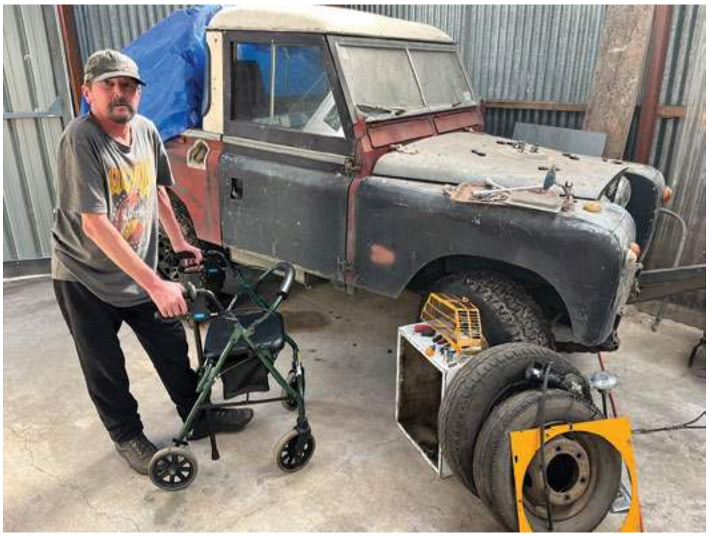
“There’s always something that needs tinkering.” On the workbench, a generator mount awaits rewelding. “My brother welded it, but backwards,” Kevin explains, smiling. “So, I took it apart, lined it up properly, and gave it back to him. I just do it. I can’t do anything else.”

A working life, built by hand

Kevin’s love of engines began early. At just 13, he bought his first car for $50 – money earned from doing a paper round. “It didn’t run,” he says. “So, I pulled it apart and learned from there.” That meant a full engine swap, and eventually, getting the car roadworthy and warranted.

From that point on, he was hooked. “Even if something didn’t need fixing, I’d pull it apart just to see how it worked.” It wasn’t just about fixing things – it was about understanding them. Systems. Mechanics. The satisfaction of figuring it out.

> *“It’s my own space. I live here. I work here. I don’t have to go anywhere. It’s just a good place to be.”*



Kevin Norton beside his Land Rover rebuild

He left school before finishing the fifth form. “The principal said, ‘You either come to school, or you don’t.’ So, I said, ‘I’m not coming.’”

He worked on a chook farm, then as a car groomer. A workshop manager noticed his instinct and offered him a mechanical apprenticeship. “That was it, really,” Kevin says.

Eventually, he spent over 26 years working at a local mill – first as a truck driver, then as a mechanic, then as second in charge of the workshop. “I knew the place too well,” he chuckles. “I’d even come in on Sundays to set everything up for Monday. No one asked me to. I just liked knowing the job was done right."

His perfectionism didn't stop at work. "I always did that little bit extra," he says. "People used to say I was too much of a perfectionist. But that's just how I was."

Improvise, modify, carry on

Kevin was diagnosed with Primary Lateral Sclerosis (PLS), a slower-progressing form of MND, in December 2018. "I'd been having symptoms since late 2016. Tripping, dragging my feet.

"My GP sat me down and said it was likely motor neurone disease."

His reaction? "Shit happens," he says plainly. "I didn't even know what it was. I figured I'd just keep going."

That's exactly what he's done. When a hip fracture made it difficult to navigate his shed, Kevin's brother Gary stepped in and helped clear a safe pathway. "There was a time I felt trapped in my room. Couldn't get out the other side of the shed. But now I can."

Kevin's walking frame doubles as a mobile toolkit. "There's a space under the seat. So, I thought I might as well fill it with tools."

His grip has weakened, but his determination hasn't. "I can't undo bolts like I used to, so I improvise. Modify. Whatever it takes." Technology has become a valuable ally.

"I never owned a computer until lockdown," he says. Now he uses it to research parts and find solutions online. "Most of what I need is easier to get from Aussie than here. I scribble notes, I Google stuff. It helps."

Making time count in his own way

Kevin's shed is full of stories. There's a toolbox he's had since he was 17, now perched on an old hospital trolley salvaged by his brother. His parents' ashes rest on a shelf beneath the flags of England and Wales – a nod to his father's and mother's heritage. "I'd have liked to go there one day," Kevin says. "I was born in Australia, but we moved here when I was three. I've never left New Zealand since."

Kevin's shed isn't just a workspace, it's a museum of memories and oddities, with stories tucked into every corner. Fantails regularly dart through, as if on cue. "They do a loop, chatter away, then fly out again," he says. In a drawer, an old video player still works. And in a family anecdote that feels almost too good to be true, his brother once cooked for David Bowie during a tour stop in Auckland.

"He was working at a hotel at the time. Bowie even signed one of his records."

Even his old workplace had its wild moments. "I was inside a boiler once when a tornado came through," he recalls. "Suddenly, I hear this roar. Next thing, a river of water comes rushing past my feet." He pauses. "Pretty close shave."

He doesn't talk about legacy. But it's here in the order of his tools. In the old tyres shifted to create a safe path. In the Chevy he dismantled during lockdown, to stay busy. Ask him what he'd tell someone newly diagnosed with MND, and the answer is simple: "Just keep going. Don't sit in a corner and wait. You don't know how much time you've got, so keep as active as you can."

He still dreams of getting the Harley running again. "My sister said she'd love to see me ride it." And you believe him because everything about Kevin Norton says: still going, still building and still moving.

Here for you

Our charity was built on the ethos of helping people affected by MND – it's the cornerstone of all we do.

If you or a loved one has MND, we're here for you. Our team of compassionate regional support advisors provide free, personalised support and advocacy to people with MND and their loved ones.

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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 for those affected by MND today, as well as funding research for a brighter future.

Ways to support

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

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