mnd
Motor Neurone
Disease NZ

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MND News

Winter 2025

Magazine of the Motor Neurone Disease New Zealand Charitable Trust

> “If I could leave a legacy, it would be that I made someone’s day a little bit brighter, a little bit easier, and a little less of a struggle. That I walked beside them.”
> – Rachel Woodworth

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www.mnd.org.nz

Message from our Chief Executive

Kia ora koutou,

As I write this, we've just had our first decent frost of the year here north of Christchurch – a sure sign that winter is upon us and that June's MND Action Month is close.

This issue shares some of the work we're doing to strengthen our fundraising and awareness efforts, and why Action Month remains a vital part of how we support the MND community.

Among our international colleagues, we might seem a little mad to carry out the Ice Bucket Challenge in the middle of winter – but it's part of what makes the New Zealand spirit so special. We're embracing that 'shock to the system' again this year and finding new ways to bring people together in support of the MND community.

You'll also find an update on our growing partnership with Bunnings for our nationwide sausage sizzles – a uniquely Kiwi phenomenon that continues to draw great support. In response to strong demand, we've introduced the MND beanie, which we're confident will stand out in the crowd.

On a more personal note, I've had the privilege of joining support group meetings in Dunedin and Wellington recently. These gatherings remind me how vital connection and peer support are – and how much people value the chance to share, ask questions, and feel heard. From practical advice about navigating the health system to broader discussions about advocacy and research, these sessions reflect what our organisation is all about.

This year's major highlight has been completing the data-gathering phase of the MND Insight Survey, led by Principal Investigator Dr Natalie Gauld, our Research Advisor and Best Practice Advocate. This is the most comprehensive survey of its kind ever undertaken in Aotearoa, and the results will give us a powerful evidence base to present to funders and policymakers. Thank you to everyone who contributed – your voice matters.

However, there is still much to do. The health and disability systems remain under pressure, and we continue to advocate strongly on behalf of people with MND and their whānau.

Ngā mihi nui

Mark Leggett

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Cover: Support Advisor Rachel Woodworth reflects on the privilege, challenges, and deep human connection at the heart of her role with Motor Neurone Disease NZ.

A special thank you

Our heartfelt appreciation goes out to the people below for their support in making the MND News Winter 2025 issue a reality.

minimum graphics for the design and layout of MND News

Stewart Motorsport for sponsoring the printing

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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

Make time count this June → *See page 9*

Nationwide Sausage Sizzle – 28 June

Join us at **Bunnings stores across the country** for a community sausage sizzle. Every sausage, drink, or beanie sold helps raise funds and awareness for MND.

Handcrafted Cuppa Tea Sets

Created with care and connection, these limited-edition ceramic cup and saucer sets are available through the **MND NZ shop.**

Each piece is:

- Hand-thrown and glazed in transparent blue
- Stamped with the MND cornflower emblem
- A tribute to the resilience of our community

Crafted by Michelle and Jacqueline, whose family journey with MND inspired this beautiful collaboration.

To sign up or find out more, visit www.mndactionmonth.org.nz

Rachel Woodworth on the heart of her work

For MND Support Advisor Rachel Woodworth, connection, honesty, and presence are the cornerstones of care. In a role where time is precious and there are no easy endings, Rachel offers something just as valuable: someone to walk beside you.

When Rachel Woodworth walks into a room, she rarely wears shoes. Not just because she prefers the freedom of bare feet, but because her clients with motor neurone disease (MND) have come to know her that way. "If I go to see a client now with shoes on, they'll say, 'What is the matter with you?' They love that I'm real."

Authenticity is at the centre of everything Rachel brings to her role as an MND Support Advisor. From her early days in trauma nursing and injury prevention to working with the Muscular Dystrophy Association, she describes her current position as one where her life experience, professional knowledge, and deeply held values finally converge. "It feels like it's a role where I can bring together all of my experience, my morals – all of that mixed in as one."

Now in her sixties (though 27 on the inside, with six decades of life and relevant work experience to draw from), Rachel is both grounded and passionate. She's known among colleagues and clients for her positivity, her boundaries, her unfiltered honesty, and her refusal to sugar-coat the reality of MND. "This is a really difficult role to err on the positive side in," she admits. "Because there isn't a happy ending."

And yet, day after day, Rachel finds a way to offer light.


Rachel travels to visit people with motor neurone disease (MND) in their homes.


Rachel has worn many hats – from nurse to MND Support Advisor – always led by compassion.

Being present in the hardest moments

"Time really, really matters." It's a refrain Rachel returns to often, especially when talking about the frustrations that come with system delays and under-resourced health services. "Sometimes, by the time our clients get the equipment they needed six weeks ago, it's no longer useful because their condition has progressed."

Rachel sees her role as providing consistency in a sea of uncertainty. "Health professionals will come and go in my clients' lives, but I'm a constant presence. The relationship that I've formed with my clients is a very trusting one."

What does that look like on a day-to-day basis? Listening. Sitting quietly. Tapping her toes to stay composed while someone shares the weight of their fear. Offering a smile. A joke. Or a simple moment of shared humanity.

My role is to support them. Sometimes, all they want is someone to give them time – because time is uncertain. It's the one thing clients don't have much of, or have little control over. Time, quality time, is of the essence".

She recalls one home visit where she simply sat in the sun with a client, neither of them speaking much. “It was one of the most meaningful visits I’ve had. Sometimes just being there is enough.”

Making a difference, one small thing at a time

Rachel believes the little things can be transformative. “One of my clients hugs me whenever I deliver paper towels,” she says with a smile.

That story began with a routine visit, during which Rachel learned the client’s family was spending over half of her disability allowance on paper towels. “It’s been life-changing for the family.”

From equipment to emotional support, Rachel tailors her approach to each individual. She understands that every journey with MND is different. “If they don’t have positives that come readily available, I share my positives and lift them up.”

She draws strength from the gratitude she receives. “They’re just eternally grateful for us as an organisation. Somebody to walk the journey with them. It’s very rewarding in a weird, weird sort of way.”

She’s also quick to credit the support of her wider team. “We don’t do this alone. Having people around you who care just as deeply is part of how we sustain each other.”

Boundaries and balance

With so much emotional labour involved, Rachel is clear about her need for boundaries. “I have to have boundaries so that I can go back in on Monday and be fresh, bubbly, and smiley – and be my authentic me again.”

That means taking Fridays off, dancing on the beach, journalling in the sun, and surrounding herself with people who feed her soul and make her laugh. “I do the best job that I can do Monday to Thursday, and then I have the best time that I can have Friday to Sunday.”

She’s also found unexpected rituals that help her reset. “I have a playlist that I dance to when I need to shake things off. Music helps me reconnect to the lighter side of life.”

Her clients may be the focus of her work, but Rachel has also learned to honour her own wellbeing: “My work is part of my life, it’s not my whole life.”

A legacy of light

Rachel doesn’t shy away from conversations about death or advocating for a good one. “What constitutes a good death is being in control, having all of your affairs in order, being comfortable, being surrounded by loved ones, and it not being a struggle.”

Support visits with Rachel are full of warmth, energy, and genuine connection.

She recalls one client who chose assisted dying and did so with clarity and courage. “She was a legend. I think we would all think differently if we were told that on a specific date, that’s your death day. We are flippant with time.”

Rachel is determined not to be flippant with hers. She sees the privilege in reaching sixty. “Everything’s a bonus from here. Life is very precious. And a good life is even better.”

She often reflects on the people who influence her work ethic and outlook. Chief among them is her late father, a practical, optimistic farmer whose presence she still feels in the form of monarch butterflies. “His analogy was, you can’t do anything about the weather; you’ve just got to wear the appropriate clothing”, and, “if you’re going to do a job, be the best at it!”

Rachel is certainly someone who walks through all seasons prepared – barefoot, real, and resolute.

“If I could leave a legacy,” she says, “it would be that I made someone’s day a little bit brighter, a little bit easier, and a little less of a struggle. That I walked beside them.”

> *“If I could leave a legacy, it would be that I made someone’s day a little bit brighter, a little bit easier, and a little less of a struggle. That I walked beside them.”*
>
> – **Rachel Woodworth**

Inside the New Zealand MND Registry

In a secure corner of the University of Otago, neurologist Dr Sarah Buchanan and researcher Dr Margaret Ryan are building something quietly powerful. The MND Registry is helping to map motor neurone disease (MND) in Aotearoa – connecting people to research, uncovering patterns, and creating a legacy of knowledge to guide care and understanding for years to come.

What is the MND Registry?

A registry of people living with motor neurone disease (MND) in New Zealand sits behind firewalls in the highest-security research databases at the University of Otago.

Over two hundred people are currently on the MND Registry. Their confidential data and details make up what the registry's Primary Investigator, Dr Sarah Buchanan – a consultant neurologist at Dunedin Hospital and researcher at the University of Otago – describes as a kind of "Swiss army knife" project: a small, focused initiative designed to support many functions, from improving care to driving research and advocacy.

"Basically, we're aiming to identify all people with motor neurone disease living in New Zealand, to understand more about their MND, and how they're getting on. For those who want to, we're aiming to use that connection to help them engage with other research opportunities," Dr Buchanan says.

From pilot to powerhouse

The Registry, funded entirely by Motor Neurone Disease New Zealand, was initiated in 2017 and curated at Auckland University. In 2024, with a view to expanding the registry's depth and capability, it shifted south to the University of Otago and is now overseen by Dr Buchanan, alongside Curator Dr Margaret Ryan, a Senior Research Fellow in the University's Departments of Medicine and Anatomy.

An immediate target for the pair is to enrol everybody with MND in New Zealand. It's understood that approximately four hundred New Zealanders live with MND at any given time. Knowing as much as possible about MND can bolster efforts for further research into effective therapies and care, improving quality of life, and finding a cure.

> *"MND generally progresses very rapidly, and having a Registry like this is something we need to have done yesterday."*
>
> **— Dr Margaret Ryan**

MND Registry Curator, Dr Margaret Ryan, and Primary Investigator, Dr Sarah Buchanan.

Registering simply involves completing a basic consent form, which can be completed online or with the support of an MND NZ support advisor or practitioner. Nothing else is needed from the person with MND, the information comes from the MND clinical records. Dr Buchanan says even the most general details help put pieces of the MND jigsaw puzzle together.

"Even if it's just gathering data about who's getting MND, how many people are in different regions, and how they're doing, that information is really powerful. It lets us connect to advocacy, look at benchmarks in MND care across the country and internationally, and gives us the power to plan other projects as well," Dr Buchanan says.

Momentum and meaning

Dr Ryan's role involves compiling and analysing the Registry's data and helping to connect it with research projects. She's eager to see greater momentum in MND research and care, driven by the Registry's valuable insights.

"MND generally progresses very rapidly, and having a Registry like this is something we need to have done yesterday. The more information we have, the more we can do- especially in supporting research that directly benefits those affected here in New Zealand," says Dr Ryan.

The Registry has already contributed to over a dozen research projects. As the number of people on the Registry grows, Dr Ryan believes there is significant potential to gain a greater understanding of why MND appears to be so prolific in New Zealand.

"Some of the previous research suggests that New Zealand has one of the highest rates of MND anywhere in the world, but we still have a lot to find out about what makes MND in New Zealand different from everywhere else. There's still a huge amount to learn."

Whilst Drs Buchanan and Ryan both want to see an uplift in people with MND joining the Registry, they're also aware that simply living day-to-day with the disease can be a fight in itself.

Dr Natalie Gauld (left), Research Advisor and Best Practice Advocate for Motor Neurone Disease NZ, with Margaret and Dr Sarah Buchanan, collaborating to grow the MND Registry.

"We know that many people out there would like to be part of research, but are limited in energy and time. But we would like everybody to know that they can still make a valuable contribution. Even just by signing the consent forms, we're able to get a really precious input from them – as we can use their MND information and therefore count everyone living with MND as part of seeing the bigger picture," Dr Buchanan says.

An essential aspect of the Registry's characteristics is the high level of security encryption and confidentiality of the data. When a person joins, the Registry staff, namely Drs Buchanan and Ryan, can collect information from their clinical records related to MND, anonymising that information for research use.

> *"We're aiming to identify all people with motor neurone disease living in New Zealand, to understand more about their MND, and how they're getting on."*
>
> **— Dr Sarah Buchanan**

Registry data is stored anonymously in a secure database maintained by the University of Otago. No one outside of the MND Registry has access to the names of people enrolled.

A quiet legacy

The Registry also carries a quiet legacy. For many, the contribution of their MND information continues beyond their lifetime. By making this data available for future research, they are helping to grow understanding of the disease and support others in the MND community. Data for 400 people with MND – including 200 currently living with the disease – is now in the Registry, with all leaving a legacy to help the MND community in the future.

Drs. Buchanan, Ryan, and MND New Zealand have set a lofty goal of having everyone living with MND in New Zealand join the Registry. With over two hundred people already signed on, and around four hundred people living with the disease here, there is plenty of scope to increase the pool of knowledge.

"Contributing to research is important for so many reasons, but ultimately, what we hear from this community is the need for better care and to carry out research that brings us closer to finding a cure. The Registry can play a small part in that on quite a few levels," Dr Buchanan says.

How to take part

People who are clients of MND NZ for connection with a support advisor and other support are not automatically part of the MND Registry.

Anyone with MND who would like to learn more or join the MND Registry can speak with their MND NZ support advisor, talk to their health practitioner, or enrol directly online at mnd.org.nz/research/mnd-registry. If you're unsure whether you're already part of the Registry, contact Registry Curator Dr Margaret Ryan at mndregistry@otago.ac.nz or call 0800 MND REG (0800 663 734) – she'll be happy to help.

> *"There's still a huge amount to learn."*

David Seymour

In memory of David Seymour, 1963–2025

In April, we lost David Seymour, a passionate advocate, generous spirit, and much-loved member of the MND community.

Diagnosed with motor neurone disease (MND) in 2020, David met his illness with courage, clarity, and creativity. Determined to face MND on his own terms, he used humour and storytelling to shift the narrative – and raise vital awareness.

One of his most well-known projects was David's Unusables – a unique and disarmingly honest Trade Me auction, created with Special Group, where he listed items he could no longer use because of MND. The listings were raw, funny, and poignant, and they struck a chord across Aotearoa. The campaign raised not only funds but visibility for what it means to live – and lose – with MND.

David also became a prominent voice in the campaign for assisted dying. His advocacy helped humanise the complex debate and brought a real-life perspective to the End of Life Choice Act referendum in 2020. He remained fiercely independent in thought and spirit, with a deep belief in autonomy, compassion, and dignity.

At his funeral, a poem written by David was read aloud. It is part protest, part prayer, part playlist – a final message from a man who lived honestly, laughed loudly, and never once put his hands up to surrender. We share it here with the permission of his whānau.

David's poem

Me & MND

By David Seymour

I wanna just keep walking, no more fast car driving. But I'm on the highway to hell, I don't wanna miss a thing. There's smoke on the water, fire in the sky, cruising down the highway. Will I ever see your face again?

Working on the night moves. Sometimes I feel I'm just dancing in the dark. There's something happening somewhere, I just don't think I'll get there.

Don't know how to say how I feel. Maybe just lie here and forget the world.

I won't put my hands up and surrender. There will be no white flag above my door.

Should I stay or should I go? It's this disease that's killing me. Listen to the wind blow, watch the sunrise one more time. Don't you forget about me, for today remember my smile, because one way or another we can be heroes just for one day. We could steal time and they could never ever tear us apart.

I'm just a working class man. The time will come, it's just not now. I'm not ready. We need to play that funky music till I die. Let's take it to the limit one more time. With a rebel yell I cry more more more!! It will be like a blaze of glory knocking on heaven's door.

Why does this disease do this to me? I don't know, I don't know, How bizarre how bizarre!

I won't put my hands up and surrender. There will be no white flag above my door.

As I walk through the valley of the shadow of death I take a look at my life and realise there's fuck all left. There is no better day than today. However it's more than a feeling, I don't dream it's over. Only the good die young so take those old records off the shelf I'll sit and listen to them by myself.

How the hell did I wind up like this? It's because they still haven't found what they're looking for, still no treatment no cure. My future in the system has been talked about and planned. It's a walk on the wild side just drink yourself more bliss. Forget about the last one get yourself another.

Even heroes have the right to dream. I just want another day in paradise.

I won't put my hands up and surrender. There will be no white flag above my door.

If the sun comes up tomorrow let it be. You really got me now you got me so I can't sleep at night yeah you really got me now.

Look at my life all tatted and torn. Hold me now, stay with me. One day there will be an answer, lord let there be an answer. Right now I can't get no satisfaction. I'm only human after all, I'm only human after all so why put this pain on me oh don't bring me down.

Each day is a gift not a given right. As I slip away into another place I dream of a world free of bloody MND! I'm a dreamer I dream away to pass the time of day.

One thing I can tell you is I want to be free, free of bloody MND.

I won't put my hands up and surrender. There will be no white flag above my door.

Make time count this June

Are you going hot or cold for MND?

MND ACTION MONTH

June is **MND Action Month** – a time to come together, raise awareness, and take action for New Zealanders living with motor neurone disease (MND).

Whether you're tipping a cuppa or pouring a bucket of ice, every action helps make time count for those affected by this devastating disease.

MND is a rapidly progressing condition that impacts movement, speech, and independence. There's no known cure – but with your help, we can fund vital research, improve quality of life, and grow support for people living with MND in Aotearoa.

How you can get involved

MND ACTION MONTH Cuppa Tea For MND

Host a Cuppa Tea for MND

Host a morning or afternoon tea with your whānau, friends, workplace, club or school – and ask for a donation to support MND research and care. It could be as simple as a cuppa in the staff room or something more elaborate like a High Tea. If you're a business, why not offer a tea-and-cake bundle with proceeds going to MND?

You can also join one of our **community support group cuppas** happening across the country:

- **Taranaki** – 18 June
- **Cambridge** – 25 June
- **Auckland & Dunedin** – 2 July
- **Christchurch** - 7 July

Everyone is welcome – people with MND, families, friends, health workers, and carers. Please contact the area support advisor for details and to RSVP.

MND ACTION MONTH ICE BUCKET CHALLENGE

Take on the Ice Bucket Challenge

Nominate a game chief executive, principal, or team leader to take the plunge once your fundraising goal is reached. Bonus points if you choose an iconic or meaningful location! You could also rally a group of volunteers, collect votes by donation, and soak the person with the most. For extra fun, auction off the bucket-tipper role.

Help spread the word by tagging us in your photos and using the campaign hashtags – every post helps raise awareness and build momentum.

Facebook:	@mndanz #MNDActionMonth #IceBucketChallenge
Instagram:	@MND_NZ #TipOrPour #CuppaTeaforMND

Wear It, Share It, Support It

Limited Edition MND Beanies

More than just a beanie – it's a statement of solidarity.

Available exclusively at **Bunnings stores nationwide from 20–29** June for $25, while stocks last.

Each beanie features:

- A leather-style MND NZ patch
- The iconic Ice Bucket Challenge logo
- A soft, high-quality design perfect for winter

Every purchase helps fund advocacy, research, and support for people living with MND.

Brothers with a cause: Trekking for MND

Brothers Mat and Darren Bowling took on the adventure of a lifetime – a demanding trek up Mt Kilimanjaro – in honour of their father, who lived with motor neurone disease (MND). The brothers signed up for the challenge to raise funds, share memories, and push themselves outside their comfort zones. What followed was a journey of connection, endurance, and reflection.

When Darren spotted an MND NZ newsletter mentioning a fundraising trek up Mt Kilimanjaro he sent it to his brother Mat with a simple idea: what if we did this? It would be a chance to spend time together, honour their father's memory, and raise funds for a cause close to their hearts.

"The motivating factors for doing the trek were about bringing Darren and me together for a block of time and raising money for an organisation that supported Dad and ourselves," says Mat. "We knew little about the disease when Dad was diagnosed, but MND NZ was there with advice and support."

The trek wasn't a reflection of their dad's life – he wasn't an adventurer or a hiker. He was a private, hardworking businessman who started with little and built a successful career. He had a strong faith and a quiet resilience.

"He wasn't someone who asked for help," says Mat. "He lived on his own for the last ten years of his life and passed away in his own home, which was important to him."

Darren adds: "I think Mat and I walking up a mountain reflects parts of his personality – one foot at a time, plan well, keep going."

Mount Kilimanjaro set the stage for an unforgettable trek in support of people with motor neurone disease (MND).

Training and trust

Training for a high-altitude trek while living at sea level wasn't simple. Mat, who lives in Papamoa, found himself climbing the local hills and Mt Maunganui repeatedly to build endurance. "The big thing was just getting miles on my legs," he says.

The physical side wasn't the worry – it was the altitude. "You can't simulate that. You have to experience it and see how your body reacts. And that's what ultimately crippled me during the trek."

Fundraising also brought its own challenges. Mat hadn't done anything like this before. "I procrastinated for months before sending anything out," he says. He eventually put up a post on LinkedIn and reluctantly joined Facebook. "Unfortunately, I hadn't established a network of friends on Facebook, so I'm not sure that was worthwhile."

Despite the hesitations, the response was humbling. Together, they raised just over $15,000 for MND NZ, a result that left them both incredibly grateful and proud. "I was blown away by people's generosity," says Mat.

On the mountain

The brothers flew into Zanzibar before heading to the base of Kilimanjaro. The long-haul travel was gruelling – over 40 hours door-to-door – but it gave them a chance to reconnect.

"During the time that Dad was ill, we saw and spoke to each other a lot. But it was great to spend a decent chunk of time together again," says Mat.

From the first steps on the mountain, the sheer scale of the operation was unexpected. "There were four of us doing the trek, and about 17 people supporting us – carrying the tents, food, chairs, everything. It was a very humbling experience," says Mat.

The camaraderie with other trekkers stood out too. The brothers partnered with MND Victoria and found shared values and stories among two fellow hikers from Australia. “It made it all the more special,” says Mat.

Darren agrees: “They were lovely people and great to meet. Both of them had had a recent bereavement, and both work in healthcare or related industries. What came across to me was that they were people who are passionate about other people and work in the space of helping others. They are pretty special individuals.”

Digging deep

Altitude sickness struck Mat hard. By the end of day two, after a climb of over 1,000 vertical metres, his body began to shut down. The next day brought another 600 metres.

“At the end of that third day, I was a crumpled heap in the tent. I could barely lift my feet. Darren took my pack for the last stretch,” Mat recalls. “In my head, I thought I might make it to the next camp, but I knew there was no way I was reaching the summit.”

Even though he didn’t make the top, he has no regrets.

“My two goals were to raise money for MND and to spend time with Darren. Reaching the summit was third on the list. And my body just wasn’t going to let me go further.”

Mat takes a breather on the Kilimanjaro trail.

Each morning brought purpose – walking for loved ones and the MND community.

Mat and Darren with fellow trekkers on the slopes of Mt Kilimanjaro.

The real reward

“There wasn’t one euphoric moment – it was the whole experience,” says Darren. “The conversations, the shared purpose, the sense of doing something that matters – that’s what stayed with me.”

Darren spoke of the quiet satisfaction in the everyday moments: lacing boots, sharing tea, tidying up after a long day. “It’s that camaraderie. It’s hard to explain, but you feel it.”

Looking back now, Darren describes the experience as deeply grounding. “The trek was tiring. It took a few days to recover and recoup. I was drained. It didn’t have a euphoric peak, but there was a satisfaction with the whole experience. It was a whole adventure, rather than a moment.”

Would they recommend it?

“Just do it,” says Darren. “It magnifies your sense of purpose. It’s good for your soul.”

“You can always find a reason to say no,” adds Mat. “But I’m glad I didn’t. This felt really nice – to do something that wasn’t for myself.”

While Mat jokes that high-altitude hiking is probably not for him, he says the experience was harder – and more rewarding – than he expected.

“Yes, I was disappointed not to make the summit. But I’m incredibly proud of what we achieved – the walk, the connection, and the fundraising for an incredibly worthwhile organisation.”

> *“Just do it. It magnifies your sense of purpose. It’s good for your soul.”*
>
> **— Darren Bowling**

MND Insight Survey – Thank you

Your voice matters: thank you for taking part in the MND Insight Survey

People across the MND community generously shared their experiences in our recent MND Insight Survey. Principal Investigator Dr Natalie Gauld extends her heartfelt thanks and explains how your contribution will help shape better support, care, and understanding.

We are grateful to so many people in the MND community who shared their experiences and thoughts in our recent surveys. We asked a huge number of questions, and I know it sometimes took hours to complete. We appreciate you putting so much time and effort into this research – particularly knowing that some of you used eye gaze technology to do it.

As I work through the analysis, I'm finding many nuggets of gold that will be useful in advocacy for our community – showing where we need change and providing evidence we can use to help achieve that change. It will also stimulate further research and be used to update health professionals and others working with our community.

We know that, for some people, the system is working well in many ways. People appreciate their "proactive OT," the way the diagnosis was delivered, support from friends and whānau, cough machines delivered without delay when needed, and a power wheelchair arriving in time. In a pressured health system, it's good to know that people with MND can be well looked after, and that there are many helpful health professionals.

At the same time, the survey helps us focus in on where there are problems – for example, a power wheelchair arriving too late, challenges getting a ramp promptly, or a diagnosis delivered poorly – and work with Te Whatu Ora and providers on how we can minimise these. We need the system to work faster where the disease is moving fast. The evidence from this survey will be extremely helpful in advocacy.

The survey analysis and reporting will take some time, as the information gathered was so extensive. We are analysing the data with academic robustness and look forward to sharing our findings with you in the coming months.

The research team includes two neurologists, Dr James Cleland and Dr Sarah Buchanan, Associate Professor Stephen Buetow, Dr Jo Hikaka, Dr Sandy Rutherford, Dr Julienne Faletau, and Tamzin Brott. We are grateful for their assistance in developing this work. We are also very grateful to many in the MND community – and staff at Motor Neurone Disease New Zealand – who provided feedback on the initial idea of the survey and on the survey itself as it was developed. This survey has been jointly funded by the Health Research Council and Motor Neurone Disease New Zealand.

Thank you once again for your valuable contribution.

Dr Natalie Gauld
Principal Investigator, Research Advisor and Best Practice Advocate
Motor Neurone Disease NZ

Dr Natalie Gauld

> *"The survey helps us focus in on where there are problems – for example, a power wheelchair arriving too late, challenges getting a ramp promptly, or a diagnosis delivered poorly."*

Support when it's needed most: the MND Support Fund

Being diagnosed with motor neurone disease (MND) changes everything. It brings a steep learning curve, tough decisions, and a sharp shift in what daily life looks like. For many people, it also brings financial pressure – especially when the public system can't keep pace with urgent needs.

That's where the MND Support Fund comes in.

Managed by Motor Neurone Disease NZ, the fund provides timely, practical support to people with MND, their carers, families, and whānau. It's not here to replace government funding – but when delays or gaps start to affect wellbeing, the Support Fund can step in to help.

Grants from the fund have helped cover everything from home modifications and respite care to mobility equipment and essential household support. It's a safety net made possible by two generous partners and the ongoing support of the MND community.

Support rooted in advocacy

Every application to the Support Fund is made through one of our skilled and compassionate Support Advisors. As well as helping people navigate the public health and disability systems, our advisors advocate for individuals to receive the full support they're entitled to. But when that system falls short – and it often does – they can help secure assistance from the Support Fund. It's all about meeting real needs, quickly and fairly.

Why the fund is needed

The Support Fund was created because too many people with MND were left without access to support they urgently needed. That gap hasn't gone away. In fact, demand continues to grow – driven by rising living costs and increasing need. That's why growing and maintaining the fund remains a top priority.

A new partnership: welcoming the Jubilee Trust

The Support Fund was first established with the support of Fulton Hogan, who remain a vital partner in making this mahi possible. In late 2024, the Jubilee Trust came on board as a second sponsor. Together, these two sponsors enable national reach, with each supporting a specific region of Aotearoa. Their combined generosity has doubled the fund's capacity and ensured that more people receive timely, practical help. We are deeply grateful to both Fulton Hogan and the Jubilee Trust for their commitment and care.

What kind of help is available?

The Support Fund offers three types of targeted grants:

- **Client Support Grant** – Up to $1500 to support a person living with MND, where other funding options are unavailable or delayed.
- **Carer Support Grant** – Up to $750 to support carers or whānau, including for short breaks or time to recharge.
- **Hardship Support Grant** – Up to $750 to assist with essential household costs, where no other support is available.

All applications are assessed by the MND NZ Support Fund Committee. Funding is limited and allocated based on need and impact.

Who can apply for grants?

The Support Fund is available to anyone in New Zealand currently receiving support from Motor Neurone Disease NZ, as well as their immediate families, whānau, and carers. To be eligible, the person with MND must have met with a member of the MND NZ Support Team and signed a Client Consent form. Support Advisors guide applicants through the process, helping ensure each application is well supported and meets the criteria.

Making time count

The impact of this support is best captured by the voices of those who've received it:

"Receiving help for a mobility scooter meant I could keep getting out for walks with my partner. We're still making memories, and I'm so thankful for that."

"The Support Fund helped pay for home modifications that made life safer and less stressful. It gave us a sense of control during a really uncertain time."

These stories reflect the heart of what the fund is all about – helping people with MND make time count.

How to apply

If you or someone you care for is living with MND, talk to your Support Advisor. They'll walk you through the process and help with the paperwork. Or contact us directly at support@mnd.org.nz.

The MND Support Fund exists because of community, generosity, and compassion. Every grant given is a reflection of that spirit.

Wayne’s way: Adapting to life with MND

Diagnosed with motor neurone disease at 70, Christchurch local Wayne Richards shares how family, humour, and positivity help him live fully in the present. “Motor neurone disease is part of my life,” he says, “but it doesn’t define me.”

Wayne Richards has lived a full and varied life. Born and raised in Christchurch, he spent decades working in the printing industry, beginning as a teenage apprentice fixing typesetting machines and eventually becoming an expert in electronics as the trade modernised. But it was people – not machines – that always mattered most.

“My family and friends have always come first,” he says. “I’ve got five kids, and they filled big chunks of my life. I loved entertaining and doing things with them. I’ve always been social, always busy.”

Sport was another passion. Wayne describes himself as a “typical Kiwi boy” who loved rugby and snooker and later supported his sons in their own sporting pursuits – one even represented New Zealand in futsal. “I’m an armchair critic now,” he jokes, “but back in the day, I tackled the biggest guys on the field and bowled them over.”

Wayne spent his weekends tinkering in the garage, building things with his hands. “I liked to keep busy. I always had some project on the go, whether it was working on cars, DIY around the house, or helping friends with odd jobs,” he says. “I’m not one for sitting still.”

Wayne was 70 when he was diagnosed with motor neurone disease. Looking back, he remembers the small signs – a limp, trouble walking, and one oddly symbolic moment: “I used to joke around with my partner, Sharon, while making the bed, jumping on it like a gymnast. One day I realised my feet wouldn’t leave the floor.”

His GP noticed something off in his gait and referred him to a neurologist. What followed was months of tests. “They did all these electrical tests on my arms and legs, and finally the neurologist sat me down and told me straight out: ‘You’ve got motor neurone disease.’ I didn’t even know what it was. I felt numb.”

That day, Wayne had a family funeral in Dunedin. “I was in shock, but I had to get on with it,” he recalls. “My partner Sharon drove, and I sat in the car, ringing my kids one by one. I can’t remember the trip – it was a blur of phone calls and emotion.

“When we got back from the funeral, Sharon organised a family meeting. We stood in the middle of the room, hugged, and cried like babies.”


With whānau by his side, Wayne joins the Walk to Defeat MND – raising awareness, showing strength, and celebrating community.

Choosing to live, not just cope

Rather than dive into research, Wayne chose a different route. “My daughter and Sharon found out everything we needed to know. I decided I didn’t want to sit and read screeds of stuff about MND. I live with it every day. It’s not the whole of me.”

That philosophy flows through everything Wayne says. “I’m living the best life I can. I’ve still got a normal life to live – well, as normal as I can. And I meet other people with MND through the support group here in Christchurch. We give each other a bit of a lift."

Wayne is now 74. He lives independently, supported by daily visits from Sharon, and he sees his children every week. Mobility is his biggest challenge. "I'm a furniture hopper around the house," he laughs, "but I use a power wheelchair when I'm out." He sold his red BMW to buy a van that can carry the chair. "That's how you adapt," he says simply.

His home is a place of independence and pride. "I love being able to still do things for myself. Even simple stuff like getting a meal ready or pottering about – it makes you feel you're still living your own life."

He still cooks his own meals when he has the energy, and Sharon and his daughter help fill the freezer for days when he doesn't. "I'm a bit pedantic," he admits. "I like my Ts crossed and my Is dotted."

It's a detail that reflects Wayne's lifelong curiosity and care. In his early years, he fixed mechanical typesetting machines. When the printing industry shifted to electronics, he taught himself to keep up. During lockdown, he took up model shipbuilding again, though he laughs that his first effort was such a mess he gave it away.

"One thing about MND," Wayne says, "you learn to laugh at yourself. Otherwise, you'd cry. You've got to keep a sense of humour. It's essential."

Wayne is a familiar face in the Christchurch MND support group, especially for people who are newly diagnosed. "We're like a family of strangers," he says. "It sounds weird, but it's true. When someone new joins, I try to meet them with a positive face. I like to crack the odd joke and make people feel at ease."

The power of perspective

What does resilience mean to Wayne?

"It means being able to bounce back. To pull yourself out of dark places. You won't have great days every day, but if you can enjoy the ones you do, that's something."

Wayne is realistic about the challenges but refuses to let them define him. "Sure, there are tough days. Days where you're frustrated or sore or tired. But they're just days. They don't take away who you are."

His message to others facing MND is simple: "Do the best you can, every day. Keep fighting the good fight. Everyone finds their way to cope."

Wayne credits his outlook to his mum. "She was open, joyful, and liked a laugh. I think I got that from her."

Family remains his anchor. "I see my daughter every day. I talk to my other kids and grandkids all the time. They give me strength, even just hearing their voices."

> *"Motor neurone disease isn't my whole life. It's part of it. It doesn't define me."*
>
> **— Wayne Richards**

As for what he hopes people take from his story?

"I hope it helps make things better for others. That it shows MND is only as scary as you let it be. I go head-on at things, just like I did with the 6ft 6 prop I used to tackle on the rugby field. Head on. Otherwise, you die."

At the heart of Wayne's story is a simple but powerful truth: while motor neurone disease has changed aspects of his life, it has never taken away the man he is – resilient, independent, and endlessly determined to live with humour, dignity, and love.

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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Web: mnd.org.nz

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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
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