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MND News

Spring 2026

Magazine of the Motor Neurone Disease New Zealand Charitable Trust





Welcome from our Chief Executive

Nau mai haere mai – welcome to the Spring 2026 MND News

Like spring itself, this year has been about growth and nurturing the seeds planted in well-tended ground. I'm incredibly grateful to our team, and our supporters, community fundraisers and grant funders who have made our mahi possible.

More support and education

We've welcomed two new roles to our organisation in the last year: an MND Educator and a Nelson-based MND NZ Support Advisor. This means we now have the largest support team we've ever had serving MND communities across the motu.

More awareness, fundraising and connection

Despite a challenging environment for many charities, we significantly exceeded our MND Action Month awareness and fundraising goals in June 2026. We continue to grow a connected, informed and inspired community through meaningful engagement and communication.

More events and opportunities to connect

It's been wonderful to see so many community awareness and fundraising events bringing people together. As I write this, we're looking forward to an evening of connection hosted by Emirates Team New Zealand, the Trek for MND, our MND NZ team days, the Walk to Defeat MND, Homes of Devonport tour, Ellerslie Car Show, and other events supporting our mission.

More advocacy

Every day, our support advisors advocate for people living with MND to receive the services and support they need. At a national level, I've advocated to government ministers, Health NZ, DSS and NASC leaders to drive meaningful policy change. I'm now working with operational leaders to develop practical solutions, including consistent coverage of clinical nurse specialist roles within Health NZ. Published evidence and community feedback show clinical nurse specialists make a real difference and enable better responses to the needs of people impacted by MND.

Investment in research

We continue to fully fund the NZ MND Registry and have contributed \$15,000 to Associate Professor Emma Scotter's MND Research Lab at the Centre for Brain Research. We are also preparing to launch a new MND Research Grants Round and have appointed a new research advisor to help deliver our 2025-2028 Research Strategy.

In this magazine, I encourage you to spend time with the remarkable story of Sharon and Francois Smith. Written in the months leading up to his death with MND, Francois' blog combines humour and honesty to create a deeply moving read. I also recommend the article that busts common myths and misconceptions about hospice services in New Zealand.

My sincere thanks to every one of you for your support. Together, our collective mahi can help make time count for people living with MND and their whānau/family.

Ngā mihi nui

Mark Leggett

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Cover: Francois Smith with brother-in-law Malcolm, wife Sharon (back left) and sister Heidi (back right).

A special thank you

Our heartfelt appreciation goes out to the people below for their support in making the MND News Spring 2026 issue a reality.

minimum graphics for the design and layout of *MND News*

Stewart Motorsport for sponsoring the printing of *MND News*

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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.

NZ Relay Service: Make phone calls by text



www.nzrelay.co.nz

The government-funded NZ Relay Service enables people to make and receive phone calls using text rather than speech. Through the app or website, you type in the number you want to call and what you want to say into a chat window. A relay assistant makes the call for you and reads your words aloud to the person on the other end of the call.

The relay assistant will type the other person's spoken responses into the chat window enabling a two-way conversation that continues until the call is complete. If you are receiving a call, the same will happen in reverse.

For people living with MND who are non-verbal or experiencing difficulties with speech, the service can be accessed using an eye-gaze device or by typing directly into the app or website. The NZ Relay Service is available 24 hours a day, seven days a week, and is free to use.

Francois Smith's final gifts: MND chronicles and letters to the future

Francois Smith died with motor neurone disease (MND) on 03 October 2025, two weeks shy of his 57th birthday and only weeks before his son Campbell turned 21. Francois chronicled his experience of living with MND in his poignant yet humorous blog during the final eight months of his life.

Knowing there would be many milestones he would not live to see, Francois wrote letters for his son to open after he died. The first was read on Campbell's 21st birthday, while others have been set aside for his upcoming graduation, the possibility of a future wedding day and other life events.

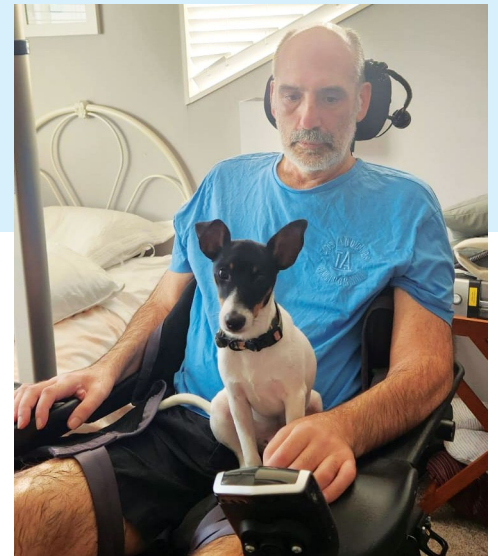
A devoted father, and husband to his wife Sharon (58), Francois was also very committed to his job and work colleagues. As the leader of the team responsible for additional services across Foodstuffs North Island stores, he oversaw Lotto outlets, petrol stations and pharmacies within Pak'nSave and New World supermarkets.

In the final eight months of his life, Francois chronicled his experience with MND in his blog that captures both the challenges of the disease and his practical, humorous character.

Francois' blog intro: *I didn't want every update to turn into a pity party. I don't do pity. The tone of the updates reflects how we operate as a family unit. We don't dwell on the negative nor shy away from it, just deal with it and continue to enjoy life.*



The Smith family.



Francois and his dog riding in the power chair.

Prior to his diagnosis, the early signs of MND were out of character for the normally energetic Francois. "He was so incredibly tired, but he was not usually a tired person. He had always been an 'active relaxer'," recalls Sharon.

The warning signs became impossible to ignore on a family holiday to Samoa, a trip they hoped would relieve his unusual tiredness. At dinner one night, he could no longer perform an everyday task. "I don't know what's going on. I can feel everything, I just don't have the strength to be able to pick up this fork," Francois told Sharon.

Back home in Auckland, Sharon insisted he see their GP who referred Francois to a back specialist. By the time the appointment arrived three and a half months later, Francois was dragging his left foot, had lost movement in one arm, struggled with his balance and slumped forward when sitting.

An MRI failed to provide answers, so the back specialist suggested a neurologist. But there was a six-month wait. Although their GP was shocked at Francois' rapid deterioration, no one could explain what was happening. Mini strokes were suggested as a possible cause. Desperate for answers, Sharon sought advice from a doctor friend in London.

"I was scared he was going to be in a wheelchair or dead before we got any answers," recalls Sharon.

Sharon's friend had begun to suspect it was MND, recognising similar symptoms to people she had treated, but she didn't share her fears with Sharon.

She advised Sharon of the need to contact the neurology department at Auckland Hospital.

Sharon insisted their GP make an urgent referral. One week later in mid-November 2024, they saw Dr Bauer at Auckland Hospital Neurology. "Dr Bauer broke the news it was MND. I remember saying, 'Well what does that mean?' I had no idea what MND was," says Sharon.

"It was a huge shock. He gave him six months to live, a year at the outside. Francois was consoling me – I was a blubbering mess. I thought he might just need some physio or something, then he would be fine."

Thanks for the words of support for the family and I. Yes, it's not the best situation but I prefer to dwell on the positive rather than live in the pit of despair. Join me in that headspace. It's quite pleasant.

Following the diagnosis, Francois stayed in hospital for four days. Recognising how quickly the disease was likely to progress, Sharon made the difficult decision to resign from her teaching job and become his full-time carer. They began navigating the whirlwind of health professional visits and preparations to modify the house to keep ahead of Francois' physical deterioration.

I could not have asked for a better partner in life than Sharon. We have walked in step through ups and downs, mostly ups. She has stopped work to care for me 24/7. The five hours daily when I have care she is advocating for my care or on call to step in. At night she sleeps in a bed next to me to attend to my needs. On a good night, I wake her once, on a bad night it's hourly.

He was soon unable to walk downstairs and couldn't access the couple's kitchen and living room. As his movement and energy continued to decline, Francois used a power chair. After a long wait, a ramp was installed at the front door that allowed the motorcycle-enthusiast to zoom up their steep driveway in his power chair, terrifying Sharon.

I can control the chair on my own, but I am normally accompanied by a responsible adult. Sharon freaks if I go hooning. I have managed to get one wheel off the ground.

While the power chair provided some freedom, his limited movement and speech caused challenges during transfers in and out of it.

The hospice stay has been fun; two nurses and I were laughing so hard that we were crying. My inability to speak and a misunderstanding led to me being twisted like a pretzel suspended from the ceiling in a hoist.

If [you thought] the pretzel was the highlight, you'd be wrong. It was when the nurse sang, "I believe I can fly"

as the human pretzel soared across the room a metre and a half above the floor. OSH note – one nurse was attached to my feet and the other to my shoulders, so these uniquely special people had me in their safe hands.

His tale of torment by a fly is a hilarious yet bittersweet illustration of the frustrations of someone locked in a failing body due to MND. Francois describes the torment as a metaphor for everything that had become beyond his control.

Now that my movement is limited to the slight movement of my legs and my head, a fly has been tap-dancing on my forehead for five days. He only makes brief appearances when others are in the room, just long enough for them to comment that the fly is irritating me, but not long enough for them to do something about it.

When we are alone, the bastard tap dances on my forehead, or does a quickstep up and down my arms, fully aware that I have not lost any feeling in my body.

**You can read
Francois' full
blog [here](#) using
this QR code.**



Francois Smith Blog

MND NZ client Francois Smith died with MND on 03 October 2025. This is his poignant and humorous blog shared with the permission of his wife Sharon Smith.



"I hope these updates gave you a unique insight into the final months of life and that it doesn't have to be all bad." - Francois Smith



Francois and Archie on the hospital bed at home.

Consider the fly experience a metaphor, for all the things on a daily basis that were once in my control but no longer, and all the skills and knowledge I applied to perform those tasks.

Others can perform these tasks for me, but often not the way I would have, 'So what?' you might rightly ask. Today the fly showed himself while I had company. I asked that able-bodied person to kill the fly. Fly spray was applied and they left satisfied that they had performed this inconsequential task. It is now day six, and I have a fly on the end of my nose giving me the finger.

So how do I cope? I accept that I have little control of the situation, trust 100% that those who are helping me are doing it to their best ability. By the way, I've named the fly George, I hope the ::~*~ dies soon!*

Francois also talks honestly about the awkwardness of some adults trying to communicate with him using his tablet and eye gaze technology. While he acknowledges their approach is simply a human reaction, talking louder and louder assuming his inability to hear, he notices children seem to adapt more easily.

The exception to this behaviour is children who treat me normally, while out on a "walk" yesterday I was approached by a few kids who had seen me around. They crossed the road for a chat and to allow me to scratch their new puppy.

On discovery that I couldn't speak or move my hands they switched gears. While speaking normally and asking yes/no questions, they checked if I was okay with dogs, then rubbed the puppy along my hand so I could feel it, chatted for a little longer, then they were off to play.

Despite his physical deterioration, less than a month before Francois died, he writes that he still has quality of life with busy days and daily laughs. Sharon agrees, "There was always something that we could find some joy or some laughter about every single

day. It didn't matter how scared or how in pain he was, he still managed to have a good laugh."

Sharon and Francois both express immense gratitude for the health professionals and carers who supported them. The list includes doctors, nurses, a physio, a speech language therapist, hospice teams and the occupational therapist who worked very hard to keep up with Francois' ever-changing equipment needs. Sharon also recalls the practical advice and support from MND NZ Support Advisor Sally King who supported them.

"Sally was a great advocate for all things medical. She remained in constant contact and provided us with emotional support during some of the harder days," says Sharon.

In September 2024, Francois describes himself as being "a few revolutions closer to dropping off the conveyor belt of life into the vat of bacon-flavoured chocolate". On 19 September, he shares some life advice in what he says is his last update so he can conserve his energy.

The mind is wonderful – if I can offer advice, get the mind right and you can cope with anything, make sure to invest in your wellbeing.

Invest time equally in family, friends and yourself, I didn't do this but should have. No regrets though, just could have done better. Well, I hope these updates gave you a unique insight into the final months of life and that it doesn't have to be all bad.

He leaves his readers with an extra gift – one last humorous update two days prior to his death in hospice.

Cam programmed a loud warning siren which I activate on the tablet in an emergency. It sounds like a foghorn. I activated it last night by accident while in an 'oxy' haze. Scared the nurses, and a sea captain patient who tried to man a fictitious lifeboat.

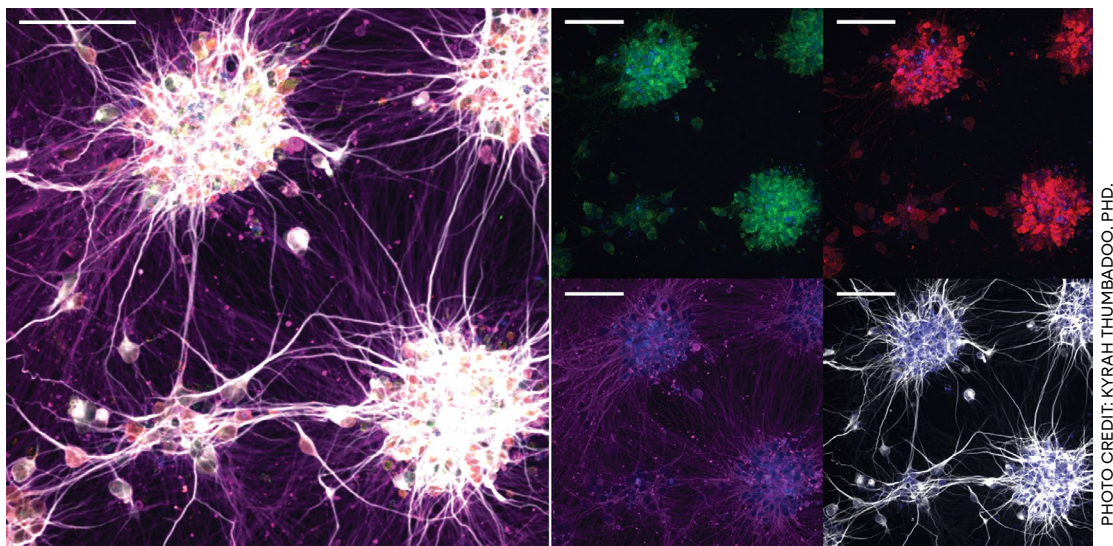
On 03 October 2025, as Francois' body was carried from the hospice his family stood together in tears, hugging one another saying their final goodbyes. Then came a moment Sharon says none of them will forget.

The hospice cook who had formed a special bond with Francois during his respite stays and his final weeks, stepped forward and performed a beautiful Māori karanga – the ceremonial call used to honour those who have passed away and acknowledge the grief of those left behind.

"She walked behind his coffin doing the karanga and we're all crying, then as the hearse drove off, she just collapsed to the ground and we ran to hug her," says Sharon.

"That would have meant so much to Francois," she says. "He would have loved it."

MND NZ awards grant to the MND Research Lab



Day 14 cortical neurons harbouring an MND-causing p.T487I mutation in the UBQLN2 gene cultured in the MND Research Lab at the Centre for Brain Research.

MND NZ is pleased to support New Zealand MND research through research grants and funding. Earlier in 2026, as part of our MND Research Strategy 2025–28, we were delighted to award the Motor Neuron Disease (MND) Research Lab a \$15,000 grant to support its research.

Based at the School of Biological Sciences and part of the Centre for Brain Research in the University of Auckland, the MND Research Lab is made up of a passionate team of 11 researchers, led by Associate Professor Dr Emma Scotter. The team does leading-edge research that includes new approaches to understanding the biology and processes involved in MND, particularly the key abnormal protein in MND and frontotemporal dementia, called TDP-43.

Emma and her team use “disease in a dish” models, in which cells are grown from skin biopsies and other tissues. This cultured tissue has all the individual features of the person’s disease and enables a wide range of techniques to be applied for further study and the development of therapies for MND.

Emma says her team is grateful for this 2026 grant and MND NZ’s commitment to ongoing annual support for the lab.

“This funding means so much. We take seriously the mandate that our research should be ‘for New Zealanders and with New Zealanders’ and this support from MND NZ both enables and champions that approach,” says Emma.

“Thank you to the wonderful New Zealand MND community who contribute time, enthusiasm, DNA and tissue samples, and funding to our research.”

The MND Research Lab has grown understanding of the genetic causes of MND in New Zealanders, spearheaded the development of genetic testing guidelines for the public health service, and is actively working on treatments to ‘switch off’ harmful gene errors. They collaborate with the domestic and global research communities, including neurologists across the country and New Zealander Professor Chris Shaw, whose UK-based gene therapy company runs clinical trials.

This funding for the MND Research Lab was provided under the MND Research Strategy 2025–28 published on our website in 2025. An annual commitment is part of the strategy. This sits alongside long-term funding of the NZ MND Registry at the University of Otago, which has been fully funded by MND NZ since it started in 2017, and a 2026 MND NZ Research Grant Round.

This research strategy has been made possible through the generosity of our donors, grant funders and community fundraisers. Together, we can make time count for people living with MND and their families/whānau.

Read more about our research strategy on our website: mnd.org.nz/research/our-research-strategy/

Hospice care and MND: Let's bust the myths

For many people, the word 'hospice' immediately suggests a building where someone goes during the final days of life. That association can make people living with motor neurone disease (MND) and their whānau/family reluctant to ask about hospice services or might mean they feel alarmed when a referral is suggested.

But hospice care is about far more than the end of life. It's about helping people with life-limiting conditions and their family to live as well as possible.

Trish Fleming, Clinical Community Liaison Manager at Hospice West Auckland says hospice care is often misunderstood. The most common myths she hears repeatedly are that hospice is just a building; just a place people go to die; and it's only for the very end of life. In fact, end-of-life care is only one part of the much broader support hospice can offer.

Trish, along with MND NZ Support Advisor Sally King and MND NZ Support Services Manager Toni Foster, helps us bust some common hospice myths below.

Myth 1: Hospice is just a place where you go to die

Reality: Hospice is a wraparound, multidisciplinary service, not simply a building. Much of the care takes place wherever the person calls home.

Hospices may have inpatient beds, including beds for respite, symptom management and end-of-life care, however, much of their work takes place in the community. While each of the 32 hospices throughout Aotearoa do things a little differently, about 85 percent of the hospice care throughout the motu is delivered in people's domestic environments.

"That could be a private home or whare, a group home, an aged residential-care facility, it could be a

"I often encourage people to find out what their local hospice offers early, so that they can get to know each other in ways that puts sparkle into everyday life."

– Sally King, MND NZ Regional Support Advisor.



Trish Fleming, Clinical Community Liaison Manager Hospice West Auckland says 85 per cent of all hospice care in NZ takes place wherever a person calls home.

prison," says Trish. "So, for people who think, 'I don't want hospice because I don't want them to take mum away', well, hospice comes to you. To support you with the care of your mum, and they support you and your family too."

MND NZ Support Advisor Sally King reinforces the message that hospice is not only somewhere you "go" to her clients living with MND. "These days hospice is all about supporting people in their own homes and allowing clients to choose which services, and how much or how little, they'd like to use," says Sally.

Myth 2: Hospice is only for the final days or weeks of life

Reality: Hospice can support people much earlier, depending on their needs and the services available locally.

Hospice does provide care during the final stage of life, but that is only one part of what's on offer. The focus is on quality of life, symptom management, preparation and support rather than on a particular number of days or weeks remaining.

"From the time someone is diagnosed with a non-curable illness, that's the time to start changing the thinking about the palliative approach to care," says Trish.

"If families and individuals can access our psychosocial support before their symptoms have run away, that contributes to whole wellness. We can help manage their symptoms so they can live,

interact and connect how they want to. We also offer a 24/7 clinical support phone service if something goes wrong after hours.”

She says Hospice West Auckland clients with MND have access to counselling, social workers, occupational therapy, massage therapy, physiotherapy and arts therapy – which provides an alternative form of communication particularly for a person who has become non-verbal.

They can also access respite care in the recently opened He Whare Korowai: Home From Home centre. One of the centre’s four beds, in a room tucked away from the main area, is specifically for respite which can provide a much-needed break for the family carers of people living with MND.

Family members can also access services such as carers courses, family and bereavement counselling and social worker support that can help with a wide range of practical matters including benefit or pension queries, legal issues such as power of attorney, making a Will and funeral planning.

Toni Foster says MND NZ generally encourages people to connect with their hospice early so they can learn what support is available, take part in activities and access services for family members. However, she notes that hospice offerings and referral practices differ, and some services may not accept an early referral if the person does not yet meet their criteria.

Sally King agrees, “I often encourage people to find out what their local hospice offers early, so that they



Hospice West Auckland’s Rongoā Garden – a traditional Māori healing space with native New Zealand flora used for medicinal, physical and spiritual wellbeing.

“Don’t be afraid. It really is a holistic and caring service that can improve quality of life for you and your family.”

– Trish Fleming, Hospice West Auckland Clinical Community Liaison Manager.

can get to know each other in ways that puts sparkle into everyday life. Respite – when people have a chance to spend a week in hospice being thoroughly spoilt – is a reset and sanity saver for many.”

A conversation with your MND NZ Support Advisor, GP, neurologist or multidisciplinary team can help identify when a referral may be useful and clarify the referral criteria.

Myth 3: Hospice care is mainly for people with cancer

Reality: Hospice supports people with many life-limiting conditions, including MND.

Cancer is often closely associated with hospice care, but specialist palliative care is not limited to one diagnosis. People living with neurological conditions such as MND, as well as dementia, respiratory illnesses, Parkinson’s disease and many other conditions, may benefit from hospice services.

Myth 4: Hospice care will be expensive

Reality: Hospices do not charge people for the care they provide.

Trish says hospice services are provided without charge to patients and whānau/family. Hospices receive some funding from Health NZ | Te Whatu Ora, but they must also raise substantial amounts within their communities often through second-hand shops, events and other fundraising activities.

Taking the first step

Learning about hospice does not commit you to using every service, and asking for information does not mean the end of life is imminent. Some hospices accept self-referrals, while others require a referral from a health professional. Eligibility criteria and available services also differ around the country.

Your MND NZ Support Advisor, GP, neurologist or another member of your healthcare team can help you contact your local hospice and understand what may be available.

Trish’s message to people with MND who are considering a referral to hospice is simple, “Don’t be afraid. It really is a holistic and caring service that can improve quality of life for you and your family.”

“I don’t have cancer. Why would I need hospice?” – Lynn’s story

Lynn’s story illustrates the comprehensive support and services that hospice provides for people living with MND – it helps bust the myths that hospice is only for end-of-life care, or only for people who are living with cancer. Lynn’s full story was originally published on the Hospice West Auckland website and is republished here with permission.

When MND NZ client Lynn Bongard was first told she should contact Hospice West Auckland, her reaction was immediate. “Why would I need hospice? I don’t have cancer. I’m not at the end of my life,” she said.

Like many people, Lynn thought hospice care was just for cancer patients, and only for the final days. She didn’t yet know that hospice supports people with a wide range of life-limiting conditions, including the slower progressing form of motor neurone disease primary lateral sclerosis (PLS), the condition she was diagnosed with in 2018.

“I didn’t know what hospice was,” she says simply. After some gentle prompting from her carer, Lynn agreed to get in touch. “So, I eventually went in and they were so helpful, the support has been wonderful!” she smiles.

PLS is a form of motor neurone disease that affects voluntary muscle control such as speaking, walking, swallowing, and breathing. It progresses slowly, and Lynn’s prognosis at diagnosis was around 15 years. But slow does not mean easy.

First came the walking stick, then the walker. Then an electric wheelchair for shopping trips that folded into the car. Eventually she needed a wheelchair full-time. Unfortunately, getting in and out of the car became harder, then impossible.

“Sadly, that was the end of my shopping outings,” she says. She used to love going to the shops, to “fiddle and faddle around.”

For someone who never “put herself forward” or asked for help, the loss of independence has been one of the hardest adjustments. Even when Roger, her husband of 52 years began taking on more at home, she felt guilty. She had always been the



Lynn with three of her ten grandchildren.

homemaker, the one running the house and family of five children and ten grandchildren and reversing those traditional roles didn’t come naturally to her.

Finding connection at hospice

Back in 2019, hospice support began as home visits from one of the nursing team. “I loved the home visits from my hospice nurse, she was a wonderful help,” Lynn says, recalling symptom management, reassurance and practical support right from the outset.

Next, she began attending patient morning teas at Hospice House. “I’m a people person,” she smiles. At first, she came with her walker. Later, in her wheelchair. She joined in groups making dragonflies, and other arts therapy groups. “Life is so interesting, and I’m so lucky. I love people, meeting people and watching life.”

Over the years, Lynn has accessed a whole range of hospice services, including counselling, massage therapy, arts therapy and physiotherapy. The ability to contact hospice’s doctor at any time, as well as the 24/7 Afterhours Advisory team, has given Lynn and Roger great peace of mind that help is always just a call away.

More recently, respite care at the He Whare Korowai – Home From Home facility at Hospice House has meant that her husband can have a proper rest, knowing she is cared for 24/7 by a familiar, experienced hospice team.

Lynn says family togetherness was her role in life, and she feels content that she has done that job well. Now she continues to live with connection, courage and determination, with hospice support. “Hospice is for me and Roger and also my whānau, which I find very soothing and important,” she smiles.

Reliable information when it matters most

A diagnosis of motor neurone disease (MND) can be overwhelming. People with MND, their families, whānau, carers, and health professionals often need to make important decisions quickly as the disease progresses. Having access to accurate, trusted information can make a real difference.



At Motor Neurone Disease New Zealand (MND NZ), providing reliable information and education is a key part of how we support people to navigate life with MND. Our resources help people understand what to expect, access support, and make informed decisions about their care.

Over the past year, we have expanded our information and education services to better meet the needs of our MND community.

Best Practice Recommendations update

One significant development is the release of our updated *Best Practice Recommendations for the Care of People with MND*. Developed for the New Zealand context, these recommendations promote a coordinated, person-centred approach to care and support consistency in MND care across the country. They provide

guidance for health professionals and care providers to help ensure people living with MND receive high-quality, evidence-based support. Hard copies are available on request.

Information resources in your language

We have also refreshed our information resources. Our two key introductory leaflets, *About MND* and *About the MND Support Service*, are now available in te reo Māori, Samoan, Simplified Chinese, and Hindi.

We are also introducing a new series of information sheets covering topics people commonly face during their MND journey. The first two, *Breathing with MND* and *Tube Feeding with MND*, are available in the same languages.

These translated resources are an important step towards more equitable access to information and support. With 25 ethnic groups currently represented within our MND community, we know language can be a barrier to understanding services, accessing support, and making informed decisions.

MND Educator

To further strengthen education and information delivery, MND NZ established the MND Educator role

in October 2025. Led by Jane Kay, the service provides education and support for people living with MND, family members, whānau, carers, health professionals, and care providers.



Jane Kay, MND NZ Educator.

Jane delivers workshops for newly diagnosed clients, facilitates online support groups for carers and family members, and provides education sessions for health professionals and aged residential care staff. She is also developing resources that complement the support provided by MND NZ Regional Support Advisors.

Our goal is simple: to ensure everyone affected by MND has access to accurate information, practical guidance, and support at every stage of the journey.

To access education and information resources, visit:
www.mnd.org.nz/resources

For educational support or professional development opportunities, contact:
Jane Kay at
jane.kay@mnd.org.nz

Freedom at the water's edge: beach wheelchairs provide new possibilities

For many people living with motor neurone disease (MND), a day at the beach can become increasingly difficult as mobility changes. But accessible beach wheelchairs are helping more New Zealanders reconnect with the coastline they love.

Maureen Sceats, who lives with the slower-progressing variant of MND called primary lateral sclerosis (PLS), spent much of her life swimming, attending aqua aerobics, running marathons, and exploring New Zealand's Great Walks with her husband, Kevin. As her MND progressed, she gradually lost the ability to walk and now uses a power wheelchair.

Living close to Buffalo Beach in Whitianga, Maureen missed being able to get onto the sand and into the ocean. Earlier this year, she spotted someone using a specialised beach wheelchair provided by the charity Toes in the Water and decided to give it a try. "For the first time in many years, Maureen was able to enjoy being on the beach again with her family," says Kevin. "She couldn't stop smiling."

What might seem like a simple beach outing was something much more significant.

"To the average person, it probably doesn't seem like a big deal to travel along a beach," Kevin says. "But for Maureen, and for many other disabled people, it

was an adventure she never thought she'd experience again."

Another family who experienced the benefits of beach wheelchairs is the Rice family from Hamilton.

Annabelle Rice says her father, Senior Constable Tony Rice, who was diagnosed with the amyotrophic lateral sclerosis (ALS) variant of MND in 2023, has always loved the ocean and surfing. Last summer, he was determined to get back into the water.

"We've been so lucky to have the incredible support of friends and family," says Annabelle. "A group of friends made it happen, they hired a beach wheelchair from Toes in the Water in Whangamatā and took dad for a swim."

The day created special memories for everyone involved and demonstrated how accessible equipment can help people continue participating in activities they love.

As summer approaches, beach wheelchairs are available at several locations throughout New Zealand, often free of charge or for a small donation. Whether it's feeling the sea breeze, joining family for a walk along the shore, or taking a supported swim in the ocean, accessible beach wheelchairs offer far more than mobility.

For people living with MND, they can open the door to experiences that may once have seemed out of reach. This summer, perhaps it's time to put your toes in the water too.

Find out more:

toesinthewater.co.nz operates accessible beach wheelchair programmes in Whangamatā and Whitianga. For other beach wheelchair and accessible beach mat options throughout New Zealand check out your local surf lifesaving club, council, or go to the website accessiblebeaches.co.nz.



Maureen and Kevin Sceats enjoying a beach wheelchair on Buffalo Beach.



Tony Rice and his mates take a dip with a beach wheelchair at Whangamatā.

The unseen coat: A strange journey

A diagnosis of motor neurone disease in March 2025 was finally the 'coat' with the right fit for MND NZ Client Murray MacDiarmid. Here, Murray shares his MND story in his own words.

We are all dressed in unseen coats. Some are stitched together in childhood. Others are shaped by work, stress, personality, chance, or genes. Most of the time, we wear them without noticing. They simply become part of us. I wore mine that way for years.

A slight slur

Then one day, a colleague noticed a slight slur in my speech. That small comment stitched the first thread of worry.

At first, the symptoms seemed ordinary enough – throat irritation, nasal congestion, difficulty sleeping comfortably, occasional changes in my voice. Like many people, I searched for simple explanations first. Reflux seemed a reasonable fit. Stress perhaps. Fatigue. Getting older. And so began a strange journey through a wardrobe of possible diagnoses.

Trying on different coats

Each specialist seemed to offer another coat to try on. Some coats felt reassuring at first. Others sat awkwardly from the beginning. Yet with every appointment came another wait before the next fitting – weeks, sometimes months, sitting in uncertainty while life continued around me.

The waiting and uncertainty began to remind me of preparing for a school ball as a teenager. Quietly wondering whether you had chosen the right clothes. Whether you would fit in. Whether others might notice something was not quite right.

Then came the unsettling feeling of arriving and slowly realising you may not be dressed for the same occasion as everyone else. Friends, family, and colleagues often noticed changes before I fully recognised them myself. They carried concern gently and encouraged further investigation, while I still hoped one of the earlier coats might eventually prove to be the right fit.

An ear, nose and throat (ENT) specialist tugged thoughtfully at the collar of the reflux coat, unconvinced it sat properly. Perhaps something



Murray MacDiarmid with his daughters Jess, Isabella, Amelia and granddaughter Maddie travelling together in Europe after his diagnosis.

structural. A growth. Some subtle dysfunction. But those sleeves did not quite fit either.

A neurology referral

Eventually, I was referred to a neurologist – though, like many specialist appointments, the wait stretched over months. By then, several coats had already been tried on and quietly returned to the rack. Carefully and methodically, she began considering new styles: stroke, tumour, myasthenia gravis.

Oddly, I found myself warming to the myasthenia gravis coat. It looked more manageable somehow. More temporary. I even spoke about it hopefully with friends and family, pointing out its better colours and gentler shape.

But the tests slowly narrowed the possibilities. Blood tests. Scans. Nerve studies. Clinical examinations.

And eventually, with kindness and quiet clarity, came the moment when the final coat was laid before me.

Motor neurone disease (MND)

The strange thing about that moment was that alongside the shock and sadness came something else, too: recognition. The coat fit: too well.

It explained every fold and seam of symptom and change that had quietly gathered around me over time. After months of uncertainty, there was power in finally understanding the shape of what I was facing.

MND is a strange condition because it often changes the body more rapidly than the mind. Thought, humour, memory, personality, and awareness may remain very much intact while speech, movement, swallowing, and strength gradually change around them. You remain yourself while also having to adapt to a body that increasingly behaves differently.

That can be difficult not only for the person diagnosed but also for those around them who may feel uncertain about how to respond. One thing I have learned is that openness helps.

People are often afraid of saying the wrong thing. Sometimes they quietly withdraw simply because they do not know how to engage. But honest conversations, humour, kindness, and ordinary human connection matter enormously. They reduce the isolation that serious illness can quietly create.

The importance of community

I have also learned how much community matters. The patience of friends. The practical support of

family. The quiet understanding of colleagues. The people who stay present without needing to solve everything. Those things carry real weight.

MND changes many parts of life, but it also sharpens perspective. It draws attention toward what remains important. I am still learning. Still adapting. Still trying to approach the future with honesty and, at times, even a degree of curiosity about the folds and stitching of this coat.

And underneath it all, I am still me. Murray MacDiarmid.

In memory of Murray MacDiarmid

Sadly, Murray died with MND on 17 September 2026. These beautiful words from his daughters announced his death.

It is with great sadness that we share the passing of our beloved dad, grandfather, brother and friend, Murray 'Muzzy' MacDiarmid. Dad was kind, strong, cheeky, with a wonderful sense of humour and passion for science, in particular physics and technology.

He was diagnosed with motor neurone disease (MND) 18 months ago, despite his diagnosis Dad didn't allow MND to stop him from doing the things he loved and ticked off a couple of bucket list experiences. From his grand tour of Europe and life in Northland, to the MacDiarmid family reunion, adventures in Tasmania, the Moonshine Boys' tramp, and exploring the West Coast of the South Island.

Introducing the 2026 Community Recipe Book



We're delighted to share the *2026 MND Community Recipe Book*; a collection of soft food recipes created by, and for, New Zealanders living with motor neurone disease (MND).

When eating becomes more challenging, finding meals and snacks that are both enjoyable and easy to eat can take a lot of creativity. This recipe book brings together practical, tasty ideas that have been tried and tested by people living with MND and their families.

This community project was coordinated by Robyn Pryor, who was diagnosed with MND in August 2022. Robyn contacted members of the MND community through a Facebook group and gathered the recipes and meal ideas that people have found work well for them.

More than just a recipe book, this collection is an example of people coming together to help one another navigate the challenges of living with MND. Grateful thanks to Robyn and each person who contributed to this recipe collection which is freely available on the information resources page of the MND NZ website.

Download the *2026 Community Recipe* book from our website information resources page mnd.org.nz/support-information/our-services/information-resources/ or use this QR code.



EVERY STEP MATTERS.

JOIN US ON SATURDAY 07 NOVEMBER

Together, we'll walk in honour of those living with MND, remember those who have died, and show every person affected by MND that they are not alone.

Walk, fundraise, donate, or share your story to help improve lives today and create hope for tomorrow.

REGISTER TODAY!

WALK
TO DEFEAT
MND



WALK.
FUNDRAISE.
DONATE.
SHARE YOUR STORY.



WWW.MNDWALK.ORG.NZ

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

Online

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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PO Box 24036

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Auckland 1345



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