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MOMENTUM

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COVER STORY:

WHAT HAPPENS TO PEOPLE WHO DON'T HAVE *what we had?*

mnd Australia

Until there's a cure, there's care.

ACKNOWLEDGEMENT OF COUNTRY

MND Australia acknowledges Traditional Owners of Country throughout Australia and recognises their continuing connection to lands, waters and communities.

We pay our respect to Aboriginal and Torres Strait Islander cultures; and to Elders past, present and emerging.

Aboriginal and Torres Strait Islander peoples should be aware that this document may contain images or names of people who have since passed away.

MND COMMUNITY

Across Australia, more than 2,700 people are currently living with MND, and each day two more Australians receive this devastating diagnosis. MND gradually takes away a person's ability to move, talk, swallow, and breathe – stealing precious moments with loved ones and, ultimately their lives.

People living with MND, their families and carers, and those who carry MND-associated genes, are at the heart of everything we do. Their courage, resilience, and determination continue to inspire and guide our work every day.

Front Cover Photo: Phil O'Neill

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WHO WE ARE

For more than three decades, MND Australia has led the national effort to defeat motor neurone disease (MND). Founded in 1993 as the peak body for the MND community, we represent and unite State MND Associations supporting people living with MND, their families and carers across Australia.

Motor neurone disease is a progressive and ultimately fatal neurological disease that damages the nerve cells controlling movement. As the disease progresses, people gradually lose the ability to walk, talk, swallow and breathe. Every day in Australia, two people are diagnosed with MND and two people die from the disease.

Through advocacy, awareness, collaboration and research investment, MND Australia has become a driving force for change. We amplify the voices and experiences of people living with MND while working to improve access to care, support groundbreaking research, and accelerate progress toward better treatments and, ultimately, a cure.

At the centre of everything we do are people living with MND, their families, carers, and communities. Together with researchers, clinicians, supporters, and State MND Associations, we are building a future where no one faces MND alone.

MND CARE: SUPPORT STARTS HERE

State MND Associations offer essential care and guidance to people living with MND, their families and carers. Connecting early ensures access to vital resources, expert support, and a compassionate community from the moment of diagnosis.

MND Info Line 1800 777 175 9am to 4.30pm Monday to Friday or visit mndaustralia.org.au

message FROM OUR CEO

Every person featured in this edition of Momentum reminds us why MND Australia exists.

Behind every research breakthrough is a family waiting for answers. Behind every advocacy campaign is a person living with MND trying to navigate a system that too often moves too slowly for a disease that never does.

As this edition goes to print, we also reflect on the extraordinary legacy of Neale Daniher AO, whose remarkable leadership, generosity and hope changed the course of MND awareness and research in Australia. Neale's contributions will continue to inspire our community for generations to come.

Across Australia, people living with MND continue to face enormous challenges accessing timely care, equipment, aged care support, palliative care, and specialist services, particularly in regional communities. That is why advocacy remains central to our work.

This year, MND Australia has continued pushing for stronger support systems, fairer access to care, and policies that better reflect the urgent realities of living with MND.

We work closely and in partnership with our Members, the State MND Associations. We've recently welcomed two new CEOs, Mary-Jane Stolp at MND Vic and Liam O'Meara at MND NSW. Without them we couldn't do our important work. Read more about the work of our State MND Associations from page 26.

At the same time, we remain deeply committed to investing in world-class MND research. The stories throughout this edition showcase the extraordinary researchers, clinicians, and lived experience advocates working together to improve treatments, preserve quality of life, and move us closer to a cure.

Progress only happens because of collaboration, generosity, and persistence.

Together, we are building momentum toward a future where no one faces MND alone.

Clare Sullivan

CHIEF EXECUTIVE OFFICER

messages
FROM OUR AMBASSADORS

Over the past six months, I have continued my strong commitment to the motor neurone disease community through advocacy, lived experience work, fundraising, research engagement, and awareness initiatives across Australia.

I have remained actively involved in the Community of Practice (COP) for MND Care meetings with Calvary Health Care, contributing lived experience perspectives to discussions focused on improving support for people living with MND and their carers. I've also attended regular staff and ambassador planning meetings with MND Australia, helping shape advocacy priorities and future awareness activities.

In December, I privately commemorated the anniversary of my husband's passing from MND, reflecting on both personal loss and the importance of continued advocacy for families affected by the disease.

A major highlight was helping organise the Shady Ladies fundraiser, which successfully raised an extraordinary $189,000 for MND support and research initiatives. The event demonstrated the power of community connection and collective action.

Additional activities included participation in LEN community meetings, attending the Parliamentary Friends on MND event at Parliament House in Canberra, and undertaking an important lived experience survey exploring how people receive a diagnosis of MND.

I have also continued engaging with MND researchers and conducting many meaningful interviews for the Let's Talk MND podcast, amplifying the voices of people living with MND, carers, clinicians, and researchers.

Jane Simpson

MND AUSTRALIA AMBASSADOR

Living with MND teaches you very quickly how much independence matters. It also teaches you that independence often depends on the right equipment, the right people, and the right support.

Before MND, if something needed adjusting or fixing, life was simple. You booked the car into a mechanic or took your bike to a specialist. But when your primary form of transport becomes a powered wheelchair, things become very different.

Finding people who genuinely understand how to adapt equipment to your changing body and needs can be incredibly difficult. Many people living with disabilities or progressive illnesses are left navigating systems where equipment is expensive, poorly tailored, or modified by providers who do not fully understand the person sitting in the chair.

After four years of living with MND, my wheelchair is now my main way of moving through the world. As my condition progresses, the chair also needs to evolve with me. Small changes in posture, strength, movement, or comfort can have a huge impact on whether I can still drive safely, leave the house independently, or participate in everyday life.

When I was experiencing issues with my walking and wheelchair setup, my neurologist suggested I speak with the STARS team at the Royal Brisbane and Women's Hospital. During those conversations, it became clear that some of the challenges I was facing were not only related to my MND, but also to the mechanics and setup of the chair itself.

I was referred to the Engineering team within the hospital, and what they did for me was remarkable.

They listened carefully. They observed how I moved, where I struggled, and what was changing in my body. Rather than offering a generic solution, they approached my situation with creativity, expertise, and compassion. The tailored adjustments they made gave me back confidence and control. Tasks that had become frustrating and exhausting suddenly became manageable again.

What sets this team apart is that they see the person first. Their work is not simply about equipment or modifications. It is about helping people remain independent, connected, and engaged in life for as long as possible.

I can honestly say I am still able to drive my wheelchair today because of this team.

A very special thank you to Oliver and his team, especially Nick, Camilla, and Nathan. What you do matters more than you probably realise.

Peter Russo

MND AUSTRALIA AMBASSADOR

VALE NEALE DANIHER AO

1961 – 2026

For more than twelve years, Neale Daniher was an extraordinary champion for Australians living with MND. Since his diagnosis in 2013, he dedicated his life to raising awareness, building understanding, and raising funds to invest in research that will one day lead us to a cure.

Neale's journey with MND was extraordinary. While many people diagnosed with MND face an average life expectancy of just 27 months, Neale fought the disease for 13 years with remarkable courage, resilience and determination.

His strength gave hope to so many Australians living with MND and showed the nation what is possible through perseverance, advocacy and community support.

Neale's tireless advocacy gave a voice to more than 2,700 Australians currently living with MND and their families. He brought MND out of the shadows and into the national conversation.

Beyond his extraordinary leadership in the MND community, Neale's recognition as 2025 Australian of the Year and his appointment as an Officer of the Order of Australia in 2021 reflected the depth of his impact on our nation.

On behalf of MND Australia, we extend our heartfelt condolences to Neale's family, friends, and the entire FightMND community. His passing is a profound loss, not only for those who knew him personally, but for every Australian whose life has been touched by MND.

Vale Neale Daniher, AO. He was, and will remain, a true hero in the fight against MND.

INFORMATION & SUPPORT

Advice you can trust

Having the right information at the right time, and knowing which questions to ask, can make all the difference to a person living with MND.

> *"I have found it extremely comforting to be able to access information and services."*
>
> \- Person living with MND

This is why we are working with the State MND Associations and people with lived experience to create evidence-based information about MND that is easy to find, understand, and use.

Information about MND is available online and can be translated into many languages using the built-in language and accessibility tools. Print guides and videos are also available.

Via the national MND Info Line, we connect people impacted by MND with information, services and support for the best possible care.

Everything you need to know about MND, all in one place.

Scan to visit
mndaustralia.org.au/info

MND Info Line
1800 777 175
9am to 4.30pm Monday to Friday

Planning for Medical Emergencies

At the 2025 MND Care Forum in Melbourne, people with lived experience highlighted that hospital admissions were stressful, especially in emergencies.

The message was clear: more support and guidance are urgently needed.

Working closely with the lived experience community, our ambassadors, the State MND Associations and clinical experts, we created Planning for Medical Emergencies, a new webpage full of information to help people living with MND feel safer and more supported when they need urgent care.

It includes tips and tools to help people prepare in advance, communicate their needs effectively, and request the extra support they need.

Employment and MND
> A guide for people living with MND

When you are living with motor neurone disease (MND), you may be thinking about whether to keep working. This guide is designed to help you make informed decisions about employment.

Employment and MND covers the following topics:

- understanding how MND impacts employment
- things to consider when making your decision
- understanding your workplace rights
- understanding your responsibilities related to living and working with a life-limiting condition
- understanding your financial entitlements including superannuation
- resources that can support you.

Employment and MND: about the series

MND can affect many aspects of a person's life, including work. This guide is one of a series that provides information about managing employment and MND. There is also a guide for carers, and one for employers.

How MND impacts employment

Many people are still in paid employment when they are diagnosed with MND. Individual or workplace adjustments can help you maintain productive and fulfilling employment for as long as possible. Reasons to stay employed include:

- financial reasons or family responsibilities
- identity and sense of purpose
- independence
- motivation
- routine
- maintaining important relationships and connections to community.

The impact that MND has on your working role depends on several factors:

- symptoms
- the type of work
- type of tools or equipment needed in a role
- specific duties of the role
- working environment.

Some of the symptoms that may impact your ability to work include:

- mobility changes
- limb weakness
- changes in speech or communication
- saliva control
- fatigue
- emotional lability (when emotional responses are different to how you feel).

Some other, less obvious changes may also impact roles at work, including anxiety, depression or mild cognitive changes.

An MND diagnosis can raise many work-related questions. Look for the table, **Who Can Offer Support** at the end of this guide to find out more.

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Employment and MND

A diagnosis of MND can bring up questions about your work life and future plans. A suite of three guides has been developed in partnership with MND Victoria in response to this identified need within the community.

These guides are designed to:

- assist people make decisions about work
- know their rights and responsibilities
- understand what support is available.

Visit mndaustralia.org.au/info

Or call the MND Info Line 1800 777 175

We are proudly delivering these projects with support from an NDIA Peer Support and Capacity Building grant, FightMND and the Australian Government Department of Health, Disability and Ageing.

What happens TO PEOPLE WHO DON'T HAVE WHAT WE HAD?

After losing her husband Phil to MND, Helen O'Neill is speaking out about the realities of caregiving, regional healthcare gaps, and the urgent need for better support.

When Helen O'Neill travelled from rural Tasmania to Parliament House earlier this year, she carried with her more than grief.

She carried the reality of what it means to care for someone living with motor neurone disease in a system that is simply not built for it.

Standing before parliamentarians at the launch of MND Australia's Parliamentary Friendship Group for motor neurone disease, Helen shared the story of her husband Phil, a fiercely independent outdoorsman who died in July 2025, just 280 days after his diagnosis.

"Motor neurone disease is not a battle," Helen told the room. "It is a war. And for Phil, MND was the winner."

Phil had lived a big life in Tasmania's northwest. He loved surfing, bushwalking, kayaking, music, photography and community. Helen describes him as magnetic, funny, and "absolutely a larrikin."

Then, almost overnight, everything changed.

Within weeks, Phil developed breathing difficulties, confusion, swallowing problems and mobility issues. By October 2024, he was diagnosed with rapid onset bulbar MND. The progression was devastatingly fast.

Helen says the response from the specialist MND Clinic team and MND Tasmania was immediate. Alongside urgent referrals for respiratory support, allied health and equipment, Phil's MND Care Coordinator and clinical team also arranged an urgent referral to palliative care, helping the family access support early as his condition rapidly progressed.

"Within six weeks of Phil's first symptoms, I went from being a wife to being a full-time, 24-hour carer," Helen says.

Helen's 52-year nursing career helped her navigate the clinical realities of MND. Even then, she says the system failed them. An urgent aged care assessment was requested shortly after Phil's diagnosis. Despite his rapidly deteriorating condition, Helen was initially told they may not hear back until the end of February.

"It was the beginning of November," Helen recalls. "I said, 'My husband will be dead by then unless we get some assistance.'"

When support finally arrived months later, it amounted to one hour of personal care twice a week and four hours of respite every fortnight.

But MND is not a disease that pauses between appointments. Phil required constant care. He needed help with mobility, feeding, ventilator use, medications, choking prevention, toileting and emotional support. Overnight, he woke every one to two hours struggling to breathe or needing assistance.

"There was nowhere for him to go," Helen says. "The system relies on families taking on that burden completely alone."

Living in regional Tasmania added another layer of complexity to Phil's care. Accessing specialised nursing support, respite services and appropriately trained providers was often difficult, delayed, or simply unavailable locally. Throughout their journey, Helen says the support of MND Tasmania was invaluable. Their MND Care Coordinator helped connect the family with services, advocated for urgent assessments, and provided guidance during an overwhelming and rapidly changing time. For Helen, that support became a critical lifeline in a system that too often felt impossible to navigate alone.

What sustained them was not the system, but community. Neighbours built ramps. Friends sourced equipment. Retired nurse friends stepped in so Helen could rest. Their daughter took time off work to help care for her father, with additional support provided by their son in law, sons, grandsons, and partners, all pitching in with chores.

Phil's mates came to sit with him, play records, reminisce and, when he was strong enough, help him continue doing the things he loved.

One of those moments came when friends rallied to help Phil achieve two final goals: riding a recumbent bike along a coastal path he had helped champion and returning to the ocean one last time.

With the help of family, surf lifesavers, and close friends, Phil was carried across the sand and into the water.

"The grin on his face," Helen recalls. "It was incredible."

Even as his world narrowed, Phil remained deeply concerned about the impact his illness was having on his family. "You people could be more constructive with your own time than taken up with me," he told Helen during one difficult conversation.

As Phil's illness progressed, conversations about dignity, choice and control became an important part of the family's journey. Early after his diagnosis, Phil chose to explore voluntary assisted dying, something Helen says brought him an enormous sense of peace. Supported by his palliative care team, GP and physicians, Phil was able to openly discuss his end-of-life wishes and options.

Helen describes the process and the healthcare professionals involved as deeply compassionate and respectful. "He didn't want to die," she says, "but he felt relief knowing he had a choice and some control." Phil often said, "I can control the MND, not have it control me." As the disease progressed, he took comfort in being able to make decisions about how he wanted his final days to look, spending meaningful time with family and friends. Helen acknowledges that voluntary assisted dying is deeply personal and that every individual and family will hold different views but says it was important that Phil's wishes remained his own.

For Helen, sharing their story publicly is about making sure others are seen and heard.

"What happens to people who don't have what we had?" she asks. "We had community. We had family. I had nursing experience. And it was still bloody tough."

That question now drives her advocacy. At Parliament House, Helen spoke plainly about the realities families face behind closed doors. She wanted decision-makers to understand that quality end-of-life care should not depend on luck, geography, or whether a family has the skills to hold an overwhelmed system together.

"People living with MND deserve to be cared for at home, surrounded by love, with the best quality of life possible," she says. "No matter their age or where they live."

> *"Motor neurone disease is not a battle, it is a war. And for Phil, MND was the winner."*

National MND Conference 2026

9 – 11 SEPTEMBER

ADELAIDE CONVENTION CENTRE

REGISTRATIONS OPEN

Register at mnd2026.org.au

For the first time, we are bringing together the Australian MND Research and Care Conferences into one national gathering, creating a unique opportunity to connect the full spectrum of expertise, experience and leadership working to improve outcomes for people living with motor neurone disease.

Over the three days in Adelaide, we will welcome people with lived experience, researchers, clinicians, allied health professionals, service providers, advocates, and policymakers from across the country.

Registration is complimentary for people with lived experience.

ADVOCACY

Fighting for Fairer Care

Throughout the past year, MND Australia has intensified its advocacy efforts to push for urgent reform across aged care and the NDIS, ensuring people living with MND are not left behind by systems that move far too slowly for a disease that never does.

This advocacy has included multiple submissions to government consultations and inquiries, including the Federal Pre-Budget Submission, the Review of Legislative Instruments for Aged Care, the NDIS Price Review, and consultations on the future design of the NDIS.

MND Australia's advocacy has also helped bring national attention to the real experiences of families navigating the aged care system. Earlier this year, the story of Graham and Gaynor Crossan featured prominently in national media after Graham, who is living with advanced MND, was denied increased home care support through the new Integrated Assessment Tool. Despite requiring ventilation support, full mobility assistance, and complex daily care, the couple were told Graham was not eligible for additional funding.

Their story sparked widespread public concern about whether the new assessment system is adequately responding to rapidly progressing neurological diseases. MND Australia and State Associations have since continued calling for greater transparency, human clinical oversight, and urgent prioritisation for all people diagnosed with MND.

One of MND Australia's strongest concerns is the growing inequity between support available through the NDIS and aged care systems. Older Australians living with MND often receive significantly lower funding despite having similarly complex and rapidly changing needs. Even at the highest aged care funding levels, support often falls far short of what families require to safely remain at home.

Read our submissions

Helen O'Neill speaking at launch of Parliamentary Friendship Group for MND alongside MND Tasmania President Chris Symonds.

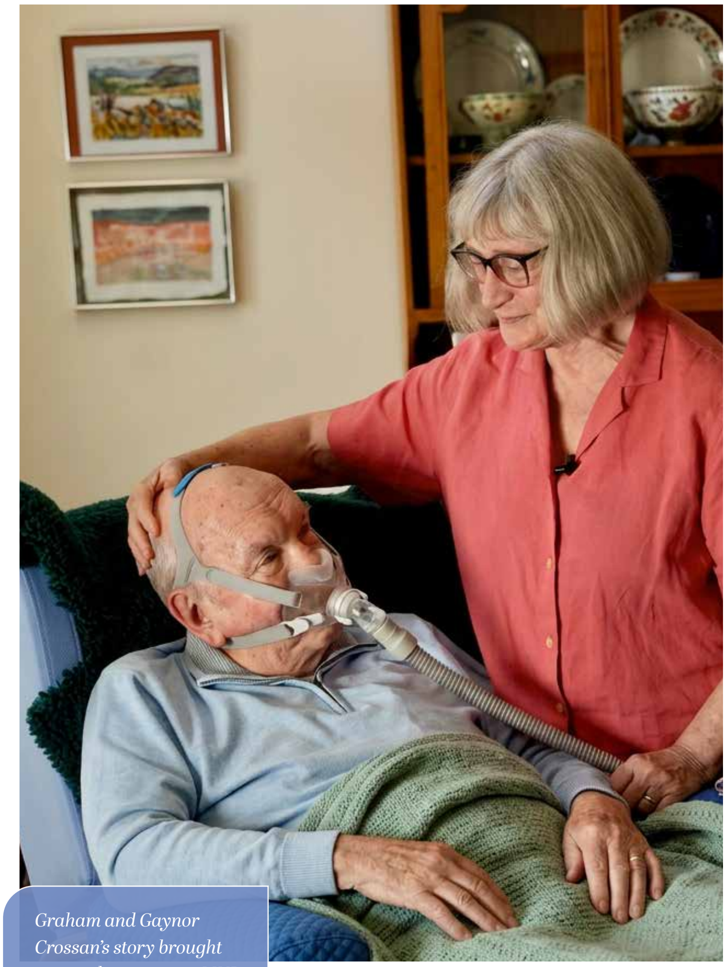
At the same time, new co-pay structures and rising provider costs are placing enormous financial pressure on households already navigating the emotional and physical toll of MND. Some families are self-funding essential care, equipment, home modifications and clinical support while waiting for approved funding to arrive.

Importantly, advocacy is being shaped directly by lived experience.

Earlier this year, MND Australia launched the Parliamentary Friendship Group for motor neurone disease at Parliament House in Canberra, bringing together parliamentarians, clinicians, advocates and members of the National MND Lived Experience Network. Among those sharing their stories was Helen O'Neill, whose husband Phil died from MND in 2025 after navigating significant aged care challenges.

Together, these voices are helping drive urgent conversations about dignity, equity, and the right to timely care.

MND Australia continues to advocate for a system that is responsive, equitable and fit for purpose, ensuring every person living with MND can access the care and support they deserve, regardless of their age or postcode.



Graham and Gaynor Crossan's story brought national attention to MND in the aged care system.

Moving forward

Maintaining independence, connection and enjoyment through mobility

Janet Hough out enjoying the beach in her modified wheelchair

When Associate Professor Taylor Dick talks about movement, she is not just talking about muscles and mechanics. She is talking about independence. About quality of life. About helping people living with MND spend more time doing the things they love.

As Group Leader of the Neuromuscular Biomechanics Laboratory at the University of Queensland, Taylor leads a multidisciplinary team of engineers, clinicians, and mathematicians working to better understand how movement changes throughout the progression of MND.

Her work recently received an important boost through an MND Australia Innovator Grant, supported by MND South Australia, helping her team explore new ways to monitor movement, improve mobility, and support independence for people living with MND.

“Movement is fundamental to this disease,” Taylor says. “Nerves die, muscles weaken, and people gradually lose the ability to move independently. If we can preserve that independence for longer, even in small ways, that can have a huge impact.”

Unlike many researchers in the field, Taylor did not come from a neuroscience background. Her expertise is in biomechanics, the study of how the body moves.

"Biomechanics is where physics meets biology," she explains. "I've always been fascinated by movement and how movement changes with health and disease."

Today, her lab studies subtle changes in walking, balance, coordination, and fatigue that often emerge early in MND. Using advanced treadmills, motion-capture technology, wearable sensors, and muscle monitoring systems, researchers can analyse movement in remarkable detail.

"We can see how someone's walking changes from week to week, month to month, and across different stages of disease," Taylor says.

The research has several goals. Understanding movement changes may help improve earlier diagnosis of MND and provide more sensitive ways to measure whether treatments are working in clinical trials.

But for Taylor, the work is equally focused on preserving quality of life. Her team is also exploring technologies such as robotic exoskeletons designed to support movement and reduce fatigue.

"For some people, technology like exoskeletons may help extend the amount of time they can spend walking, moving, or participating in activities that are meaningful to them."

Importantly, people living with MND have been involved in shaping the research from the very beginning.

Helping to guide the project as coinvestigators are Janet Hough, a former physiotherapist living with MND, and her husband Peter, who is also a retired physiotherapist.

Janet is also a member of MND Australia's National MND Lived Experience Network (LEN) and the Lived Experience Research Advisory Panel (LERAP), helping ensure the perspectives of people living with MND remain central to research and policy discussions.

Janet has accessed and embraced a range of technologies to help her continue doing the things she enjoys. She uses an electric trike to stay active outdoors and a treadmill with a built-in harness system to walk safely at home.

For Taylor, seeing Janet explore and apply different movement technologies has reinforced the importance of designing research around real lives and real goals.

"It's not simply about mobility for mobility's sake," Taylor says.

> *"It's about helping people maintain connection, enjoyment, and participation in everyday life."*

Recently, Janet and Peter travelled from Melbourne to Queensland to visit Taylor's lab. During one discussion, Peter offered a perspective that reshaped Taylor's thinking about the goals of her research.

"My original dream was always to help people maintain independent walking for longer," Taylor says. "But Peter said to me, 'If technology can help someone do more of what they love for a period of time, then you've achieved your goal.' That really stayed with me."

For Janet, that means continuing to stay active outdoors, spending time at the beach, and keeping connected with her grandchildren.

"That conversation completely changed my thinking," Taylor says. "This research isn't just about movement itself. It's about preserving the things that fill people's cup."

Looking ahead, Taylor hopes movement research becomes a much larger focus within the MND research landscape.

"Finding a cure is absolutely critical," she says. "But improving quality of life right now matters too. If we can help people maintain independence, participation, and connection for longer, that's incredibly meaningful."

Assoc Prof Taylor Dick
Neuromuscular Biomechanics Laboratory
The University of Queensland

Taylor Dick in her laboratory with study participant Rob Taylor.

Continuing the Mission

Building on Professor Justin Yerbury's vision for MND research

Prof Justin Yerbury's research group at the University of Wollongong

When Dr Christen Chisholm received the 2026 MND Australia Bill Gole Research Fellowship, it marked more than a professional milestone.

More than a decade earlier, the same fellowship had supported her mentor and close friend, Professor Justin Yerbury, one of Australia's leading MND researchers, who died of MND in 2023. For Christen, the connection is deeply personal.

"There's something incredibly special about following in Justin's footsteps," she says. "He believed passionately in this research and in mentoring people around him."

Christen didn't take the traditional path into MND research. After studying science at the University of Wollongong, she initially worked in cancer research before stepping away from research altogether. She retrained as a teacher, spending years teaching biology and chemistry in London and later across the Illawarra while raising her three daughters. But her enthusiasm for scientific research never completely left her.

"I always loved it," Christen says. "I loved the problem-solving, the mysteries, the discovery. It was always in the back of my mind."

Through her long friendship with Justin's wife, Rachel, Christen watched Justin's remarkable scientific career unfold over many years. She also witnessed the devastating progression of his MND after symptoms emerged in 2016.

In 2018, shortly after Justin underwent life-extending ventilation surgery, Christen decided she wanted to return to research and support his work. In 2019, Christen joined Justin's lab at the University of Wollongong, beginning research into one of the defining features of MND: the toxic build-up of misfolded proteins inside motor neurons.

Justin's research focused on proteostasis, the systems cells use to maintain healthy proteins. In MND, these systems fail, allowing proteins to clump together and damage motor neurons.

"He believed the collapse of these protein control systems was central to the disease," Christen explains. "The question became: how do we help cells clear those toxic proteins before they cause damage?"

During her PhD, Christen worked on a groundbreaking genetic therapy designed to identify harmful proteins, tag them, and direct them toward the cell's natural waste disposal systems.

Early results were promising. In laboratory cells and mouse models, the therapy reduced toxic proteins, protected motor neurons, and slowed disease progression. But one major challenge remained: getting treatments into the brain.

"The brain is protected by the blood-brain barrier," Christen says. "Most drugs simply can't cross it."

Now, through her Bill Gole Fellowship, Christen is exploring a new approach that combines mRNA technology with focused ultrasound to help deliver therapies into the brain more effectively.

The mRNA technology, similar to that used in COVID-19 vaccines, packages treatments inside tiny lipid nanoparticles. Focused ultrasound then uses low-energy sound waves to temporarily open the blood-brain barrier, allowing therapies circulating in the bloodstream to pass into the brain.

"It's a really exciting time," Christen says.

> *"The technology that emerged during COVID has opened doors for so many diseases, including MND."*

For Christen the work remains closely tied to Justin's legacy. Even while living with MND himself, Justin continued to lead research, mentor students, and push scientific boundaries.

"He was extraordinary," Christen says. "Even as communication became harder, he remained completely driven to keep contributing."

Christen says support from organisations like MND Australia has been critical not only to her own work, but to the entire MND research community in Australia.

"The MND research workforce we have in Australia today really exists because of decades of investment from charities like MND Australia," she says. "Very little MND research funding comes from government sources, so these fellowships and grants are absolutely vital."

She believes sustained funding has helped build a collaborative and highly connected community of Australian MND researchers, many of whom have dedicated their careers to the field.

"That continuity of funding keeps researchers in the sector," Christen says. "Without it, we risk losing expertise and momentum."

Continuing Justin's work now feels both scientific and deeply personal.

"To continue building on the ideas he believed in means a great deal to me," she says. "That's Justin's legacy."

Dr Christen Chisholm

ASSOCIATE RESEARCH FELLOW

University of Wollongong

more than a DATA POINT

SEEING THE REAL LIVES AND EXPERIENCES BEHIND THE DATA

Our Day at the Botanics by Ann Allan

For more than two decades, Susan Hoskins worked in some of the world's most challenging public health settings.

Originally from Scotland, Susan spent years working with low- and middle-income countries as an epidemiologist focused on the healthcare needs of marginalised populations. Her work focused on how better data could improve healthcare systems and outcomes for communities.

But it was caring for her mother, Ann, while she was living with MND, that ultimately changed the direction of Susan's career.

Today, Susan is MND Australia's Head of Epidemiological Research, bringing together her global research expertise and deeply personal lived experience to help improve the lives of people living with MND.

"I've spent my whole career looking at data and populations," Susan says. "But now, every data point represents a person. It's completely changed how I see this work."

By 2023, Susan was living in Australia with her young family when her mum experienced a series of unexplained falls in Scotland that Ann's clinical team believed may have been caused by a stroke.

"At the time she fell, she was still teaching French, German, and Spanish in a high school in Edinburgh," Susan says. "She was incredibly independent and full of energy."

"But when Mum came to stay with me in Sydney later that year, I knew something was very wrong the moment she got off the plane."

Over the following eight weeks, Ann's condition deteriorated rapidly. After receiving an MND diagnosis in Sydney, Susan accompanied her back to Scotland, intending to stay for only a few days. Instead, Susan stayed in Edinburgh and, together with her siblings, became Ann's full-time carer, sleeping on a mattress on her mum's bedroom floor for the final eight months of her life.

"I saw firsthand how this devastating disease affects everyone around the individual living with it," Susan says. "With my healthcare academic background, I was well-placed to navigate the health system and understand clinical conversations, but ultimately I was just a daughter caring for her mum, the same way so many thousands care for their loved ones with this disease each year."

Despite the enormous challenges, Susan is determined that the story is not only one of loss. Ann continued to live meaningfully and joyfully throughout her illness, supported by family, carers, friends, her faith, and the Scottish healthcare system.

"We never talked about Mum dying from MND," Susan says. "We talked about Mum living with MND.

Susan was determined to support her mum's wish to get out of the house every day, right up until her final days. They visited galleries and museums, attended concerts and theatre performances, and participated in all the activities that Ann loved, even joining in wheelchair dancing at Scottish country dances. They also found unexpected joy through art therapy. Although Ann had never considered herself artistic, she began mouth painting after losing the use of her hands.

"At first, the paintings were terrible," Susan laughs. "But then they became this incredible source of purpose and connection."

The family eventually held exhibitions and fundraising events featuring Ann's artwork, raising money for MND charities in Scotland. For Susan, those experiences reinforced something she now hopes to bring into MND research in Australia: the importance of quality of life.

"Of course, we need cure research," she says. "But while people are living with MND, we also need to understand what helps them live better."

That belief now underpins her work at MND Australia.

Susan's work is focused on strengthening Australia's MND data systems and building a clearer national picture of the disease. Currently, Australia still lacks comprehensive data on how many people are living with MND, survival patterns, regional differences, and the experiences of different communities.

"We are building on years of incredible commitment to this disease in Australia, but there's so much that we still don't know,' she says. "We need better data so we can ask and answer better questions."

Her vision includes developing stronger national registries and research platforms that can help identify not only patterns of disease, but also what improves quality of life for people living with MND and their families.

"What kinds of support make the biggest difference? What about improving assistive technologies, counselling, or creative therapies? Susan says. "These are things we can measure and learn from."

For Susan, the work remains deeply personal. On her desk sits a photograph of Ann smiling.

"When I look at data now, I don't just see numbers," she says. "I see people. I see families. And I think about how we can help change that experience for others living with MND."

Investing in THE FUTURE OF MND RESEARCH

MND Australia funds a dynamic research grants program to uncover the causes, improve care, and develop new treatments for MND. Every year, we allocate research fellowships, innovator grants and PhD top-ups to Australian-based MND researchers. Our research grants program is wholly funded through donations and bequests. In 2026 MND Australia awarded the research grants listed below.

MNDA RESEARCH *fellows*

Dr Christen Chisholm | **UNIVERSITY OF WOLLONGONG**

Bill Gole MND Research Fellowship

Dr Zeinab Eftekhari | **UNIVERSITY OF QUEENSLAND**

MND Australia Postdoctoral Fellowship

INNOVATOR GRANT *recipients*

Dr Sandrine Chan Moi Fat | **MACQUARIE UNIVERSITY**

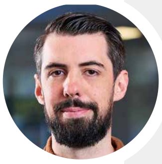
Jenny Simko MND Research Grant

A/Prof Taylor Dick | **UNIVERSITY OF QUEENSLAND**

Charcot Award, supported by MND South Australia

Dr Nida ul Fatima | **MACQUARIE UNIVERSITY**

Phyllis Diana Seman MND Research Grant



Dr Liam Koehn | **MONASH UNIVERSITY**

Peter Stearne Familial MND Research Grant

A/Prof Albert Lee | **MACQUARIE UNIVERSITY**

Charcot Award, supported by MND Australia

Dr Alexander Mason | **UNIVERSITY OF WOLLONGONG**

Col Bambrick MND Research Grant

Dr Andrew Reading | **UNIVERSITY OF TASMANIA**

Daniel Veysey MND Research Grant

Dr William Reay | **UNIVERSITY OF TASMANIA**

Murray Geale MND Research Grant

Dr Thais Sobanski | **UNIVERSITY OF QUEENSLAND**

Fat Rabbit MND Research Grant

A/Prof Gabriel Trajano | **QUEENSLAND UNIVERSITY OF TECHNOLOGY**

NTI MND Research Grant

Prof Bradley Turner | **UNIVERSITY OF MELBOURNE**

MonSTaR MND Research Grant

PhD TOP-UP *scholars*

Sophie Matis

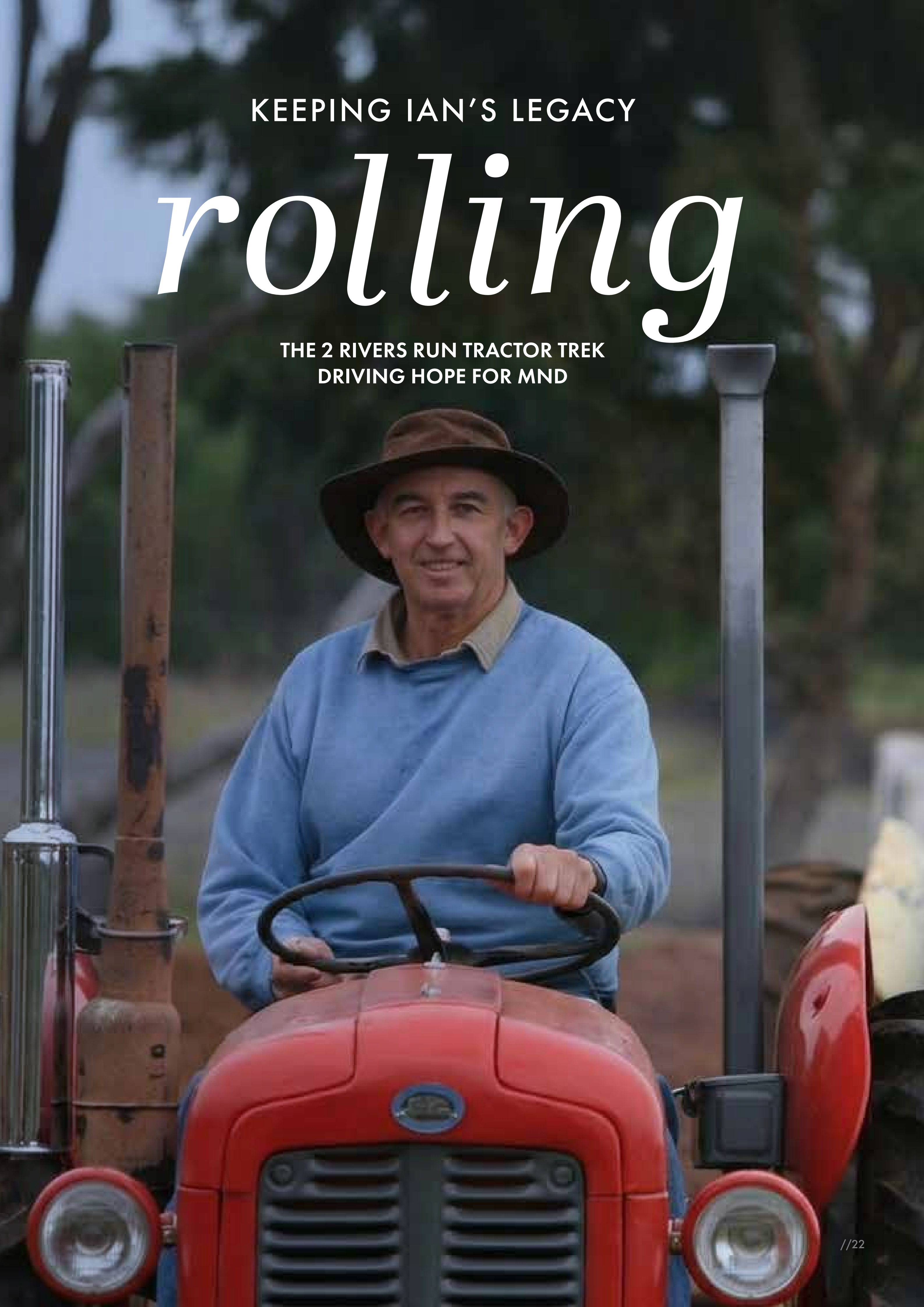
UNIVERSITY OF SYDNEY

Natalie Teh

UNIVERSITY OF QUEENSLAND

KEEPING IAN’S LEGACY *rolling*

THE 2 RIVERS RUN TRACTOR TREK DRIVING HOPE FOR MND



For six days, a convoy of vintage tractors rolled slowly along the back roads of northern Victoria. Travelling at little more than 20 kilometres an hour, they stopped in small country towns, rattled donation tins, shared meals, and sparked conversations about motor neurone disease.

This year, the 2 Rivers Run Vintage Tractor Trek raised over $100,000 for charity with an extraordinary $87,000 raised for MND Australia's research grants program. $5,000 of that total was donated by the Geary Family's Philanthropic Trust. The event brought together 53 participants, 38 vintage tractors, and communities across the region.

The trek was founded by Ian Sneddon, a much-loved community leader from Jerilderie who passed away from MND in 2019.

"Ian just loved bringing people together," says his wife, Robyne Sneddon. "He was involved in everything. Golf, Tidy Towns, the Rural Fire Service, local council serving as the Mayor, junior sport, the RSL. He always wanted to help."

Ian's love of vintage tractors began with an old grey Ferguson tractor left to him by his uncle. What started as a shared hobby with friends soon became something bigger. Together with close friend Phil Horwell, Ian launched the first tractor trek in 2014 to raise money for men's health and cancer research in regional communities.

The event quickly became a much-loved regional tradition. Then Ian was diagnosed with MND.

"When Ian was diagnosed, the committee decided future fundraising would go to MND," explains 2 Rivers Run Committee Secretary Robyn Cole. "That became the main reason we chose MND Australia as our charity."

Ian was still able to participate in his final trek before he passed away from MND in 2019.

"He couldn't drive much by then," Robyne recalls, "but he still came along. I followed the tractors in our motorhome and helped with meals and support along the way."

After Ian's passing, the event evolved into something even larger than one person's story.

"Originally it was very much about Ian," Robyne says. "But now so many people connected with the tractor trek have had family or friends affected by MND. It's become about the whole community."

Held every second year, the week-long trek travels between rural towns using quieter back roads, stopping for fundraising events, meals, and community gatherings. This year's oldest tractors included rare 1936 and 1938 Lanz Bulldogs, drawing crowds wherever they went.

"There's definitely more awareness now," says Robyn. "As soon as someone hears we're fundraising for MND, they say, 'I knew someone who had it.'"

That awareness is growing across regional Australia, where many families have experienced the devastating impact of the disease firsthand.

> *"MND is something more and more people are hearing about and understanding. People want to help."*

Robyn says.

The response this year exceeded all expectations. The previous trek raised around $45,000. This year, donations climbed past $100,000 before final figures were counted.

"When we hit around $70,000 during the trek, I started to think maybe we could get close," Robyn says. "But to raise this much was incredible."

For MND Australia, those funds will directly support critical research projects aimed at improving treatments, care, and ultimately finding a cure.

"He would be over the moon," Robyne says of Ian. "So much money is going to help other people and families in our position."

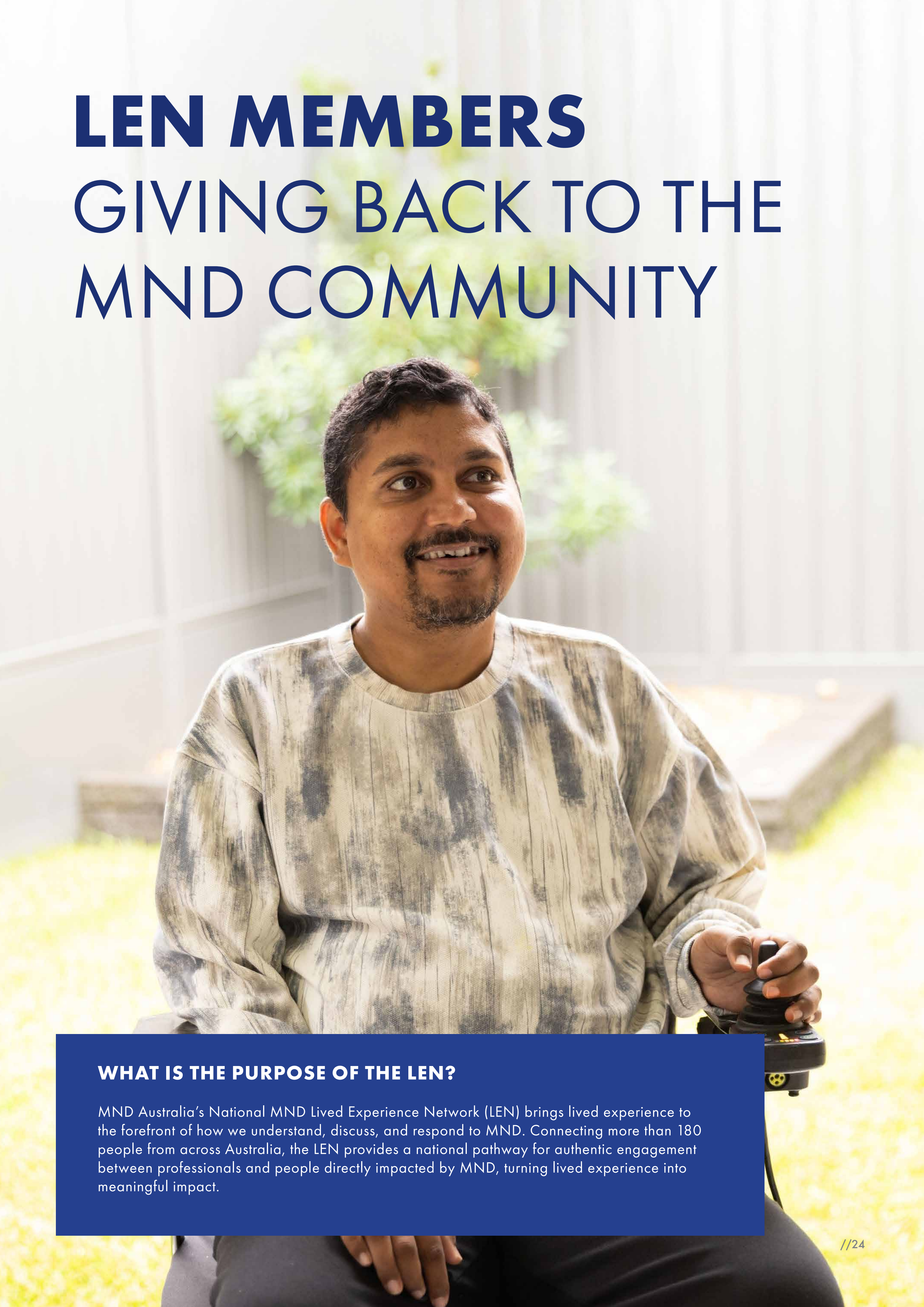
Ian's legacy continues beyond the tractor trek. The Jerilderie community also hosts the annual Ian Sneddon Golf Day, another fundraiser supporting people living with MND and funding vital research.

It is a reflection of the kind of person Ian was: practical, community-minded, and determined to get things done.

"He wasn't one to sit on an idea," Robyne says with a laugh. "He'd say, 'Let's just do it.'"

While the tractors may move slowly, the impact of the event is anything but small. Every kilometre travelled and every donation collected is helping drive vital MND research forward and ensuring families living with MND feel supported, understood, and never alone.

LEN MEMBERS GIVING BACK TO THE MND COMMUNITY



WHAT IS THE PURPOSE OF THE LEN?

MND Australia's National MND Lived Experience Network (LEN) brings lived experience to the forefront of how we understand, discuss, and respond to MND. Connecting more than 180 people from across Australia, the LEN provides a national pathway for authentic engagement between professionals and people directly impacted by MND, turning lived experience into meaningful impact.

LEN MEMBERS IN ACTION

Members of our Lived Experience Network (LEN) work to drive more compassionate, informed, and effective outcomes for the MND community. Over the past six months, they have contributed to a wide range of projects shaping research, care, advocacy, and awareness. A few highlights include:

- Partnering with Canberra Health Services MND Clinic and the University of Canberra to help design new research exploring the experiences of older Australians living with MND and their caregivers.
- Sharing lived experience through media, surveys, and interviews with organisations including the ABC, NDIA, and Department of Health.
- Working with FightMND on care grant review panels and a new advisory group focused on First Nations and culturally and linguistically diverse communities.
- Joining research advisory groups for new projects, such as UNSW's MND Care Coordinator and Bridging Health Equity Gaps studies.
- Discussing emerging MND treatments and participating in new Australian research related to cognition, AI, diagnosis experiences, sensation, constipation, and brain computer interface.

LEN MEMBERS SUPPORTING THE WORK OF MND AUSTRALIA

LEN members are also playing an increasingly important role within MND Australia itself, with 34 members now actively contributing to the organisation in a recurring volunteer capacity, via board representation, various advisory groups, and the Ambassadors program. Recent highlights include:

- Helping shape MND Australia's new strategic plan and upcoming National Conference.
- Speaking at MND Australia's Parliamentary Friends event in Canberra.
- Co-designing new resources on gastrostomy, self-advocacy, and emergency care planning.
- Assisting with development of new engagement resources, ie: Engagement Checklist & Guide to Paid Participation for People with Lived Experience.
- Contributing to the preparation of new grant applications.

One clinician-researcher reflected:

> *"Working with the LEN from the very beginning has ensured this project reflects real needs, not assumptions. The openness and willingness of LEN members who shared their stories, ideas, and experiences with us, has been invaluable in shaping a more meaningful and relevant project."*
>
> - Gemma Wall, Canberra Health Services MND Clinic

Professionals interested in engaging people with lived experience in their work, can learn more here:

People with lived experience can learn more about joining the LEN here:

IN PARTNERSHIP WITH

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FIGHT ~~MND~~. IT TAKES PEOPLE

State MND CEO UPDATES

Liam O'Meara
CEO,
MND New South Wales

When I stepped into the role of CEO at MND NSW, it wasn't just a professional decision. It was deeply personal — shaped by family, loss, and a belief that we can build something stronger for people living with motor neurone disease. My family has been profoundly affected by MND. Within three years, I lost my dad and two uncles to this disease. Those years taught me about courage, care, and the quiet resilience that families draw on when life changes in ways they never expected.

I learned how to support someone when their voice fades. How to adapt when mobility shifts. How to hold onto dignity in moments that feel anything but dignified. And I learned the strength that comes from simply showing up for the people you love.

That lived experience is something I carry with me — not as a burden, but as a compass. When the opportunity to lead MND NSW arose, it felt less like a career step and more like coming home.

This organisation is built on compassion and action. It's powered by people who understand that time matters, that support matters, and that no family should navigate MND alone. I knew I wanted to be part of that — to contribute to a community that had once held my own family through its hardest moments.

Stacey Thorpe
CEO,
MND Queensland

Over the past six months, we have continued advocating strongly for equitable support and specialist services for people living with MND across Queensland. A major focus has been engaging directly with parliamentarians through Queensland's Parliamentary Friends of MND group, helping raise awareness of the unique and complex needs faced by the MND community.

Queensland remains the only state in Australia where the State MND Association does not receive ongoing state government funding. While there has been increased investment in broader neurological initiatives, the needs of people living with MND are distinct and require specialised, disease-specific expertise and support.

At MND Queensland, we have continued strengthening our multidisciplinary service model to ensure people living with MND can access highly specialised care throughout their journey. This year, we are expanding even further with recruitment underway for a dedicated dietitian, adding to our growing team of MND-specific allied health professionals. Once established, we will have five dedicated disciplines working collaboratively to provide holistic support tailored specifically to people living with MND and their families.

One project we are especially proud to have contributed to this year is leading the development of MND Australia's new speech and communication resources for people living with dysarthria, a condition that affects speech and communication for many people living with MND. Developed alongside people with lived experience, these resources help people prepare for speech changes, explore communication options early, and remain connected as the disease progresses.

This work reflects the importance of specialist MND expertise and practical, person-centred support. Alongside advocacy, our focus remains on ensuring every Queenslander living with MND can access expert care, trusted information, and support when they need it most.

Dr. Samantha Mead
CEO,
MND South Australia

As we move through our 40th anniversary year, MNDSA continues to adapt to a changing landscape for people living with motor neurone disease. We have observed a notable shift in recent months, with an increasing number of referrals coming through for those who are 65 and over and therefore are not eligible for support through the NDIS. This trend reflects both the ageing demographic of those diagnosed and the evolving complexities of access to supports. In response, our team is strengthening collaboration with SA Government, stakeholders and the community aged to ensure continuity, dignity and high-quality care for every client.

This milestone year also brings exciting opportunities to celebrate and connect. MNDSA is proud to co-host a special gala event with MND Australia during the National Conference, to be held in Adelaide from 9–11 September. On the Saturday following the conference, we warmly invite our community to join us for our annual Walk to Defeat MND—a 5km walk departing from the Adelaide Convention Centre along the picturesque River Torrens. To participate, please register with Michelle Ward at fundraising@mndsa.org.au.

We are also planning our annual Parliamentary Friends Group event in September- another powerful opportunity to showcase the strength and unity of our community across government, research, clinical care, volunteers and supporters.

Chris Symonds
President,
MND Tasmania

MND Tasmania continue to support its 60 members with strengthening partnerships between the Tasmanian State Government, Fight MND, Country Care, the Tasmanian Community and MND Victoria, who deliver the services.

A Care Grant through Fight MND has allowed for the purchase of 12 powerchairs to go into the MND Tas Equipment scheme. The Equipment Scheme has completed its first year of operation partnering with Equipment provider Country Care. Increased equipment donations from the community have expanded the scheme with delivery to our members provided within three days after OT approval.

A recent funding announcement by the Tasmanian Government has seen a significant contribution to Care and Research within Tasmania. The announcement has come at time when the budget is under increasing pressure to deliver services. We thank the Premier and Health Minister for their support.

The MND Tasmania Board will continue to strengthen partnerships to improve the services to our members.

Mary-Jane Stolp
CEO,
MND Victoria

Over the past six months, MND Victoria has continued expanding support for people living with MND, their families and carers, with the organisation now supporting almost 650 people across the state. As demand for services continues to grow, we are also seeing increasingly varied experiences of disease progression, reinforcing the importance of flexible, person-centred care models.

One significant milestone this year has been the launch of a new statewide genetic counselling service in partnership with Monash Health. Funded through proceeds from MND Victoria's long-running MND Charity Superball fundraiser, the service will support people and families seeking information and counselling following genetic testing for MND.

In May, more than 1,500 people took part in the annual Great MND Relay, raising more than $360,000 to support MND Victoria's services. Across the past five years, the event has raised more than $1.5 million to help expand advisor and support services for people living with MND, particularly those over 65 who often face significant funding gaps.

This year has also seen continued growth across MND Victoria's carer support, volunteer and equipment programs. More than 75 volunteers now support the organisation across community engagement, peer support, social connection and practical assistance, while the equipment service currently supports 525 people with access to more than 3,800 items.

Alongside service delivery, MND Victoria continues strengthening its strategic direction and advocacy efforts, with renewed leadership across State Council and a continued focus on sustainability, impact, and improving outcomes for people living with MND.

Maeve Egan
CEO,
MND Western Australia

MNDAWA has had the support of WA Health for many years by contributing State funding to MNDAWA's MND Advisory Service, an integral care coordination and navigation service underpinned by emotional support to people living with MND and their carers in WA.

Recently, WA Health announced the undertaking of the inaugural Western Australian Neurological Health Strategy (WANHS) an Australian-first initiative being developed by WA Health to improve access to coordinated, person-centered care for individuals living with neurological conditions. MNDAWA welcomes the invitation from WA Health to participate on the advisory panel as part of the strategy formulation. The WA Neurological Health Strategy will be ready for release on world brain day July 22nd, 2027.

MNDAWA have extended and enhanced our support and education programs. Gather is a trusted place to connect with community, find support and access education for Western Australians impacted by MND. Gather programs offer education, support and events underpinned by emotional support. Gather events are tailored based on feedback from people living with MND and their carers.

The MNDAWA Board have recently welcomed Lianne Jiang, Postdoctoral Research Fellow, Perron Institute, and Honorary Research Associate, Personalised Medical Centre, Murdoch University. One of Lianne's first initiatives is to form a Patient Research Focus Group.

MNDAWA are committed to providing person-centred support and specialist care to people affected by MND in Western Australia.

YOUR SUPPORT CHANGES LIVES

Your generosity drives vital research to better understand, treat, and ultimately cure MND. Your tax-deductible donation helps maintain momentum—every dollar makes a difference.

DONATE NOW. CLAIM YOUR TAX BENEFIT BEFORE JUNE 30.

Clare Sullivan
MND Australia CEO

PAYMENT DETAILS

Cheque – Payable to MND Australia
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Account: 00902053

Donate Online

Scan the QR code or visit mndaustralia.org.au/donate to make a secure donation instantly.

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