NOVEMBER 2025

MOMENTUM

ISSUE 002

INSIDE:

A GIFT OF GRACE

HOW ONE WOMAN'S LEGACY IS POWERING MND RESEARCH

mnd Australia

MND CAN'T WAIT

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 breath – 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.

CONTENTS

What is MND?

Motor neurone disease (MND) is a progressive neurological condition that affects the motor neurones, the nerve cells that control movement. As these neurons die, muscles weaken and waste away, gradually taking from people their ability to walk, speak, swallow, and ultimately breathe. The lifetime risk of developing MND in Australia is about one in 300 by age 85, with around 2,752 Australians currently living with the disease. More than half are diagnosed after turning 65.

For most, the disease progresses over months rather than years, bringing significant disability and complex, constantly changing care needs. The average life expectancy after diagnosis is just 27 months and one in three people die within the first year.

Research shows that MND develops through a combination of genetic, environmental, and age-related factors. 15% of cases are familial, caused by an inherited gene mutation. Understanding how these factors interact is key to unlocking better prevention, treatment and ultimately, a cure.

Coordinated, multidisciplinary care is essential. Neurologists, physiotherapists, occupational therapists, dietitians, respiratory specialists, and allied health professionals must work in step to manage symptoms and maintain quality of life.

The state MND associations are the backbone of support for people living with motor neurone disease and their families. They help people navigate government funding, access vital equipment, join support groups, and receive essential carer assistance. These are just a few examples of the extraordinary work they do every day.

Assistive technologies, such as power wheelchairs, communication devices, and respiratory supports, play a vital role. This equipment, alongside practical home modifications, help people remain independent.

In Australia, two people are diagnosed with MND and two people lose their lives to it every day. With no known cure, the need for action is urgent. Every person living with MND should have access to expert advice and support when they need it.

MND Australia is driving research, advocacy and care innovation, moving us closer to a future free from this devastating disease.

MND IN AUSTRALIA

Key facts 2025

2,752

Australians living with MND

Expected to rise to 4,304 by 2050.

896

Deaths annually

Projected to 1,462 by 2050.

2

Approved medications

Riluzole (Rilutek®, Teglutik®) and Edaravone (Radicava®). A third, Tofersen (Qalsody®), is under TGA consideration.

24

Specialist MND Clinics nationwide

Provide multidisciplinary care and clinical trial access.

30+

Over 30 Australian MND researchers funded in 2025

Supported through MND Australia's national grants and partnerships.

Every day in Australia, two people are diagnosed with MND and two people lose their lives to it. Together, we can change this story.

Who We Are

For more than thirty years, **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 that support people and families affected by this devastating condition.

Through advocacy, awareness, and collaboration, MND Australia has become a driving force for change. We amplify the voices of people living with MND across Australia and around the world.

At the centre of our work is a clear purpose: to fund world-leading research, accelerate new treatments, and strengthen care for every Australian living with MND. In 2024, as we marked thirty years of progress, partnership, and persistence, our commitment remains unchanged, to create a future where no one faces MND alone.

message FROM OUR CEO

This year, MND Australia has worked tirelessly to drive real change for people living with motor neurone disease. Our national advocacy focused on a pressing health care inequity: the funding gap between aged care and the NDIS.

I have been constantly engaging with Ministers, parliamentarians, and their key staff, as well as key contacts in the public service. We've fought to ensure that aged-care reforms deliver fairer and faster access to essential supports. We've been working to shape the Support at Home Program, the Aged Care Rules and Pricing, and ensuring politicians including those involved in the recent Senate Inquiry understand the needs of people with MND. But until people with MND receive equal funding regardless of age, our work will not stop for a minute.

We've also made gains in research and collaboration. Australian researchers remain at the forefront of global breakthroughs in genetics, cell biology and quality-of-life innovation. Progress ranges from improved sleep and breathing supports to new technologies helping people live better and longer.

Looking ahead to 2026, our focus will be on connecting Australia's registries, biobanks, and datasets into a unified National MND Database. This will give us the knowledge to improve care today and accelerate progress toward a cure tomorrow.

I would like to thank Teva for their sponsorship of Momentum Vol 2, allowing us to bring you these stories and cover most of the printing and postage.

Our impact is only possible through the dedication of our state associations, researchers, donors, volunteers and lived experience community. Together, we are advancing care, driving discovery and building hope. Thank you for standing with us, for believing that every action brings us closer to a future free of MND.

Clare Sullivan, CEO.

messages
FROM OUR AMBASSADORS

"Being an MND Australia Ambassador over the past six months has been one of the most rewarding and humbling experiences of my life. Living with MND, I see every day how this disease impacts not just those diagnosed, but their families, friends, and communities. Through this role I have had the privilege of helping to bring more awareness to what MND really looks like, the reality behind the statistics.

I have worked alongside the passionate team at MND Australia to help chip away at their vision for a world without MND. That has included meeting with researchers to share my lived experience, reminding them that behind every data point is a person, someone fighting for time, dignity, and hope. I have also spoken with members of the community to help spread the message that MND can happen to anyone, and that the challenges go far beyond the physical.

One of the key messages I always share is the importance of **self-advocacy**. Living with MND means becoming your own voice, asking questions, pushing for answers, and making sure you are heard. I am proud to be working with the MND Australia team on building a stronger toolkit for families, to help them navigate the emotional and practical ups and downs of the journey.

Conversations really do save lives. The more we talk about MND, openly and honestly, the more understanding, empathy, and support we can create. So, if you would like to know more about MND, its impact, or how you can get involved in the many initiatives MND Australia is leading, please reach out. Every conversation brings us one step closer to change.

'til next time,

Peter Russo

MND Australia Ambassador

Scan the QR code to hear his words firsthand and gain a deeply personal glimpse into life with MND

It's been an incredibly rewarding and busy few months being involved across various areas of the MND community, from research and advocacy to education and storytelling.

A highlight has been participating in the MND Australia Research Grant program, where I've supported various researchers in their applications for funding. It's encouraging to see so many dedicated minds focused on advancing our understanding of MND and improving outcomes for those affected.

I've also attended several scientific seminars on MND, which are fantastic opportunities to stay up to date with the latest research developments and to connect with experts across Australia and beyond.

In addition, I continue to contribute to both the National MND Lived Experience Network (LEN) and the Lived Experience Research Advisory Panel (LERAP), ensuring that the perspectives of people with direct experience of MND are included in research and policy discussions.

Beyond MND Australia, I've been actively involved with a Community of Practice at Calvary Hospital, working alongside others who care for people living with MND. This has been an invaluable space for sharing insights, learning from each other, and finding ways to improve care and support.

A particularly special moment this year was being invited to present at both the Macquarie University MND Gala Night and the Smeg Australia Gala, two inspiring events raising vital funds for MND research at Macquarie University MND Disease Research Centre.

And, of course, I've had the privilege of interviewing some truly remarkable people for the Let's Talk MND podcast. Their stories of courage, love, and resilience continue to move and motivate me and I can't wait to share more of these conversations soon.

Together, all these experiences remind me that while MND presents immense challenges, the community surrounding it is equally powerful, united in hope, compassion, and determination to make a difference.

Jane Simpson

MND Australia Ambassador

ELIZABETH ABRAHAMS

Hope and Resilience: NAVIGATING LIFE WITH MND

I started to notice something was up while playing soccer in 2022. I was at a new club and I just felt sluggish, and thought it was because they put me in defence, which wasn't my preferred position. But hiking throughout the next year also became increasingly challenging.

When I fell over at Christmas in 2023 while playing cricket with the kids I knew something was wrong. The message just didn't get to my leg that I wanted to run. That's when I really began to worry. Diagnosing MND can be quite a lengthy journey. Thankfully for me, I received my diagnosis in the space of three months, when I was 37 years old.

I flew to Sydney from my home in Perth to see a specialist, Professor Dominique Rowe, to help expedite the process, and also saw the team at the local MND clinic. I remember sitting in the that small room in hospital after having tests conducted, my daughter waiting for me in the waiting room, and the doctor said to me, 'It's not good'. It wasn't my life that flashed before my eyes, it was my three children's.

I thought of everything that I knew I was going to miss out on: watching them grow, pursuing their dreams, being there to support them when they needed. I was a wreck for a good while after that, grappling with the reality that my life will be cut short.

"Life can be really rich when faced with the reality of our immortality."

It was made worse after the sudden passing of my Mum, my biggest support and best friend, only three weeks later, and then a marriage breakdown.

Adapting is a word that is thrown around a lot in the MND community, especially for the newly diagnosed. It isn't easy at the start, almost incomprehensible. But life can be really rich when faced with the reality of our immortality. I'm lucky in a sense that I seem to be slowly progressing.

Eighteen months in I am still completely mobile and independent, but a lot slower than I used to be. The fatigue is difficult to manage, it doesn't help that I'm a notorious night-owl, but I allow myself the down days to recoup.

Life is continuing on as normally as possible, though I've had to step back significantly from a job that I love at Bunnings and change roles to something less physical. I've had to give up a lot, including running, which was like therapy to me.

I can't climb up the ladder to my daughter's bed and kiss her head while she's sleeping, or participate in the parent's versus children match at her local soccer club. But I'm still here and I'm still able to experience everything I was able to before, albeit a little differently. I've joined an amazing group, Break the Boundary, that offers mountain biking and hiking to those with disabilities. I have a scooter to allow me to get out onto the trails with the kids.

In the days after my diagnosis; I had the realisation that I have never lost someone truly close to me. And that kind of brought me some comfort, that I would leave this world having loved so hard without ever feeling true heartbreak ... until I lost Mum and my world shattered for the second time in a matter of weeks. But her passing showed me just how fragile life is, that it can be gone in an instant, with no chance to say goodbye.

“It’s a daily reminder to make the most of every moment.”

What I am facing is so horrendous, but I have a unique opportunity to ensure that I remain present in my children’s lives and special occasions. It’s a daily reminder to make the most of every moment.

MND hasn’t had many breakthroughs, treatments are scarce, and those that are available have varying results. None of them are a cure. I’m grateful that organisations like MND Australia, their state associations, and Fight MND have helped keep MND in the public arena for many years here in Australia now. There isn’t a lot of hope for an individual when given this diagnosis, but hope is what we need, and these organisations help keep it alive. I encourage people to donate to MND Australia to help fund crucial research and ultimately help find a cure.

Published in the Herald Sun on Tuesday, 14 October 2025

celebrating

ONE YEAR

OF THE NATIONAL **MND LIVED EXPERIENCE NETWORK**

Launched in September 2024, the National Lived Experience Network (LEN) connects people impacted by MND with professionals across care, advocacy, research, and information development. In its first year, the LEN has grown to 170 members nationwide and supported over 80 engagement activities, resulting in more than 300 lived experience contributions.

Early feedback is highlighting stronger partnerships, deeper insights, and a growing appreciation of the value that lived experience brings. There's also growing international interest in the LEN model, with other MND organisations around the world expressing interest in replicating our approach.

"The whole process was very easy from a logistical perspective. The members of LEN recruited for our focus groups were fantastic—they were open and willing to share their experience."

- Professional (anonymous)

Over the past 12 months, LEN members have generously shared their time, expertise and stories across a wide range of initiatives. We would especially like to thank the LEN members who have played a vital role in embedding lived experience into MND Australia's work over the past year.

"Being part of the LEN has given many of us what MND so often tries to take away - purpose, meaning, and hope."

- Phil Camden (LEN member, living with MND)

We would also like to extend a special thanks to our LEN Approval Panel who support oversight, quality and continuous improvement.

The LEN is proudly delivered by MND Australia, with additional funding support from FightMND.

ROB TAYLOR

Game On: FINDING CONNECTION WHEN **MND CHANGES EVERYTHING**

When fatigue lifts, Rob Taylor logs on. The former IT professional, diagnosed with motor neurone disease in late 2023, plays online with his adult son several nights a week, a ritual that gives them both room to talk and to breathe. “I can disappear from reality and become the avatar that doesn’t have a disability,” Rob told ABC News. “I don’t dream that I have a disability.”

Rob’s gaming setup has evolved with his condition. Adaptive controllers now let him use feet or mouth switches so he can keep playing as his hands weaken. “As my hands deteriorate, I can keep adapting the system to my needs,” he said. The point isn’t the high score, it’s the space it opens with family: “When I’m gaming with my son, I can break those barriers down a little.”

Clinicians say that matters. MND Queensland’s Director of Care Services, Alicia Edwards, notes that accessible gaming can be “fun, rewarding and fairly low energy,” especially when features are easy to find. Her team, working with MND Australia, built practical guides for people with MND and their allied health teams because “what worked one month may not work in the future.” The right tech, she says, helps preserve quality of life as needs change.

For Rob, the benefit is simple. Even on tough days, the screen becomes a meeting place. “Even though it’s an avatar on screen, it’s still connecting … I use it to connect with my son.”

For more information and resources head to mndaustralia.org.au/gaming

This is a summary of the article published by ABC online on 1 September 2025

Racing Against Time: GILL AND TONY'S STORY

Before motor neurone disease entered their lives, Gill and Tony Lewis shared a love of racing. They each owned cars built for competition and spent weekends on the track taking part in time trials. It was a shared passion that shaped their marriage, the planning, the travel, the gentle rivalry. Away from racing, life was full: family, grandchildren, and the simple pleasure of keeping busy. Tony was always on the move, often walking tens of thousands of steps a day.

The change came quickly. What began as small signs of weakness became a steep decline. Within months, Tony's strength and balance were gone, and the man who once thrived on movement now spends much of his time resting with his BiPAP breathing machine. "It's like living in a parallel universe," Gill says. "You're watching life happen around you and just trying to manage the best way you can."

Gill works hard to keep that balance. She spends time reading MND research and following the connections between lived experience and care. She also quilts. "I quilt to keep myself sane," she says. The half-finished designs on her wall are evidence of the next project and her way of staying grounded, something she can still control. "People who are miserable all the time don't survive," she adds. "Black humour keeps us going."

What frustrates her most is the system. "My Aged Care works at a glacial pace," she says. "If I request a pressure-area cushion, I can wait two or three months and pressure areas don't wait for approval. I can't go and buy something without approval from my aged-care provider." Even simple requests are rejected. "Protein supplements get knocked back because they're not on the care plan," she says. "I get incensed to the point that I've been emailing and copying in my local MP."

What frustrates Gill most is the system's inability to keep pace with the disease. "MND moves quickly, but everything around it moves slowly," she says. "There's no sense of urgency, no understanding that every delay matters."

For Gill, caring for Tony is a mix of love, persistence, and constant advocacy. The cars are still part of their story, reminders of a time when speed and freedom defined their days. Now, life moves more slowly, measured in small victories: a good night's sleep, a day without pain, a quiet moment together.

"You just keep going," she says. "You find the small things that make it bearable."

Building a Smarter Therapy for MND
INSIDE **DR AZIN AMIN'S** PEPTIDE PROJECT

At The Florey Institute of Neuroscience and Mental Health, affiliated with the University of Melbourne, Dr Azin Amin is developing novel, rationally designed peptide therapeutics aimed at protecting motor neurons and reaching the brain's most guarded regions.

Azin joined the MND Laboratory in 2017 under the guidance of Associate Professor Fazel Shabanpoor, an expert in peptide and oligonucleotide therapeutics, Professor Brad Turner, a leading authority in MND and neurodegeneration, and Dr Nirma Perera, an autophagy expert. It was during this time that she first discovered her passion for MND research. Years on, she continues this work in close collaboration with A/Prof Shabanpoor, whose specialist expertise and supportive mentorship provide ongoing scientific leadership on her peptide development program. Together, they are engineering peptides that are more selective, more stable, and able to cross the blood–brain barrier, opening new possibilities for treating neurodegenerative diseases.

Their research targets autophagy, the cell's internal recycling and cleanup system, which is impaired in MND. By boosting this pathway with custom-designed, blood–brain barrier–penetrant peptides, Azin aims to reduce the toxic protein buildup that contributes to motor neuron degeneration. Rather than a single cure, the ambition is a targeted, disease-modifying therapy that could form part of future combination treatments to extend both function and quality of life.

Azin says funding from MND Australia, through the Bill Gole Postdoctoral Fellowship, has enabled her to pursue innovative therapeutic strategies that may not otherwise have been explored, peptide candidates that are uniquely designed and developed within the lab and represent a fresh direction in the search for safer, more adaptable drugs.

Grounding the work, Azin regularly meets people living with MND and their carers through lab visits and community events. Those experiences bring purpose and urgency: visitors often leave more hopeful, and the researchers more driven to deliver tangible progress.

The next phase involves AI-guided optimisation of peptide structure and function, followed by preclinical evaluation of the most promising candidates. It is careful, cumulative work, reflecting a modern shift in MND research toward precisely targeted therapies that can advance from laboratory discovery to clinical impact.

Through MND Australia's support, Azin and her colleagues are expanding what targeted treatment for MND could look like, step by step, molecule by molecule, keeping hope firmly grounded in science.

Dr Azin Amin / **UNIVERSITY OF MELBOURNE**
Bill Gole MND Research Fellowship

Untangling MND:
HOW FAT METABOLISM COULD HOLD NEW CLUES TO MOTOR NEURONE DISEASE

When PhD student Clare Low joined the Motor Neurone Disease Laboratory at the Florey Institute of Neuroscience and Mental Health, she stepped into a world of complex questions with few easy answers. “I started my journey in neuroscience at the University of Melbourne,” Clare says, “and during my honours year, I worked on dementia research. But when I joined the MND lab, I realised how much there was still to uncover about what makes motor neurons so vulnerable. That challenge really inspired me.”

Supported by a Melbourne Research Scholarship and the MND Australia PhD Top-Up Scholarship, Clare’s project — Untangling the Role of Lipid Droplets in Motor Neurone Disease — explores how changes in the way cells handle fats and energy may influence neurodegeneration and inflammation in MND.

“Traditionally, research has focused on protein aggregation and inflammation,” she explains. “But there’s growing recognition that metabolic dysfunction, how our cells process and store energy, could play a major role in MND.”

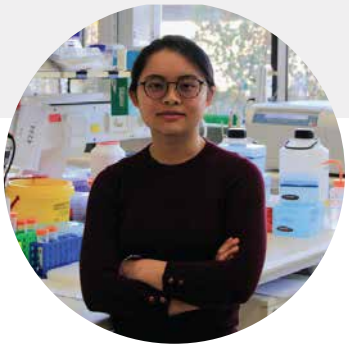
At the centre of her research are lipid droplets, tiny fat-storing structures within cells that help regulate energy, stress responses, and inflammation. “These droplets act as both energy reserves and protective buffers,” Clare says. “We’re investigating how disruptions in their formation and function might make motor neurons more susceptible to degeneration.”

To achieve this, Clare employs a combination of molecular imaging and model systems, including human neuronal models, patient-derived stem cells, and mouse models of MND, to investigate how lipid metabolism is altered under stress and in the presence of MND-linked mutations. A recent collaboration with researchers in Canada allowed her to learn and bring back new techniques rarely used in MND research, expanding what’s possible within the field.

“It’s exciting to bridge the gap between fundamental cell biology and MND research,” she says. “By understanding how fat metabolism interacts with inflammation and cell stress, we can start to identify new pathways that explain why motor neurons fail, and hopefully reveal targets for therapies that slow or prevent that process.”

Although Clare doesn’t work directly with patients, she often meets people living with MND and their families who visit the Florey’s laboratories. “Those encounters are incredibly grounding,” she says. “There’s a deep sense of urgency in this field, every small discovery could one day make a real difference.”

Clare’s work, and the scholarships that support it, reflect the growing importance of nurturing early-career researchers in Australia’s MND community. “Funding from MND Australia makes this kind of work possible,” she says. “It gives us the freedom to test new ideas, learn from international peers, and push the boundaries of what we know. Every advance, however small, brings us closer to better treatments and, hopefully, a cure.”



Yi Ling Clare Low / **PhD student**
The Florey Institute of Neuroscience and Mental Health
University of Melbourne

Exploring cognition in MND

DR REBECCA FRANCIS, FLINDERS UNIVERSITY

As a speech pathologist, Dr Rebecca Francis has seen firsthand how motor neurone disease steals not just movement, but connection. “Almost everyone with MND will experience some impact on their ability to swallow or speak,” she explains. “Those changes affect so much more than physical function. It touches communication, quality of life and relationships.”

At Flinders University, Rebecca’s clinical experience and research work converge with a clear goal: to normalise clinical conversations about Cognitive and Behavioural Changes (CBC) in MND and improve care for both people living with MND and their families. Her PhD, completed in 2025, explored the interaction between cognitive and behavioural changes in MND and dysphagia (impaired swallowing), and clinical approaches for people and their families. “Swallowing management strategies need cognitive engagement to enact, but it was unclear how cognitive changes in MND impacted these strategies” she says. “Understanding thinking and behaviour is important as it can not only impact how we manage swallowing problems, but it can also impact family relationships and people’s overall wellbeing.

My goal is to improve care approaches for cognitive and behavioural changes and to normalise these conversations in MND care. It’s also important to remember that CBC does not happen for everyone with MND and some people may experience mild changes to their thinking/behaviour, while others may experience more severe changes.”

Now, supported by funding from MND Australia and MND South Australia, Rebecca leads a national study focused on a key question: How do people want to learn about and manage cognitive and behavioural changes that may accompany MND? By partnering with people living with MND and their families, her team seeks to co-design more effective information and support tools. “People are telling us what works, what doesn’t, and how they envisage their care,” she says.

Rebecca credits the Lived Experience Network (LEN), which connects researchers with people who want to participate in studies. “Recruitment can be one of the hardest parts of research,” she says. “The Network has completely changed that. It allows us to hear directly from those living the reality of MND, ensuring their voices shape the science.”

For Rebecca, the impact goes beyond data and publications. It means equipping families with the tools to face an unrelenting disease with confidence and compassion. “Every insight we gain helps clinicians communicate better, plan earlier, and make daily life easier,” she says. “That’s what drives me, helping people to better understand MND and hopefully this understanding improves their wellbeing.

A GIFT OF *Grace*

HOW ONE WOMAN'S LEGACY IS POWERING MND RESEARCH

When Eileen Grace Bignall lost her voice, she refused to lose her spirit.

Known simply as "Grace" to most who knew her, she was one of twelve children raised in a small dairying community in northern New South Wales. Born during the Depression and coming of age through the Second World War, resilience and optimism were stitched into the fabric of her life. Hard work came naturally, but so too did laughter, music, and faith.

Grace spent 37 years as a schoolteacher, nurturing generations of children in Gunnedah and later in Port Macquarie. She taught with energy, humour, and when she wasn't in front of a classroom, she was at the piano, accompanying school choirs, musicals, and assemblies with the same warmth that marked her teaching. For hundreds of children, Grace was the sound of music and belonging.

Then, in her late years, came a diagnosis that changed everything. Motor neurone disease (MND) stripped Grace of her voice, a cruel irony for someone who loved conversation and slowly took away her ability to play, walk, and move. Even as her world narrowed, Grace's faith and composure never faltered. In her final weeks, she took joy in small things: sunshine on her face, blue skies, the company of her family.

As MND began to reshape her life and the lives of those around her, Grace moved into aged care. There, as her voice faded, so too did much of her agency, a reality faced by many living with the disease. Determined that others might one day have a different experience, Grace made a quiet but powerful decision. From her modest estate, she arranged a series of donations to motor neurone disease research, not as an act of charity, but of conviction. She believed that research was the path to progress, a way to turn pain into purpose. Her daughter Robyn remembers her saying that a gift to science was "a way of making a positive out of a negative."

Grace passed away before knowing exactly where that donation would lead. But in 2024, her legacy found its home in an MND Australia Innovator Grant awarded to ***Professor Peter Catcheside***, a world-recognised sleep and respiratory physiologist at Flinders University.

Professor Peter Catcheside

Professor Catcheside's work examines how MND affects breathing during sleep, a vital area of research aimed at improving quality of life and potentially extending survival for people living with the disease. His project builds on a growing body of Australian-led research into sleep monitoring, early detection, and non-invasive ventilation, areas that translate rapidly from laboratory to bedside.

With support from the Grace Bignall Innovator Grant, Professor Catcheside and his multidisciplinary team at Flinders University are developing Medbug, a new device that could transform how breathing problems are detected and managed in people with MND. The system uses a slim motion-sensing strip that sits on top of a mattress, paired with a bedside device to record breathing motion and sound.

Using advanced respiratory analysis and machine learning, it can automatically track and assess breathing quality, snoring, and airway obstruction without the need for cumbersome wires or overnight hospital studies. Importantly, the project also involves people living with MND and their carers in co-designing the device to ensure it is comfortable, practical, and meets their real-world needs.

For Robyn, the connection between her mother's generosity and this work is tangible. Grace's belief that research could one day lighten the burden for others is now being realised through every data point, every discovery, every incremental improvement that helps someone breathe a little easier or sleep a little longer.

It's a reminder that every donation, no matter its size, is not just a transaction, but a continuation of someone's story.

Eileen Grace Bignall's life was shaped by teaching, music, and kindness. In death, her legacy is helping others find time, time to talk, to breathe, to live.

BRINGING CARE AND RESEARCH TOGETHER

PACTALS 2025

In September 2025, MND Australia co-hosted the Pan-Asian Consortium for Treatment and Research in ALS (PACTALS) Congress at Melbourne's Convention and Exhibition Centre, the first time the entire MND sector had gathered under one roof. More than 650 delegates attended, including clinicians, researchers, allied-health professionals, state association teams, and almost 100 people with lived experience of MND.

"For the first time, we brought everyone together, from laboratory scientists to care researchers, State MND Association staff and clinicians, and people living with MND," said Clare Sullivan, CEO MND Australia. "The conversations, the learning and the relationships formed will accelerate progress toward new care models and medical breakthroughs long after the conference ended."

Running alongside the scientific program, the 12th MND Australia Care Forum focused on practical, person-centred care. Sessions explored wellbeing, communication and the evolving best practice in multidisciplinary support. This really reinforced how collaboration across healthcare, community care, and lived experience can improve outcomes today.

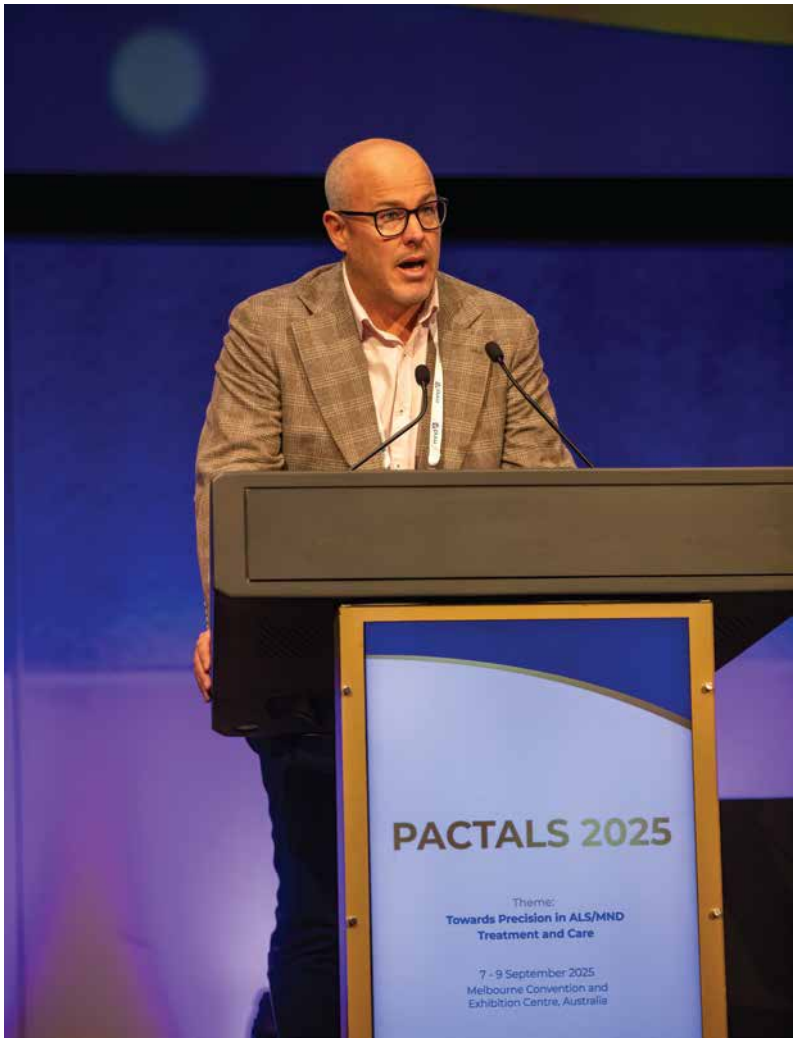
“It’s those immediate outcomes that matter most,” Clare said. “When healthcare professionals and carers share knowledge and learn from each other, it helps people with MND right now.”

The congress theme, “Towards Precision in ALS/MND Treatments,” also showcased groundbreaking research. Some of the presentations highlighted the use of artificial intelligence in drug repurposing, new insights into genetic MND and early intervention, showing the proven power of multidisciplinary care to extend and improve quality of life. Delegates described a palpable energy among early-career researchers and a renewed commitment to linking discovery with everyday care.

Behind the scenes, the event was a true partnership, delivered by MND Australia, PACTALS, MND Victoria, and the national team, including Morag Millington, Maddie Catlin, Louise Henry, and Laura Birks, with special thanks to Jo Whitehouse from MND Victoria for her leadership.

The success of PACTALS 2025 was not only in what was learned but in the connections forged. It’s the relationships that last; they’re what drive momentum.

MND can’t wait - and neither can we.



SAVE THE DATE:

MND Australia Research and Care Conference, 9–11 September 2026, Adelaide.

STATE MND CEO UPDATES

Graham Opie
CEO, MND New South Wales

This year, our priority at MND NSW has been ensuring people with motor neurone disease have access to the right equipment, support and care when they need it most. Our Equipment Loan Program, FlexEquip has continued to grow, providing essential assistive technology, from communication aids and power wheelchairs to specialist beds, often within days of a request. We also expanded our carer program, adding dedicated capacity to support families as they navigate the demands of caring. At the same time, tighter coordination with MND-specific NDIS planners has cut plan wait times from months to weeks, helping people access supports faster and with less stress.

While funding inequity persists, our focus is on what changes lives today. We have strengthened our navigation and education teams, support coordinators and advisors who guide people onto the right pathway (NDIS or My Aged Care), to remove administrative roadblocks. Our approach is to enable independence, not institutionalise, providing the information, equipment and coaching that help people make their own choices, maintain dignity and protect quality of life.

Despite financial headwinds, we're investing where it counts: practical, timely support for people living with MND and the families who stand beside them.

Stacey Thorpe
CEO, MND Queensland

Across 2025 MND Queensland has focused on building out our extensive range of MND expert services by adding psychology and carers programs to ensure we are providing holistic support to the entire family. We launched a dedicated psychology program providing no-cost, MND-specific mental health support for people, carers and bereaved families. Our psychologist understands the unique trauma, urgency and rapid change that MND brings, ensuring people can access support immediately. Alongside this, our new carers program offers tailored help for those supporting a loved one, creating space for honesty, connection and practical solutions that reduce isolation and long-term emotional strain.

At MND Queensland, we've built a fully integrated, multidisciplinary service model shaped by what people with MND and their families have told us they need most. The Ancil Allen survey reaffirmed the value of expert, wraparound, disease-specific care and that's the foundation of our approach. It's a model grounded in partnership, evidence, and compassion. To ensure its future, we need sustainable investment that allows us to plan ahead, retain specialist staff and continue delivering quality care for Queenslanders. We're inviting the Queensland Government to work with us and with the broader MND community, to make equitable, person-centred care a shared priority for every person living with MND, their carers, and support teams.

Dr. Samantha Mead
CEO, MND South Australia

This year, we took a major step forward in bringing South Australia's MND community together through the 2025 MND Research, Care and Collaboration Symposium, co-hosted by MND SA, Flinders Health and Medical Research Institute, and the Southern Adelaide Local Health Network. More than 80 delegates, researchers, clinicians, service providers, and people with lived experience joined us to explore how science and care can work hand in hand to improve lives. The event created new connections, strengthened existing partnerships and renewed our shared focus on collaboration as the path to progress.

The highlight of the day was Professor David Berlowitz's keynote on sleep and breathing research, reminding us how evidence and practice come together to improve quality of life right now. The symposium was about more than research, it was about building community, translating discovery into action and giving people living with MND a voice at the centre of every conversation.

We are proud to play a role in uniting care, science, and lived experience in South Australia, driving shared purpose and real outcomes for the people and families we support every day.

Chris Symonds
President, MND Tasmania

MND Tas have had a fantastic year partnering with MND Vic, Fight MND, our Tasmanian State Government and all our support team to deliver expanded services to the 60 members and families in Tasmania.

The newly established Equipment scheme, provided in partnership with Country Care is gaining traction for our members to gain access to equipment without delays.

A third Advisor to help share the caseload has provided improved support.

MND Tas has a close relationship with the University of Tasmania's Menzies Institute and the Wicking Center with MND Tas Board members from the Menzies Research group and involvement in the MOOC.

Jo Whitehouse
CEO, MND Victoria

At MND Victoria, our focus is simple, to walk alongside every person living with motor neurone disease and their families from the day of diagnosis through every stage of their journey. Our programs remain the foundation of that care: the MND Advisor and Counselling Service, which provides dedicated support from diagnosis through to end-of-life; our Equipment Service, which ensures people have timely access to the assistive technology they need; and our Education, Intake and Volunteer Programs, which connect people, families, and professionals to vital information and community.

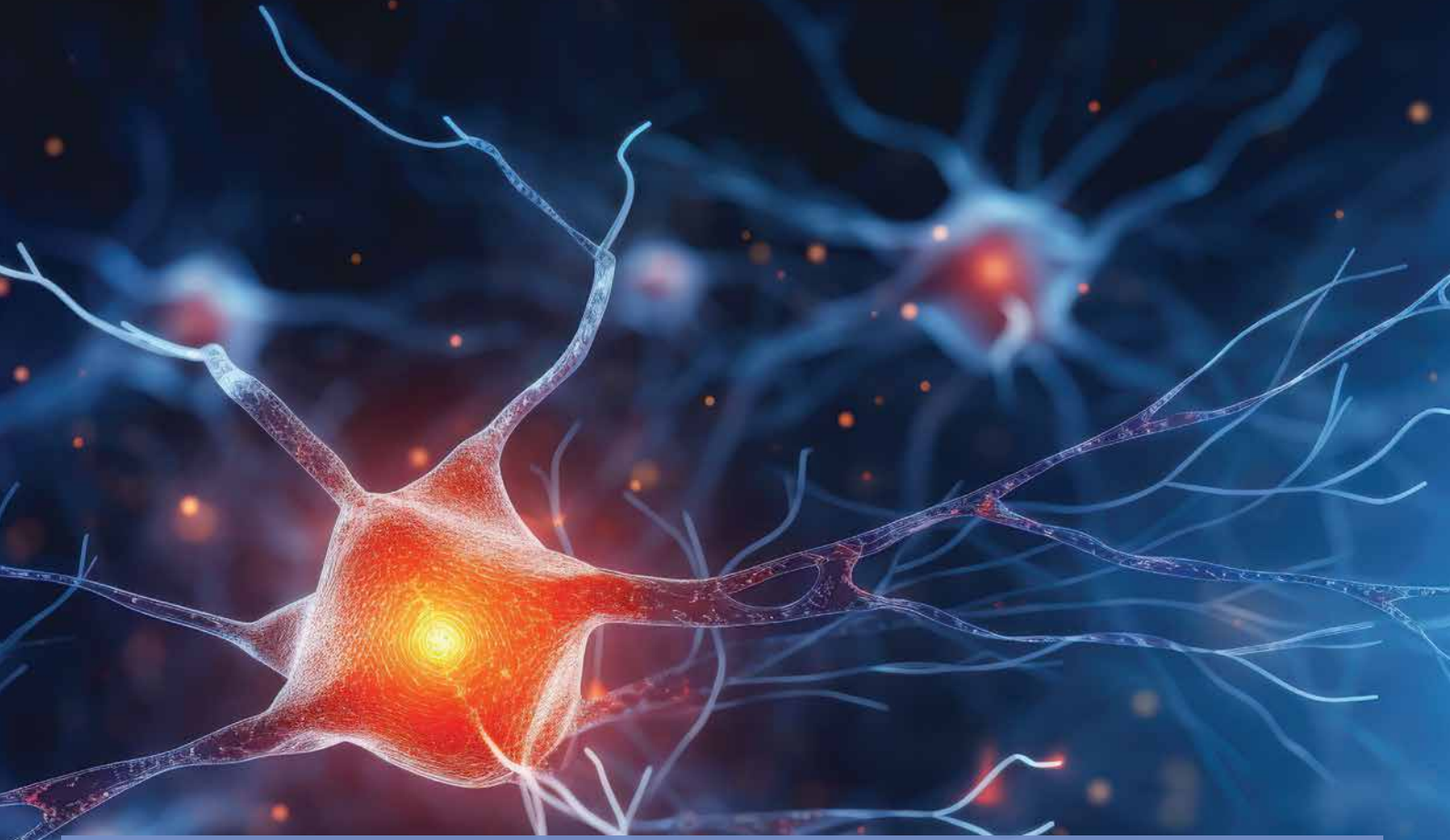
This year, we've continued to strengthen these services, ensuring continuity, responsiveness and compassion remain at the heart of everything we do. Our advisors now support smaller caseloads so they can spend more time with each client, while our education team continues to build awareness and understanding across the MND Community. As we look ahead to the Victorian election next year, it gives us an important opportunity to advocate for improved palliative care and funding equity. Speaking of advocacy, we are currently in the fifth year of our "Shut Up!" fundraising campaign, which invites Victorians to experience silence in solidarity with those who lose their voice to MND, raising both awareness and vital funds for care and research. Collaboration across states and with MND Australia has never been stronger and by working together, we can keep improving care, building understanding and ensuring every Victorian living with MND has the support they deserve.

Maeve Egan
CEO, MND Western Australia

At MNDAWA, we take immense pride in the strides and enhancements made this year. Every decision strategically and operationally is made with our mission front and centre: To deliver person-centred support and specialist care to people affected by MND in WA. There is good evidence that person-centred care leads to improvements in wellbeing and quality of life. This approach ensures continuation of service and allows staff to take time to build rapport with clients. The value of this support is evidenced through testimonials such as this statement received from a carer, recognising the importance of human connection, "The individual care provided by the MNDAWA team has been outstanding, with their compassion and good humour complemented by their efficiency in getting on and getting things done when my wife needed anything."

This year we have worked hard to ensure our person-centred care is underpinned by best practice in all areas of our service provision. Following an extensive NDIS certification audit, MNDAWA is now a NDIS registered provider. A significant amount of work took place in preparation for the audit that allowed us to thoroughly and comprehensively review and enhance robust governance and operational management systems. We are well established and ready to navigate system and sector challenges and advocate in an ever-changing NDIS and aged care system fraught with barriers and limitations in responsiveness, decision-making and funding.

In the coming months we will be increasing our signature 'You, Me and MND' program which informs and supports the person living with MND as well as their carer, while continuing to expand our education delivery to health professionals across Western Australia. By investing in education across all levels of care, the Association hopes to increase awareness, advocate and build stronger, more connected support systems to ensure high-quality and effective care for those affected by MND.



RADICAVA® IV INFUSION (EDARAVONE) NOW LISTED ON PBS FOR ELIGIBLE AUSTRALIANS WITH ALS: A STEP FORWARD FOR TREATMENT ACCESS

MND Australia acknowledges the recent inclusion of RADICAVA® IV infusion (edaravone) on the Pharmaceutical Benefits Scheme (PBS) for adults diagnosed with amyotrophic lateral sclerosis (ALS), the most common form of motor neurone disease (MND). This listing marks an important development in treatment access for a defined group of Australians living with ALS.

KEY FACTS:

RADICAVA® IV is now PBS-listed for adults with ALS who:

- Are independent in daily activities
- Have normal respiratory function
- Commence treatment within 2 years of symptom onset

This decision enables subsidised access to eligible patients, improving affordability of treatment that may slow disease progression in its early stages.

MND Australia supports the principle of timely and equitable access to therapies for all people living with MND. The PBS listing of RADICAVA® IV provides an option for those who meet the specific eligibility criteria. We also recognise that many people living with MND may fall outside of this criteria and continue to face limited treatment choices.

Like all medications, RADICAVA® IV may cause side effects, ranging from minor to serious. We encourage people living with ALS and their caregivers to consult their healthcare team and refer to official Consumer Medicines Information before starting treatment.

INFORMATION & SUPPORT

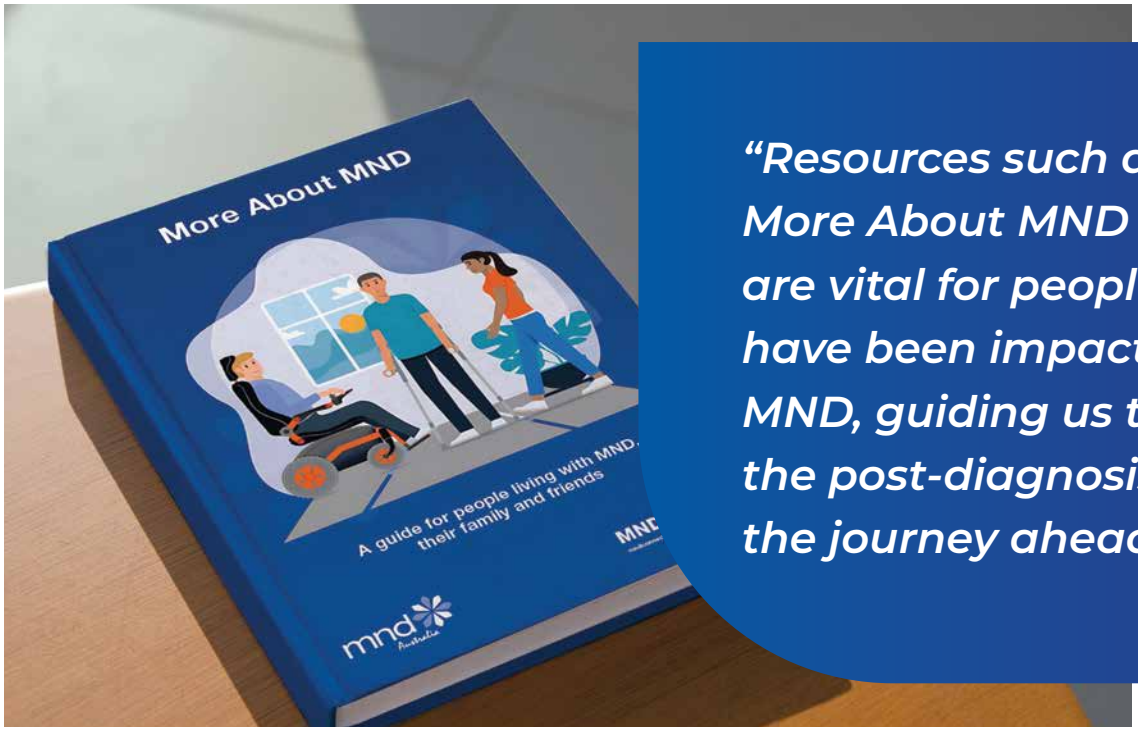
ADVICE YOU CAN TRUST

In collaboration with the State MND Associations and people living with MND, MND Australia offers a suite of evidence-based, easy to use information resources for people living with MND, their families and friends.

Through our information and support portal, we offer resources in a variety of formats, including web pages, animations, videos and downloadable guides. Our resources are designed to give people a better understanding of MND, including causes, symptoms, treatments, and planning ahead.

We also offer a range of tools to self-advocate within the health system, make decisions about care and assist people to live as well as they can for as long as they can. We also connect people impacted by MND with services and support to ensure they get the best possible care.

MND Australia is a Healthdirect Australia trusted information partner.



"Resources such as the More About MND booklet are vital for people who have been impacted by MND, guiding us through the post-diagnosis fog and the journey ahead."

The MND Info Line and mndconnect.org.au are partly funded by the Australian Government Department of Social Services through an Information, Linkages and Capacity Building (ILC) grant.

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.

MND CAN'T WAIT – PLEASE DONATE NOW

Clare Sullivan
MND Australia CEO

PAYMENT DETAILS

Cheque – Payable to MND Australia
Direct Deposit – BSB: 062-152
Account: 00902053

Donate Online

Scan the QR code or visit **mndaustralia.org.au** to make a secure donation

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Free call MND Info Line 1800 777 175 (9am to 4.30pm Monday - Friday)

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