IMPACT REPORT
2025

Until there is a cure, there is care.

mnd Western Australia

Staff

Chief Executive Officer	**Maeve Egan**
Manager – Partnerships and Community Engagement	**Sarah Wiley**
Manager - Support Services	**Jessica Audino**
Accountant	**Ling Lee**
Administration/ Finance Officer	**Anne Northall**
Administration	**Anita Nici**
Fundraising and Events Coordinator	**Trudy Renshaw**
Marketing Coordinator	**Jasmin Woodhall**
MND Advisors	**Anntoinette de Clifford** **Joan Ellis** **Emma Evans** (South West region) **Cathy Trunkfield**
Respiratory Physiotherapist	**Vivienne Travlos**
Occupational Therapists	**Rohan Moore** **Sophie Nunn**
NDIS Support Coordinators	**Jodie Nicks** **Emma Arnett**

Board of Management

President	**Guy Marchesani**
Vice President	**Prof Samar Aoun AM**
Treasurer	**Helen Kraus**
Secretary	**Sam Brayley**
Members	**Maureen Bathgate** **Melissa Cashman** **Lisa Gregory** **Lachlan Haughey** **Paul Rogers** **Dr Dev Nathani**

REGISTERED CHARITY
acnc.gov.au/charityregister

mnd
Western Australia

Motor Neurone Disease Association of Western Australia

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In the spirit of reconciliation, MNDAWA acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Honorary Accountant

Tony Silipo

Patron

Hannah Beazley MLA

Ambassadors

Michaela Carr
Keith Potger AO
Kirsten Whitby

Spicers

Our thanks to Spicers Paper for the donation of paper for 2025 MND Impact Report.

What is MND

Motor Neurone Disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate muscles, people with MND lose their ability to walk, speak, swallow and ultimately breathe.

MND affects each person differently. Initial symptoms, rate and pattern of progression and survival time can all vary widely. Average life expectancy for people living with MND is 27 months from diagnosis.

Over 2,600 Australians are living with motor neurone disease (MND). Every day in Australia, two people are diagnosed with MND and two people die from the disease.

In Western Australia, at any given time, the MNDAWA is supporting approximately 200 people living with MND, as well as their families.

Contents

Vision

MNDAWA ensures the highest quality care for West Australians impacted by MND.

Mission

MNDAWA delivers person centred support and specialist care to people affected by MND in Western Australia.

Values

Care // Inclusivity
Respect // Equity
Collaboration // Quality

Our Reach and Impact

As we reflect on the 2024-2025 financial year, 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. Person-centred care is and always has been the linchpin to the way MNDAWA supports and cares for people living with MND and their families. There is good evidence that person-centred care leads to improvements in wellbeing and quality of life and it is with this approach that we go about our work.

This year we have worked hard to ensure our person-centred care is underpinned by best practice in all areas of our service provision. We underwent a rigorous certification audit to ensure our compliance with the National Disability Insurance Scheme (NDIS) practice standards. The NDIS practice standards are the quality standards that need to be met by NDIS registered providers. 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 pleased to report we received accreditation by the NDIS Commission. With this strong foundation of best practice and person-centred care, 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.

We also concertedly set out to enhance our education reach by delivering more education and information sessions to allied health professionals and extending our You, Me and MND programs for families. We have managed to extend this educational reach outside the Perth metro area, with further outreach to regional WA on our agenda for the coming year. Our equipment loan pool continues to be a vital and critical resource for assistive technology and respiratory care. We thank Fight MND, Care Cure Support and the Stan Perron Charitable Foundation for their grants that allowed us to purchase equipment so that we can maintain and resource this service. Thanks to a grant from the Wearne Charitable Trust, we have been able to extend our counselling both for individual and group forums. The continued support of the Scottish Masonic Charitable Foundation also contributes to the cost of our respiratory service, and we are appreciative of their long-standing support.

Our fundraising and events this year have been wide-reaching and successful in raising awareness as well as raising vital funds that ensure we can continue to provide the services we offer. We thank all those who have fundraised, volunteered and donated to our organisation this past year. Our events also provide solace and comfort through a coming together and unitedness in strength and solidarity.

Karen Brown, Maeve Egan and Guy Marchesani

We rely heavily on volunteers particularly during event times and are continually amazed by the dedication, time and effort put in by so many people volunteering their time and expertise throughout the year. We are so grateful to all who contribute to the work we do voluntarily.

Importantly, we acknowledge and deeply appreciate the continued funding support of the Western Australian Department of Health, which enables us to sustain our MND Advisory Service. We also extend our heartfelt thanks to our Patron Hon Hannah Beazley MLA, whose advocacy and support have assisted in raising awareness and for her role in co-convening our Friends of Parliament event. Thanks also to our Ambassadors Keith Potger AO, Michaela Carr and Kirsten Whitby for their contributions over many years.

We would like to acknowledge the hard work of the MNDAWA team and the commitment of the board members in steering the organisational strategy in an ever-changing environment. Our commitment to those living with MND and their families is unwavering.

We will continue to keep abreast of developments in research and hope for a world without MND. Until there is a cure, we are here to provide care and support in any way we can.

Maeve Egan (CEO)
and Guy Marchesani (President)

> **"...the support and care we have received has been invaluable. We felt quite overwhelmed in the beginning of our journey, but the personal contact from MNDAWA has made a profound impact in our lives."** – *Wife of MNDAWA client.*

MNDAWA supported
302
people living with MND

242
resided in the Perth region

60 resided in regional or remote WA

106
were under 65 years of age

196
were over 65 years of age

179 male

123 female

3072
Individual consultations conducted

736 pieces of equipment were loaned

We provided bereavement support to 74 carers who lost a loved-one to MND

From the Treasurer

I am pleased to present the Treasurer's report for MNDAWA for the year ended 30 June 2025. The Association achieved a surplus of $929,080, an improvement on the previous year, primarily driven by increased donations, bequests and fundraising events. These gains were partially offset by higher costs. It is worth noting that some bequest income was received late in the financial year and will be utilised in future periods.

FINANCIAL HIGHLIGHTS

Total Income: $3,486,503

This represents an increase of $749,462 compared to the prior year, largely due to higher donations, bequests and fundraising income.

Grant Income: $780,539

This year's grant income includes the Fight MND grant of $185,234 which continues to support the Association's equipment service and educational programs. The WA Department of Health continues to be our major funding source for our MND Advisory Service. Additional grants were received from the Scottish Masonic Charitable Foundation, for respiratory support of $20,000 and the Wearne Charitable Trust for grief counselling services of $50,000.

We also received a grant of $154,418 from Care, Cure and Support for respiratory devices and increased respiratory service hours and $30,000 from the Stan Perron Charitable Foundation to add new items to our communication devices loan pool. These grants will be recognised as income in the next financial year.

Donation Income: $778,836

Donation income has continued to grow steadily throughout the year, supported by a range of generous contributions including a substantial donation of $400,000.

Bequest Income: $457,842

This year we were fortunate to receive several generous bequests and we express our sincere gratitude to the families and estates involved.

Fundraising Income: $887,454

Fundraising income rose substantially this year due to the continued success of events such as the Walk to Defeat MND (Perth and Bunbury), Unite Against MND and the Dive for Dollars. All of these events exceeded the prior year's results, reflecting strong community support and the dedication of our events team and our volunteers.

We are very grateful for the numerous community groups who organized events to support MNDAWA, collectively raising over $314,413 this year. Notably, one community fundraiser champion participating in the HBF Run for a Reason raised an outstanding $83,000 with total event contributions totalling $153,800, the highest ever amount received by the Association for the event and the top fundraising result for any charity in Perth. In addition, we received $35,653 from Red Dot. The ongoing commitment of our community continues to be a major source of strength for MNDAWA.

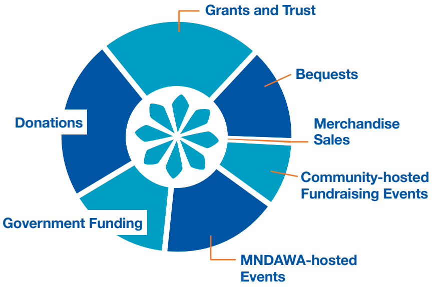
In summary, MNDAWA's financial position remains strong. The grant funding continues to sustain our MND Advisory service, our equipment service and education programs. Fundraising activity remains a vital source of income that provides additional support to the Association's operations.

Looking ahead, NDIS service income may face challenges due to the reduced billable rates for respiratory physiotherapy and travel costs under recent government adjustments. We will continue to manage service delivery costs prudently to maintain financial sustainability. Like many organisations, we are also facing rising operating costs, which place additional pressure on our fundraising efforts. Nonetheless, with continued community support and strong governance, MNDAWA remains well positioned for the year ahead.

I would like to sincerely thank the Association's staff for their hard work and dedication, my fellow board members for their support and our many supporters, donors and volunteers for their invaluable contributions throughout the year.

Helen Kraus, Treasurer

Income Sources



Life Members

Since our establishment in 1983, the MNDAWA is fortunate to have been supported by inspiring and dedicated individuals. From health professionals who have gone beyond their professional commitment, family carers who have used their lived experience to help others, and volunteers who have seen the opportunity to make a difference - Life Membership is awarded in recognition for providing extraordinary service to the Association over a period of at least ten years.

- Karen Brown
- Dr Sue Coyler
- Dr Rob Edis
- Janet Johns
- Christine Kingsnorth
- Marie Macdonald
- Emanuel Manolios
- Peter Murray
- Keith Potger AO
- Jon Sanders
- Helen Sjardin
- Karen Smart
- Julie Touchell
- David Whiteman
- Ross Whiteman

Professor Samar Aoun AM

After 13 years, Prof Samar Aoun AM will be stepping down from her position on the MNDAWA Board. We thank Samar for her dedication to supporting, leading and advocating for the MND community. Samar's service on the MNDAWA Board included five years as President (2018-2023) and six years as Vice President (2015-2018 and 2024- 2025). She also served as the President of MND Australia in 2023.

In addition to her active participation on the MNDAWA Board, Samar has initiated and overseen the development of several governance policies and procedures vital for MNDAWA compliance. She has developed and led MND educational programs to regional and rural areas, which were highly commended by health professionals from all disciplines, putting MNDAWA at the forefront of providing education and raising awareness in the field. Samar oversaw the expansion of vital services to the MND community, with a particular focus on supporting MND family carers.

Prof Aoun is Perron Institute Research Chair in Palliative Care at the University of Western Australia and the Perron Institute for Neurological and Translational Science. As a researcher, she is recognised as an international leader in the promotion and advocacy of public health approaches to palliative care and led this approach for those living with grief and bereavement and specifically for MND. Her research programs on supporting family carers at end of life and the public health approach to bereavement care have informed policy and practice at the national and international levels.

Samar was awarded the 2023 WA Australian of the Year, and in 2025 was presented with a Member of the Order of Australia Award (AM). She was also recognised in 2024 within the MND community, receiving the MNDAWA President's Cup award as well as a Lifetime Achievement Award from MND Australia. Internationally, she received the 2018 Medal for Excellence from the European Society for Person Centred Healthcare.

The Board and staff at MNDAWA thank Samar for her significant contribution and look forward to continuing to collaborate. We will follow Samar's next projects with interest, particularly the work of Compassionate Communities Australia whose mission is to "enhance community capacity for supporting those caring, dying and grieving and strengthen community action for system change".

Support in Regional WA

South-West resident David has been living with MND since 2024. He has found great comfort in the support of the MNDAWA team, stating "I can't praise them enough, I don't know where we would be without them"

Following David's diagnosis, his doctor contacted MNDAWA to provide a referral. From this prompt connection, we have been able to provide ongoing support for David and his wife Allison.

David and Allison (pictured below) moved from Perth to Busselton for a change in lifestyle. Having only lived in the South-West for two years before facing a diagnosis of MND, they were adamant to remain in the country. They are thankful that, with the support of the Regional MND Advisor, they have had access to high-quality care and have been connected with necessary services, despite being outside of the metropolitan area.

"They helped tremendously with the initial applications, paperwork and referrals" said David, adding that his local home-care provider was amazed by how quickly his Home Care Package was approved and implemented.

David's MND Advisor sees him every 4-6 weeks, with contact maintained between those visits. With her in-depth knowledge of MND progression, and relationships with local services and providers, the MND Advisor ensures David has the necessary referrals and access to the equipment and support he needs.

For Allison, having the right equipment makes a real difference in her life as a carer. "Knowing that David could safely get out of the chair by himself affects our lifestyle". When assessing equipment requirements, our team consider not only the client but also their carer, as there is often a physical demand placed on this support person. The recommendations of an Occupational Therapist and the correct equipment can significantly ease and improve daily activities.

When David met someone whose family member had been diagnosed with MND, his first piece of advice was to contact MNDAWA. He noted that he "felt comfortable to discuss his experience because his MND Advisor had empowered him".

David's story demonstrates that with person-centred care, an individual's lifestyle and priorities can be put first and a support team can be built around them, providing reassurance and guidance through the challenges.

Person-Centred Care

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

We do this by first getting to know the person for who they are, beyond their diagnosis. We build a relationship, learning about the needs and values of the person, fostering trust and establishing mutual respect. Then, we walk alongside the person living with MND and their family, from their early days of diagnosis and right through their journey. Being person-centred means we meet each individual where they are, providing what they need at any given time. This allows our team to offer unique support, to focus on the person and their family and to provide care based on human connection.

Within two days of being connected with MNDAWA, individuals are contacted by an MND Advisor, a safe and consistent advocate who will help navigate the physical, practical and emotional challenges of living with MND. Clients have described feeling a deep sense of relief from the support and reassurance offered through this initial contact. The MND Advisor can then refer on to our in-house allied health professionals (including Occupational Therapy (OT) and Respiratory Physiotherapy as well as external providers, becoming a vital connection for medical, community and disability services.

Our OT offers a proactive, practical support system. We help people adapt as their function changes, whether that's with recommendations of adaptive equipment, compensatory techniques, home modifications, or planning-ahead for future needs. The aim is to keep people as independent and comfortable as possible, for as long as possible. These strategies are introduced with sensitivity and compassion, allowing for people living with MND to have choice and control over this aspect of their care.

Our Respiratory Physiotherapist aims to improve the quality of life and reduce respiratory hospital admissions through maintaining lung health, improving breathing comfort and developing strategies to keep airways clear. The choice of treatment offered is based on careful assessment of the person's needs and preferences.

We offer a free equipment loan service unlike any other in the state, offering access to critical equipment at no cost. Depending on the person's symptoms and progression, this may include respiratory devices, mobility aids such as wheelchairs and specialised beds, or communication devices. This service often bridges the gap for our clients, while they are awaiting funding or equipment through other channels. The right equipment can make a real difference in their ability to continue daily tasks and is generally delivered within just days of the request being approved.

NDIS Support Coordinators help clients access the funding and services they want and need, and make sure those supports are tailored to their individual needs. With strong connections to health professionals across WA and access to the latest information and research, we are well-positioned to advocate for our clients.

The practical and emotional support extends to carers and family.

Our team lighten the mental load for families by providing guidance and clarification through what can be an overwhelming journey. The support for carers also extends to bereavement support through the MND Advisor and through bereavement support groups facilitated by a grief and loss counsellor.

This person-centred care is echoed by the entire MNDAWA team. Across partnerships, fundraising, community engagement and our administrative functions, our team is respectful and responsive to the needs of each individual and family we support.

Education and Support

Our education programs support and extend the reach of our person-centred care. By sharing our extensive knowledge of MND we can empower informal and formal carers in the home, hospital or residential care settings.

Empowering Families

The support offered by the Association focusses on the carer and family as much as on the individual living with MND.

We facilitate a range of programs where participants receive relevant education and information relating to MND, explore emotional support and learn valuable strategies, techniques and self-care tools to support themselves.

Programs such as You, Me and MND are designed for people living with MND and their families. Through different series of this program, we offer appropriate education and support for those who are newly diagnosed, or who are further along in their journey with MND. The carer-specific series empowers families with knowledge and confidence to care for themselves whilst caring for their loved one living with MND. The programs build a strong emotional foundation, that will assist participants with the changes taking place in their life.

With a collaborative, community-building approach, we often invite speakers from relevant organisations such as Carers WA and Palliative Care WA to present, providing participants with valuable information and opportunities for connection.

Over the past year we have introduced a series of online support programs for carers, facilitated by a professional grief counsellor. These programs offer support and guidance for current carers to understand and acknowledge anticipatory grief, carer fatigue and self-awareness of support needs as well as support for bereaved carers navigating the loss of their loved one to MND.

These programs offer so much more than simply education, they offer a safe and supportive environment to share and connect with others to ensure no one travels this journey alone.

Upskilling Community and Acute Setting Providers

It is our belief that people living with MND receive the highest quality support when there is a well-informed, collaborative care team surrounding them.

Over the past year we have proactively increased our education delivery across the state, with a focus on building an understanding of what MND is, how it can progress, and the unique ways it affects each person. These sessions help participants develop the knowledge, skills and confidence to provide care that respects each individual's needs, preferences, and experiences, ensuring support is truly person-centred and responsive.

Our specialist staff have presented to large groups and one-on-one, reaching nurses, residential care workers, allied health professionals and other support staff. This has been met with overwhelmingly positive feedback from participants, leading to improved outcomes for people living with MND.

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.

Informal Peer Support

With an understanding of the benefits of peer support and the strength of a supportive community, MNDAWA continues to foster opportunities for personal connection. This is seen through a range of initiatives including regular social events for carers, volunteer-led coffee catch-ups and our major events.

These events create a sense of belonging, provide a platform for shared experiences, offer access to support networks, and instil a sense of hope for the future.

760

health care professionals (in both community and acute settings) attended 39 metro and 4 regional education sessions

413

people living with MND and carers attended 36 metro and 6 regional support groups

Giving Time, Giving Hope

The time, energy and compassion of our volunteers contribute to the success of the Association. Without the time and experience they generously donate, many initiatives and events simply would not happen.

Each volunteer brings their own personal reason for giving, united by a shared dedication to our mission. In return, our volunteers are offered rewarding opportunities to gain experience, build social connections and see the impact of their valued contribution.

Volunteers are engaged with the Association in a range of roles across four key areas:

EVENT SUPPORT

Volunteers provide hands-on support from setting up, selling merchandise and taking donations through to cheering on walkers – it wouldn't be the same without them!

OFFICE ADMINISTRATION

Greeting visitors with a smile – through the front door or over the phone, our weekly office support volunteers support our administrative staff.

BOARD OF MANAGEMENT

All members of our Board of Management volunteer their time and expertise, dedicated to the best interests of our clients and the MND community.

COMMUNITY REPRESENTATION

Extending our reach across the community are the champions who take it upon themselves to host an event or activity to raise funds and increase awareness.

2493
hours donated

A value of
$120,000


Lauren pictured with her dad and brothers.

LAUREN JURY ARMITAGE, VOLUNTEER

“I’m a lifelong fan of volunteering; it’s such a great way to get involved and contribute to your community and to causes close to your heart. I first chose to volunteer for MNDAWA about two years after my dad passed, just before Christmas in 2022. He’d been diagnosed with MND about three years earlier and chose VAD. My Dad was a super pragmatic, positive guy but he still, unsurprisingly, found it exceptionally frustrating dealing with the challenges MND threw his way. Even when he got a bit rude and obnoxious, the MNDAWA team always had his back – they were always there to support him. The whole team were patient, good-humoured and realistic and had my dad’s utmost respect. I thought by volunteering, I could try and begin to repay the favours and goodwill the Association showed my dad (and us). Once I started volunteering, I met all the lovely staff and other volunteers who made me feel super welcome.

Volunteering is a great window into the efforts that go into making the Association the amazing community-serving, positive and hopeful organisation that it is. I feel privileged to work alongside these awesome people. Also, all the events and volunteering opportunities are always so well organised and run, which makes it easy to say yes whenever I can.

The MNDAWA community make me feel included, and they give me the opportunity to contribute – in a small way – to the fight against the disease.”

PETA BIRD, NORTH METROPOLITAN TAFE

(Liaison for event management student volunteers)

“We were contacted initially to discuss participation in the ball and the quiz night. We like to work with different organisations, not just corporate. I think it is important for the students to put something back to the community. It has always been an easy-going involvement, the MNDAWA staff have been a pleasure to work with.

The students get a lot out of it as well, gaining experience through watching an event take shape. Over the years I have seen how much the Association appreciated the support of our student volunteers and I have grown to understand the huge volunteer base that makes these events happen.”

JOHN FLOOD, VOLUNTEER

Ten years ago, John’s sister (in Ireland) was diagnosed with MND. Not being familiar with MND, John made contact with MNDAWA to find out more about what his sister would be facing. The support he received made a lasting impact and he felt inclined to give back to the Association in memory of his sister and to help raise awareness.

Through volunteering at MNDAWA events with his wife, John has benefited from being part of a caring community, building connections and has felt comforted by deepening his understanding of what his sister went through.

He enjoys the social aspect of volunteering and the chance to put a smile on someone’s face by helping out.

Empowering Carers to Support their Loved-Ones

Stuart's work in the healthcare sector gave him a strong theoretical understanding of the physical, emotional and practical demands on a family carer. The experience of caring for his wife Lynne as she lived with and sadly lost her battle to MND gave him a new perspective on family carers, professional care and support services.

Stuart kindly shared his story, having felt that the care MNDAWA's team provided to both him and Lynne "made a difficult time more tolerable."

Stuart and Lynne have two sons, one who lives in Perth, the other in Chicago with his wife and two children. In Stuart's words, Lynne was "a tower of strength" to her family. She was "caring, patient and intelligent".

Lynne was diagnosed with MND in November 2024. Looking back, Stuart notes that there were signs as far as fifteen months prior to this that Lynne's health was changing.

In December, as her strength began to deteriorate, Lynne had a significant fall, breaking a hip and requiring a four-week stay in hospital. The transitional care she received upon discharge resulted in 46 different people coming to the house in the first 10 weeks. Some of them more than once. For example, "In the first 12 days, we had 10 different support workers providing daily personal care." Stuart added. "All the support workers did a good job but what was missing was familiarity, consistency and the opportunity to build rapport. Human connection is just as important, maybe more so, than technical skills"

This is where MNDAWA stepped in as the constant. During her recovery from the fall, moving Lynne from her chair was a two-person job. With their son visiting from the US, Stuart had the help he needed. However, as their son was due to fly home, Stuart became concerned about managing the physical requirements of caring for Lynne on his own. Stuart reached out to MNDAWA and the MND Advisor arranged for the delivery of loan equipment at no cost and provided the support the family needed. Stuart was heartened when the necessary equipment arrived on time as promised, his first sign that MNDAWA was different to many other providers.

The MNDAWA person-centred approach to care ensures continuation of service and allows staff to take time to build rapport with clients. Stuart praised this support: "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 Lynne needed anything."

Stuart felt at ease, knowing what he and Lynne needed was usually just a phone call away, whether that was equipment, advice, referrals or just a friendly voice. Alongside MNDAWA's services, they also drew on the guidance of an Occupational Therapist, who not only met Lynne's immediate needs but always had an eye to the future, pre-empting her next requirements and lining up that next piece of equipment. Lynne also received support from

> “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 Lynne needed anything.”

MNDAWA’s Respiratory Physiotherapist, as well as connections to other services including palliative care, hairdressing and a manicure.

MNDAWA’s assistance was augmented by an in-home care provider, who gave consistent and reliable support. Following the 12-week Transitional Care Program, Lynne moved to a Home Care Package. Stuart could see the emotional and physical toll the role of primary carer could have, so the couple decided to engage an in-home care provider to support them. “Intellectually, I understood the role of a carer, I knew what people say about carers’ stress. But when you wake up every morning knowing that you've got a daily care routine that could take four or five hours, as well as all the phone calls and advocacy plus all the routine domestic chores you don’t have the time to be managing it all yourself. With many years of experience in the aged care industry I could have managed the package myself but emotionally and ultimately physically, I just couldn’t do it.”

Lynne lost her battle with MND in July 2025. Once Stuart and the family were ready, our MND Advisor assisted with the return of equipment and ensured that other families could benefit from a service which Stuart described as “brilliant”.

MNDAWA continued to support Stuart through grief and bereavement support programs.

Stuart takes comfort in knowing that the support will continue to be offered to him. “I am still receiving support from the MND Advisor and Counsellor. I don’t wish for my life to be defined by MND, but the emotional support to get through this stage is invaluable.”

Stuart’s story shows the heart of MNDAWA’s work, providing not just practical care, but connection, dignity, and hope that endures for families long after their loved one’s journey with MND has ended.

Advocacy and Community

Dianne is living with MND.
With the support of her husband she shared her experience.

Having lost her mother to MND in 2024, Natalie emphasised the value of the care and support that MNDAWA provided.

WA Parliamentary Friends of MND

In Western Australia, the Parliamentary Friends of MND group continued to engage with the Association, with a key event held in recognition of Global MND Awareness Day. We invited two families with lived experiences to speak at this event, giving honest and informative insights, highlighting the value of MNDAWA's support.

The group was established in 2023 and is co-convened by Hon Hannah Beazley MLA, Hon Pierre Yang MLC.

Australia-wide Representation

MNDAWA is part of a strong network of state-based associations, connected by MND Australia, the national peak body for MND care and advocacy. While these associations operate independently, we share the credence that 'until there is a cure, there is care' and this adage belief underpins all that we do.

MNDAWA collaborated with this network to develop advocacy initiatives, including a major awareness campaign which highlighted the need for high-quality care right now, for the 2,600+ families across Australia which are living with this disease. Our CEO, together with the network met with federal politicians to highlight the urgent needs of people affected by MND. The network collaborated on a strategic election campaign in early 2025, culminating in five key priorities to address the critical gaps in care and resources:

1. Fund MND Australia to build a National MND Dataset (MND Insights Platform)
2. Maintain the NDIS Priority Eligibility Decision Pathway
3. Establish a fast-tracked pathway to access the Aged Care system
4. Fund Aged Care supports to comparable levels to the NDIS
5. Include genetic counselling under Medicare.

Australia's national peak body for MND care, advocacy & research

I have recently been diagnosed with MND

I am a family member, carer or friend

I am a health professional or service provider

I want to support MND Australia

Learn about MND

Explore our information, events and resources to help people living with MND, families, friends, carers, and healthcare professionals navigate MND with confidence.

mnd Australia

Global MND Awareness Day

On 21 June each year we join with MND associations across the world to recognise Global MND Awareness Day – a chance to share information and awareness of the disease to the general public. The significance of this date being a solstice symbolises a turning point, with the community expressing hope that this day will be another turning point in the search for cause, treatment and cure of MND.

Thanks to the support of the Eleanor Mounsher Fund, the Association continues to host a lunch on Global Day for our clients and their guest. Through this event we acknowledge those impacted by the disease and share hope of a future free from MND.

Across the state, major infrastructure and landmarks light blue to raise awareness. MNDAWA shared a message of hope on Global MND Awareness Day, which was viewed over 15,000 times on social media channels.

Unite Against MND in the ENCHANTED GARDEN

At our sixth annual Unite Against MND ball, our community came together for a magical night in the Enchanted Garden. The room of over 600 guests was silenced as Professor Merrilee Needham delivered a keynote address, speaking about her experience not just as a neurologist caring for people living with motor neurone disease, but as a human being walking beside patients and their families through one of life's hardest journeys.

What makes Unite Against MND so special is the incredible diversity and spirit of the people in the room. From first-time guests to long-time supporters, every table holds a story of love, loss, courage, and commitment. Many come to honour a friend or family member, others to stand in support of the wider MND community. The energy on the night is equal parts joy and determination, as guests laugh, cry, dance and give generously, united by a shared purpose to make a difference.

✻ Unite Against MND is held annually, visit the website for details and to secure a ticket to the next event.

> **"Such a wonderful night and an honour to be part of. Well done"** – *event volunteer*

> **"Absolutely fabulous night. A big thank you to all the organisers for making the event an awesome spectacle."** – *event attendee*

Walk to Defeat MND

The Walk to Defeat MND has grown exponentially over recent years. With record numbers in 2025 (over 1,700 participants across Perth and Bunbury) we made a real visual impact with our sea of blue walking together, creating an opportunity to raise awareness and start conversations.

This event has become a milestone on the calendar for many families and teams in our community. It is touching to see the connections made on the day, and the camaraderie of walking in honour or walking in memory of a loved one.

❋ **Join us for the next Walk to Defeat MND in Perth or Bunbury. Registration opens January 2026.**

> **“Congratulations on raising the amount you did to help support the families affected by this hideous disease. There was such a fantastic turn out of caring people to help bring awareness to MND! Well done to all the crew!”** – *event attendee*

A Caring Community

We have a strong community of supporters who take the initiative and lead events and activities to raise funds on our behalf, reaching beyond our direct audience. Many of these individuals have a personal connection or motivation to fundraise. We have the utmost gratitude and respect for the dedication and creativity of these individuals.

While there are too many to feature individually, it is our hope that each and every one of these community champions understands the true value of their contribution.

Their fundraising effort goes beyond the dollars raised – it starts conversations, sparks awareness and it sends a message to the families living with MND that they are not alone.


mnd
GIANTS


the gate
Bar & Bistro


snap fitness
Help Us Support
MND


believe

2024-2025 Highlights

July 2024

Unite Against MND – Under the Sea

November 2024

Drive for MND (Hosted by Care Cure Support) // Annual General Meeting // Lights of Blue

September 2024

Pamper Day // Let's Get Quizzical for MND

October 2024

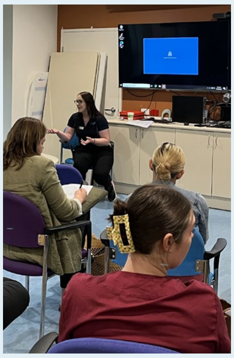
Carers' Week Conference (hosted by Carers WA, sponsored by MNDAWA)

December 2024

Annual MNDAWA Awards // Client and Carer Christmas Lunch (Perth and South West)

March 2025

Dive for Dollars // Pamper Day



May 2025

Australasian Neurological Conference and Expo (Hosted by NCWA, sponsored by MNDAWA) // Walk to Defeat MND Perth // Regional Education // Volunteer Week Morning Tea // Palliative Care Week breakfast (hosted by Palliative Care WA) // Carers Lunch // National Respiratory Upskill Seminar // HBF Run for a Reason // MND Guidelines Inaugural Meeting

April 2025

Walk to Defeat MND Bunbury // Lunch with Neale Daniher (hosted by Auspire)

June 2025

Global MND Awareness Day (Perth and South West events)

With your support, person-centred care is available to every family affected by MND.

mnd Western Australia

www.mndawa.asn.au