

Autumn 2024

# MND news

The newsletter of the Motor Neurone Disease Association of South Australia



- REGISTER NOW....Walk to Defeat MND 2024
- Latest news, research & events
- New staff and much more...

Until there's a cure, there's care

mnd   
South Australia

# Message from the CEO

The start to 2024 has been a busy one for the Association with the determination to set ourselves up for the year ahead, evolving the services we can offer people diagnosed with MND.

The year started with a busy period recruiting for a number of roles due to staff departures towards the end of last year and recognition that some of our roles need to change to align with our strategic direction. People have commented to me about staff turnover at MNDSA, but like any business, staff leave for a number of different reasons including retirement and lifestyle choices or because they find working with terminally ill patients too difficult and distressing.

Like many other organisations, MNDSA is experiencing challenges in the current recruitment market. It has been widely reported in the industry how changes in the NDIS and Aged Care Systems as well as labour shortages in the sector are impacting providers. MNDSA is no different. We are recruiting staff to work in a rapidly changing industry and with terminally ill clients. This presents a considerable challenge in attracting the right candidates. We also pride ourselves on having a compassionate and caring team, which is why we take the time to ensure that we get the right people on board, because constant change can be very disruptive for everyone. Our staff are supporting a community who are extremely vulnerable and often with changing needs. This can be very stressful for all involved, which is why we remind everyone of the need for respectful communication and understanding. We are all working together trying to get the best outcomes for people and families with MND.

MNDSA are strong advocates for our community, and you will read more about this on page 15. We are also continually advocating through MNDA and our National network to try and ensure that issues experienced through the NDIS and Aged Care systems are addressed appropriately and where possible highlight systematic errors that can be fixed. This has included MNDSA heading up a national initiative to connect with NDIS management to improve response times and outcomes for MND clients.



CONNECT  
ADVOCATE  
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The NDS released a “State of the Disability Sector Report” at the end of 2023. This report highlighted how “Disability service providers reported their worst financial year yet. With more organisations running a deficit and far fewer breaking even, keeping services going is getting harder than ever”.

Like any business, MNDSA faces the issues of rising costs of doing business. The NDIS have not raised the prices we can charge for services for a number of years. We are also matching through charitable fundraising the government funding received to support our non-NDIS clients almost dollar for dollar. Increases in wage costs, vehicle expenses, compliance fees, technology infrastructure, insurance premiums, supplier charges and other costs all need to be covered for us to operate. Demand for services keeps rising. Currently the only way we can meet the gap is through donations, fundraising and bequests.

Growth in our equipment pool has been achieved through donations and grants but a shortage in cough assist devices means we want to purchase more with funds raised from the Walk to Defeat MND.

Past bequests have made a real difference to our growth and the services that we can offer at MNDSA. A major bequest to MNDSA, designated for research a few years ago, helped us to bring clinical trials for MND to South Australia for members of our community to participate. We share on page 11 how you can assist by including MNDSA as a charity in your will.

You will see on page 14 we have a number of events planned in the year ahead which are aimed at not only bringing our community together, but also raising awareness and necessary funds - whilst having some fun along the way. We hope you can participate and support us.

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

**Karen Percival CEO**

# MNDSA Staff Update



## **Serena Racar, Philanthropy & Partnerships Manager**

Joining the team in March, Serena has a wealth of experience in the not-for-profit sector. She is already out and about meeting our corporate partners, and is looking forward to meeting our community members at the Walk to Defeat MND. While there are many challenges in raising awareness and securing funding, she loves coming to work each day in a caring and likeminded environment, to help make a difference to the lives of our MNDSA clients and their families.

**Fun Fact** Serena's work desk is covered in memorabilia from the TV show *Friends*, which is her true favourite.

## **Madison Grigg, Events & Community Engagement Officer**

Madi joined the MNDSA team in mid-February, and has a passion for events and supporting people with Motor Neurone Disease. Her father passed away from MND in 2022, so it is a disease very close to her heart. She is wanting to raise money and awareness to make a real difference in people fighting against MND. Madi loves being creative and meeting new people as part of her role, and has experience in administration and events from her former employment.

**Fun Fact** Madi describes herself as a "crazy dog lady", and is obsessed her German Shorthaired Pointer puppy, Macy.



## **Tom Mitchard, Marketing Coordinator**

Tom joined the MNDSA team in early February, and is passionate about communicating for purpose. He takes joy in being able to share positive news stories and making people aware about the work of MNDSA. He will be focusing on social media, e-news, and quarterly print newsletters. Tom also works part-time in a college and has experience as a social media manager at a church.

**Fun Fact** Tom enjoys spending time with his three-legged dog, Gracie, who loves to run!

## **Elizabeth Langwade, MND Support Coordinator**

Liz started with MNDSA in early March, and brings a wealth of experience as a registered nurse and supporting clients and families. Liz is keen to put her knowledge of navigating the aged care system into practice for the benefit of the MNDSA community. Her favourite part of the role is meeting and spending time with clients and families whenever needed to provide much-needed support.

**Fun Fact** Liz loves to travel, and has called Australia home for 13 years, since moving from the UK.



## **Arkie Simmonds, Business Support Officer**

Joining the team in February, Arkie brings a diverse range of administration skills to the MNDSA team. Having lost a family member to MND, it is a cause close to her heart. Arkie wants to help support, advocate, and raise awareness for MND in a hands-on way. She is enjoying learning the many facets of her role, interacting with our community, and working with our incredible team.

**Fun Fact** Outside of work, Arkie enjoys spending time with her family and getting out in the garden.

# MNDSA Board Update

It has been a great start to 2024 for MNDSA.

The organisation continues to grow and evolve with a number of personnel and structural changes within the organisation. To our new starters, I welcome you and will be forever grateful to the contributions you make not only to the organisation, but to the MND community at large. I firmly believe we have the launching pad to continue to increase our support and care for our clients across the community.

We are on the eve of one of our key fundraising events: The Walk to Defeat MND. The board and the MNDSA team have put a lot of effort into the event, and it is a truly a special time for our community. It is a time to gather, reflect, and support those who are experiencing MND, and those who have lost their fight. We have a number of commitments from individuals within the State Government, and in our community, to be 'ice-bucketed'. This event is an important fixture on the calendar, and we are committed to making this event bigger and better than ever. We share on page 5 how to register and I ask you to please come along.

Our advocacy efforts continue with the State Government, who continue to be incredibly supportive and continue to collaborate and work with us to evolve and expand our services.

On a national level, it gladdens me to see a flurry of activity supporting the state MND associations. Through research, policy, and advocacy support at a federal level, this will only assist the state organisations in becoming stronger. A strong MNDA is a key pillar and cornerstone in building the continued success of the state associations.

It is also important to note that we have our annual trek to the Bay of Fires in Tasmania. I have had my arm twisted (and had knee surgery) and have signed up to the Bay of Fires Trek.



It's an incredible opportunity to work together as a group towards a fundraising goal. I would be honoured if some more of our community would join me on this once-in-a-lifetime experience.

Over the last few months, we have welcomed Nicola Buley and Stacie Attrill to the board. Both bring a wealth of experience and knowledge in their respective areas, and will be incredibly valuable additions to the board. I thank them for making the commitment to our great organisation.

With regards to the ongoing board, we welcome Tony Simmons. Tony has a wealth of experience and will further elevate the skillset we have at a board level. Tony is passionate about our cause, and we are incredibly lucky to have him on board. Please join us in welcoming him into the MNDSA family.

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

**Andrew Danson**  
Chair

## Welcome Tony Simmons to the MNDSA Board!

Tony has substantial experience in providing financial advice to high net worth individuals, to small-medium sized business owners, and in the Not for Profit sector. His private wealth experience is complemented by over 40 years' experience in the provision of taxation, accounting, business and strategic planning advice to a range of business and professional clients.



# Walk to Defeat MND

## Come join us on Sunday 19 May 2024

Walk to Defeat MND 2024 is the flagship annual community event for MNDSA. Held in the beautiful grounds of Adelaide's Pinky Flat, it is a relaxed, 4.5km fundraising walk on flat, wheel-friendly terrain.

Every year we welcome a sea of people in blue t-shirts and Never Give Up beanies, with over 800 members of our MND community who gather at the beautiful grounds of Pinky Flat to soak up the atmosphere before and after the walk around the River Torrens.

Join us for a family-friendly (and pet-friendly) morning of fun, entertainment, great food, and a leisurely walk, all for an important cause.

When you Walk to Defeat MND, you'll be showing your support for people with Motor Neurone Disease and helping to fund care and support for South Australians and their families affected by this devastating disease. There is a 1:300 lifetime risk of being diagnosed with MND by the age of 85—and those who are diagnosed should never walk alone.

Join us on the Walk to Defeat MND, to help support South Aussies living with Motor Neurone Disease.

**MNDSA's target is to raise \$150,000 to help us fund essential equipment and vital services.**

**WE CAN'T DO THIS WITHOUT YOUR SUPPORT**

To learn more and to register for the Walk to Defeat MND, scan the QR code:



To enquire about corporate sponsorships, Dunk Me 4 MND, or other fundraising opportunities, call us on (08) 8234 8448, or email [fundraising@mnDSA.org.au](mailto:fundraising@mnDSA.org.au)



**Walk as an individual!**  
Create a fundraising page and invite friends and family to sponsor you.



**Walk as a team!**  
Raise \$10,000 together, and help purchase a cough assist machine.



**Dunk Me 4 MND!**  
Boost your fundraising and take on our Dunk Tank.

# Living with MND

## Small tools making a big difference

There is a lot of helpful equipment available for hire from our MNDEquip warehouse. Our Allied Health team has helped us list six tools that may have flown under your radar—but can make a big difference to people living with MND.

### 1. Obi Feeder

Obi is an innovative adaptive eating device for individuals with upper extremity strength and mobility limitations. Using customisable accessibility switches, Obi allows the user to control what they eat and when. Obi increases independence, social interaction, meal enjoyment, and wellbeing.



Image: Wila Products

### 2. Zeba Shoes – Hands-Free Sneakers

Zeba shoes look and feel like regular sneakers, but their collapsible heel technology allows the user to simply slip them on, without having to bend down or tie them. They fit comfortably and snug, and are available in various sizes and colours.



Image: Zeba Shoes



## Allied Health Staff Update

**Oliver Siney and Rebecca Dawson have joined the MNDSA Allied Health team as Occupational Therapists in 2024.**

Ollie is a new graduate Occupational Therapist, who worked with MNDSA as a 4th-year university student and as an Allied Health assistant in 2023. He is excited to join the team as an OT this year, and eager to continue working with the MND community to provide holistic care to maximise independence.

Bec has worked as an OT since 2009, with adults with disabilities in various community-based roles. She has extensive experience working with clients with degenerative neurological conditions, and enjoys finding solutions to meet clients' unique needs and improve their quality of life.

### 3. Eye Gaze Devices

Eye Gaze Devices track a user's eye movement to control a computer or tablet. Eye Gaze Devices can be used for communication, but also for computer control so people can keep reading books, accessing the internet, playing games, connecting with family and friends, and controlling aspects of their environment.



Image: Tobii Dynavox

#### 4. Wonder Sheet Plus

The Wonder Sheet Plus is designed for those that may require extra support and stability when transferring in bed. The sheet is made of a polyester/cotton blend for grip and stability, with a satin panel which allows users' hips and legs to move and roll with greater ease.



Image: Neeki Designs

#### 5. Neck Collars

Neck Collars can be useful for people with MND who have muscle weakness. Using a neck collar will support a person's head, this can improve comfort and their ability to perform activities.



Image: Calvary Care

## MNDEquip

Our MNDEquip warehouse is fully stocked with a diverse range of assistive equipment, which can give our clients comfort, ease, and accessibility to perform tasks independently.

Clients are able to access hire equipment from our MNDEquip warehouse at subsidised rates. These fees ensure our equipment (often acquired through donations and grants) can stay clean, maintained, and in working order for longer circulation to benefit our community.

Our Allied Health team can help our clients learn more about what equipment is available to improve quality of life.

**To enquire about equipment hire:**  
contact 8234 8448 or email us at [equipment@mndsa.org.au](mailto:equipment@mndsa.org.au)

#### 6. Hoists

Hoists are an essential piece of equipment that provides a safe and comfortable way to lift and move patients who have limited mobility, reducing the risk of falls and injuries. MNDSA have a range of hoists and different slings in stock and ready to go.



Image: Handicare

# MNDSA Thank You

## All Japan Day

In February, MNDSA was chosen as Charity Partner for All Japan Day 2024. With more than 800 Japanese cars showcased on the day, they raised money in honour of car enthusiast and MNDSA client, Luke Nussio, who passed away in November 2022.

Money raised from car registrations and event merchandise, as well as a raffle and our own merchandise sales, contributed towards an amazing \$13,642.95 donation!

We would like to say a huge thank you to everyone involved that helped make the event possible.



## Bunnings BBQ Fundraiser

Associate Professor David Schultz, one of our Trek Champions, has signed up to join us on our Bay of Fires Trek this year (his 3rd consecutive MNDSA Trek) and has already been hard at work raising funds!!

David hosted the sausage sizzle at Edwardstown Bunnings in January and again at Easter and has already smashed his Trek fundraising goal!! Thank you David for your unwavering support and for once again taking part in the Trek!

*Learn more about the Trek on page 16.*

## FROCK Vintage Fashion Show

In late March, Finesse Models Australia held the FROCK vintage fashion show. This was a celebration of fashion and rock from the 50s to the 80s, showcasing vintage threads, new retro-styled designs, and entertainment from Adelaide cabaret icon, Hans.

Proceeds from ticket and bar sales were donated to the work of MNDSA. Thank you very much to Finesse Models Australia for donating \$2,000, and to Bar 55mL for donating \$3,000.





# MNDSA Thank You



## Volks Enthusiasts Club of SA

The Volks Enthusiast Club of South Australia (VECSA) runs an event each year called RATEX. In March 2024 the event was run as a fundraiser for MNDSA.

The current President of VECSA lost his Mum 5 years ago to MND, and MNDSA assisted his parents during the very tough 20 months from diagnosis to the end. Unfortunately, last year one of his Mum's cousins was also diagnosed and is currently being supported by MNDSA. Andrew decided to give back to MNDSA as thanks for the support that we gave to his relatives and their support networks.

The event ran from Adelaide to Tasmania (return) over 2 weeks and involved 15 participants in some 8 old VWs and a support Toyota Landcruiser. Thank you for the \$3,500 raised for MNDSA.

## BAE Systems Australia

BAE Systems held a community fundraiser at their Edinburgh facility in late March, in memory of their colleague, David.

Over 20 staff were nominated and "Ice Bucketed" with some great outfits on display.

\$2,197 was raised for MNDSA and a lot of fun was had along the way!!



## Harcourts Foundation

Harcourts have been amazing supporters of MNDSA for many years, having seen directly the impact that MND can have on families.

We would like to thank them again for their kind donation following another successful quiz night.

We welcomed Julie Goodger and Scott Torney to our offices to present a large \$4,000 cheque.

## Interested in running a Community Fundraiser?

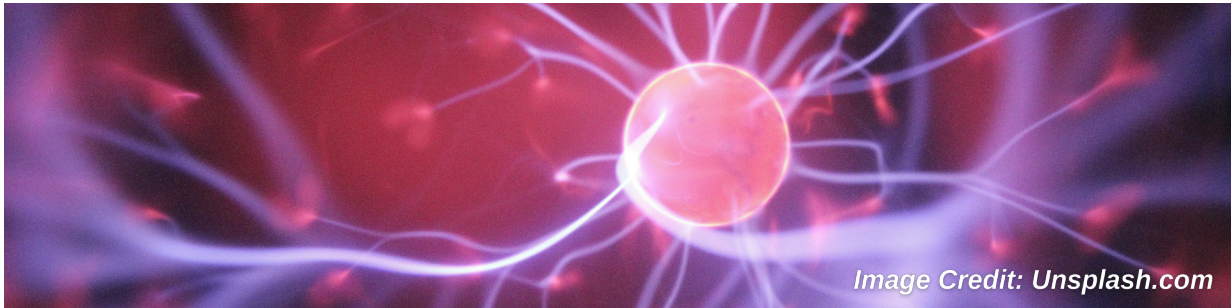
Community fundraising is vital for MNDSA to provide all the services and supports that we do to our community. If you wish to learn more on how you can help please contact MNDSA on [fundraising@mndsa.org.au](mailto:fundraising@mndsa.org.au) to get started or call our office on 8234 8448 and ask to speak to our Events and Community Engagement Officer

**For fundraising tips, scan the QR code**



# MND Education & Research

## MND Australia - Drug Trials



The second part of a Phase 1 clinical trial for the drug SPG302 is due to begin soon in Australia. SPG302 has been developed to target the synapse in nerve cells. One major aspect of MND is the loss of these synapses. This drug is designed to increase the number of synapses in the nerve cell.

Recruitment for this trial has not yet commenced, however it is anticipated that this will commence shortly. Trial sites for the next phase of SPG-302 are yet to be confirmed. To find out more about this trial and other MND research updates, visit: <https://www.mndaustralia.org.au/articles/>



## State of Play Webinar Updates



STATE OF PLAY  
2024

HOW TECH RESEARCH  
CAN HELP PEOPLE  
LIVING WITH MND



**State of Play** is a Webinar Series organised by MND Research Australia (MNDRA). The most recent webinar takes a look at how tech research can help people living with MND. MND Australia's Dr Ben O'Mara talked about the 'Game on with MND' project looking at how we can make gaming more accessible for people with MND and Dr Taylor Dick from the University of Queensland talked about exoskeletons as mobility aids.

To review past webinars or to register for upcoming webinars in 2024, visit: <https://www.mndaustralia.org.au/research/research-news-updates/state-of-play>



# A Charitable Legacy for MNDSA

By leaving a bequest to MNDSA, you are creating a legacy of care and compassion for the future and for those who will be diagnosed with MND and require our support.

**A Will is a legal document that reflects who and what is most important to you – including the causes that you support. At a time of emotional distress, your Will provides your loved ones with a clear understanding of your wishes.**

**Many donors ask what they need to do to leave a bequest to MNDSA.**

Bequests are critical in helping us provide the best care possible. Bequests play an integral role in our medium and long-term funding strategy.

Your bequest can be general to support the key priorities of the Association or it can be specific to a certain area – it's up to you.

**Your options are limitless in terms of the legacy you can leave:**

- Whole estate
- Residual gift
- Percentage or fractional gift
- Specific gift
- Share Portfolio

Preparing a will is an important milestone for all of us. This information has been compiled by MNDSA and is general in nature.

It should not replace formal legal advice such as that provided by a lawyer or trustee company.

**We thank you for considering a bequest to MNDSA.**

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

For more information and a confidential discussion about leaving a bequest to MNDSA, contact:

📞 08 8234 8448

✉️ [ceo@mndsa.org.au](mailto:ceo@mndsa.org.au)



## Suggested wording for your will

Based on your personal situation and preferences, the following wording may be used to make a bequest to MNDSA.

*"I (insert name here) bequeath to the Motor Neurone Disease Association of South Australia Inc (ABN 87 026 807 478) for its general purposes:*

- *All of my residuary estate, **OR***
- *\_\_\_\_\_ % of my residuary estate, **OR***
- *The sum of \$ \_\_\_\_\_ **OR***
- *List asset or assets **OR***
- *My share portfolio of stocks or shares*

*free of all duties, and the receipt of the Secretary or other authorised officer of the Association shall be a complete and sufficient discharge for the Executor(s), who will not be bound to the application of this gift."*

# Personal Story

## Run for John - by Grant Archer and Clare Raimondo

*John Raimondo was diagnosed with MND in March 2022, and passed away less than six months later. In honour of John, his daughter Clare and her husband Grant have committed to 'Run for John' in the London Marathon this April. We spoke with Grant about their journey and what this opportunity means to them.*

### How did you come to the decision to run in the London Marathon?

There were a number of factors that led us to this place. MND took John away from us so quickly. From initial signs in March, until his death in September the same year, we saw the horrible march of the disease as it stripped away his movement, his words and then his life.

MNDSA were with us throughout this journey and so we decided to do something positive to help people living with MND, and channel that effort towards supporting MNDSA because of the support they had given John and his family as he faced and fought the condition.

The idea of a marathon came to us as a great vehicle to achieve this. We had both run marathons many years ago, and we both knew how much physical and mental effort it took to prepare yourself for that event. We had also watched as John and others living with MND had their capacity for movement cruelly stripped away from them. The idea that we could honour that fight by cherishing the movement we had—and, in some ways, fight alongside John and others by undertaking the event—seemed to fit.

We chose London because it is such a big stage to bring that challenge to. Also, London is where John met and fell in love with his wife Hilary, when they were both just starting out in life and exploring the world.



### What impact on your normal lives has fitness training and all the other layers of preparation taken?

It's a seven-day-a-week commitment, really. We started from quite a low level of fitness, so it began with a walk/run regime, before building up to 4 to 5 organised runs a week. This is in addition to other activities to help prepare the body for the challenge, like pilates, physio, massage, stretching, and some gym work.

It changes the way you structure your week, and especially your weekends. Sunday mornings are for long runs, so you have to look at how you plan your time to make sure you eat properly the night before (lots of pasta). The pantry takes on the appearance of a chemist's lab, with all the carb mixes, gels, et cetera, that you need to fuel your runs.

I'm retired, but Clare still works full-time, so we also have to adjust things like dinner time to take into account the fact that after work is the only time she can get her run in.



John with Clare as a baby (L), and as an adult (R) (Supplied)

### **What has been challenging in the lead-up to the marathon, and how have you overcome?**

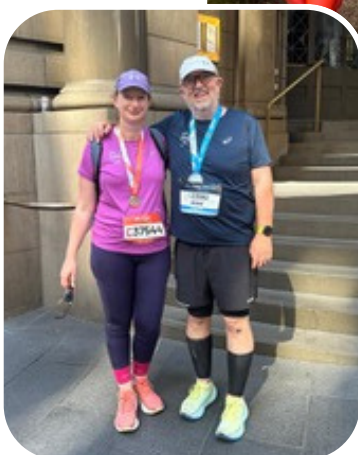
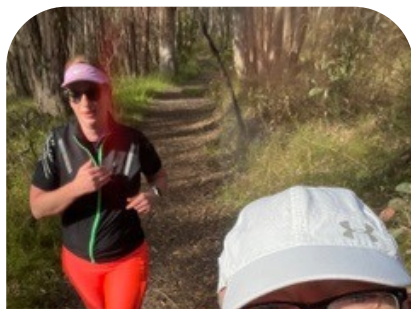
Training can be gruelling, and we have both suffered some minor-to-moderate injuries and niggles along the way.

Fundraising and raising awareness of MND and the work of MNDSA is also a challenge as neither of us were massive users of social media beforehand, so adapting ourselves to that was a massive learning curve well outside of our comfort zone.

Sometimes you can wonder what on earth you did with your time before running took over, it's like adding another part time job to your week.

Overcoming the physical and mental challenges really comes down to focussing on your personal "why". Your "why" is the underpinning reason that you took on the challenge, and it drives you forward even in the tough and uncomfortable moments. When it's cold dark and raining and you don't want to take that run, remember your "why" and suddenly the barriers fall away.

Every step is one step forward. I have had times where I have been running with sore knees, I'm tired, it's cold and it really isn't fun, where I pause and focus on my why, and realise just how much John would have given to have taken that next step, that I have to cherish the opportunity that I have and move forward.



*Follow @run\_for\_john on Instagram to see Clare and Grant's journey so far.*

### **What are the next steps of your challenge? What are your goals?**

Physically, we both want to finish the marathon as healthy as we can. Neither of us are looking for PB's—we want to enjoy the day, and the tribute to John and the deeper meaning it entails for us.

To take part in a marathon with over 30,000 other people will be an incredible experience in of itself. To do so, having brought the message of the fight against MND, and raising somewhere in the order of \$10,000 for such an incredible organisation as MNDSA is enough of an achievement for us—that's for certain.

### **What tips do you have to someone undertaking such a challenge for the first time?**

Take the time and really think about your "why"—because that really is the key. It will be different for everyone, and it should be deeply personal and basically unique to you. Once you have that, then every other issue becomes a step towards your target, not a problem. Forward is still a pace when it is taking you towards your "why". Injuries become opportunities to learn more about how your body works and adapt your training because you remain focussed on your "why". When your bed is reeeeeally comfortable on a wet and windy long run morning, your "why" gets you up and ready.

### **What do you hope this fundraiser will be able to contribute to?**

We've had the opportunity of seeing the incredible support that MNDSA offers to people living with MND and their families. Karen (MNDSA CEO) reached out to Clare early in John's journey, and the help she received straightaway was incredible. The work MNDSA do to help people maintain dignity, and an ability to maximise the opportunities of enjoying what we think of as the normalities of daily life, is inspiring. To be able to contribute towards that in any way is a privilege.

**Support Clare and Grant as they 'Run for John' in the London Marathon on 21 April 2024**

**To learn more and to donate towards their fundraiser, scan the QR code here:**



# Calendar of Events

<p>Sunday 19 May <b>Walk to Defeat MND</b></p>		<p>Wednesday 19 June <b>MNDSA Friends of Parliament Event</b></p>
<p>Friday 21 June <b>MND Global Day</b></p>	<p>Friday 26 July <b>Day of Hope and Remembrance</b></p>	<p>Friday 23 August <b>MNDSA Trekkers Trivia Night</b></p>
<p>Thursday 10 October to Tuesday 15 October <b>Bay of Fires Trek</b></p>		<p>Friday 1 November <b>MNDSA Gala Dinner</b></p>

## You, Me & MND

Meet other people on their MND journey, share experiences and learn from each other.

South Colonnades Tavern Beach Rd, Noarlunga Centre	Central Westies Bar & Bistro 57 Milner Rd, Richmond	North The Grove Tavern Golden Grove Rd, Surrey Downs
<p>Join us from 11.30am to 1.30pm</p>		
<p><b>May</b></p> <p><b>S</b> Monday 6th <b>C</b> Tuesday 14th <b>N</b> Wednesday 8th</p>	<p><b>June</b></p> <p><b>C</b> Tuesday 11th <b>N</b> Wednesday 12th</p>	<p><b>July</b></p> <p><b>S</b> Monday 1st <b>C</b> Tuesday 9th <b>N</b> Wednesday 10th</p>
<p><b>August</b></p> <p><b>C</b> Tuesday 13th <b>N</b> Wednesday 14th</p>	<p><b>September</b></p> <p><b>S</b> Monday 2nd <b>C</b> Tuesday 10th <b>N</b> Wednesday 11th</p>	<p><b>October</b></p> <p><b>C</b> Tuesday 8th <b>N</b> Wednesday 9th</p>
<p>Listen to guest speakers on a range of topics Meet and talk with our Client Services team Enjoy each other's company in a relaxed environment</p>		



You can register for any of our events at [my.mnlsa.org.au/events](http://my.mnlsa.org.au/events) or via this QR code

If you need assistance, please call our office on 08 8234 8448

# Advocacy in Action

**Living on beautiful Kangaroo Island has many wonderful perks, but it comes with its challenges too - even more so, when diagnosed with MND.**

When MNDSA heard that one of our clients, Ian, could not travel to important appointments at the Flinders Medical Centre MND Clinic, we started asking why....

What came to light was that Ian and his wife, Pauline, had booked the Ferry but they were advised that Sealink procedures would not permit them to remain in their vehicle during the crossing. Moving Ian out of the vehicle in the manner suggested was going to cause distress and discomfort. They thought nothing could change so were about to cancel their trip with the view that they could not travel.

Knowing how a trip to the mainland would result in improvements in Ian's quality of life, MNDSA went into action to try and come to a resolution with Sealink to support Ian's safe transportation.

Connecting with their CEO and Operations Manager, we highlighted the plight of Ian, his MND diagnosis and the issues that were preventing them travelling to the mainland.



*"We are feeling truly thankful to have the wonderful supportive MNDSA Team help guide us through Ian's journey."  
said Ian's wife Pauline*

We were delighted when Sealink worked hard to find a workable solution that met their legal and risk management obligations, whilst also permitting safe travel for access to appropriate health care.

MNDSA OT Ollie assisted with escorting Ian and Pauline on their crossing. Whilst on the mainland they certainly made the most of their time attending the MND Clinic for vital medical care and also MNDSA offices to assess further equipment needs.

MNDSA are grateful to Sealink for helping us make a difference.

*Ian commented "We are so very grateful and appreciative of the arrangements that you have been able to negotiate with Sealink and understand how much work and effort would have been involved to achieve this"*

# Bay of Fires Tasmania 2024

MNDSA's Annual Trek has become an eagerly anticipated adventure on our event calendar. The trip is limited to only 20 participants, and we welcome trekkers from all walks of life and fitness levels. If you're thinking about participating in 2024, why not get in touch to find out more...

Discover the spectacular beaches along the east coast of Tasmania, experience the rainforest and relics of mining history. Do this knowing that with every step taken we'll raise vital funds to enable the best possible care and support to be delivered to South Australians currently living with MND and those are yet to be diagnosed in the future.

Highlights of this trip include visiting Boulder Point, Deep Creek, Picnic Rocks, Eddystone Point, Ansons Bay, Policeman's Point, and Humbug Point Loop.

Dates: 11 to 14 October 2024 - 4 day challenge

Fundraising Target \$3,500 per Trekker

Accommodation: Twin share in a 4-star Hotel

Difficulty: ranked 3/5 for ability

Limited to maximum 20 participants. Sign up now and secure your spot with your first instalment of only \$475.

For full details and to register just scan the QR code below or visit:

<https://inspiredadventures.com.au/event/mndsabayoffires2024/>



mnd   
South Australia

INSPIRED  
ADVENTURES



# Meet some of our 2024 MNDSA Bay of Fires Trekkers!



## Andrew Danson, MNDSA Chair

I invite you to join me in a heartfelt tribute to my father, Peter Danson, who bravely battled MND.

Your generous contributions will not only commemorate Peter's resilience but also make a significant impact on the lives of those currently fighting MND. Every dollar raised will propel MNDSA closer to groundbreaking research, enhanced patient care, and, ultimately, a world without Motor Neuron Disease.

Together, let's transform grief into action and celebrate the enduring spirit of those who have faced this formidable adversary.

## Renee Bennett

In October 2024, I will be embarking on a special trek in honour of my dad who passed away in May and my poppa who passed away in 2011, both from motor neurone disease.

I'm extremely passionate about this cause as, while there is no cure, we can provide support and comfort for others.

I want my dad and poppa's legacy to live on by helping others and you can help too, simply by donating to our MNDSA Trek or, for the adventurous ones, joining us on the Trek. It will be a once in a lifetime experience.



## Gayle Barry

In 2022, we lost our dad and poppa, Murray, to MND. This photo (left) was taken with dad driving the baler, only weeks after his diagnosis in October 2021.

This year, I am trying to fundraise \$3,500 to help give back to MNDSA, whose support was invaluable throughout dad's illness.

It only takes a minute and any money you can give, no matter how large or small, will go a long way to helping me reach my target.



Donate to our  
Bay of Fires Trekkers  
by scanning the QR code:



# VOLUNTEERING for MNDSA!



## Do you want to be a part of the Walk... without having to walk?

We are always looking for new volunteers to help out at our Walk to Defeat MND event.

From looking after the registration desk, to selling merchandise, there are lots of opportunities to help the day run smoothly and to support the work that MNDSA does - even if you don't feel like walking!



Together, we can create positive change and build a better future for our community. Join us in our mission and be a part of something truly impactful. Volunteer with MNDSA today!

## Meet our new Volunteer Coordinator Bea Logothesis

Bea joined the MNDSA team in early February, having previously worked as a Service Manager at another disability provider. Bea loves working in the disability sector and particularly with volunteers, so is excited for this opportunity to combine her passions.

Bea is working towards growing our volunteer numbers and reviewing potential new programs, so that we can do more to support our community. She loves to work with volunteers and to see how they help make a difference to our clients' lives.

Our volunteers are passionate about their roles and the experiences they can provide our clients.

## Join Us in Making a Difference!

Are you passionate about giving back to the community and making a meaningful impact? We invite you to lend your time and skills to MNDSA

At MNDSA, we're dedicated to providing and promoting best possible care and support for people living with MND. But we can't do it alone – we need your help. Whether you're a seasoned volunteer or new to giving back, there's a place for you here.

Volunteer opportunities abound, from hands-on projects to behind-the-scenes support. Whether you have a few hours a week or a whole day to spare, your contribution can make a real difference in the lives of those we serve.

If you'd like to sign up to be a volunteer, we'd love to hear from you!  
Call us on (08) 8234 8448, or email [volunteer@mndsa.org.au](mailto:volunteer@mndsa.org.au)

# HAVE YOU REGISTERED TO MARCH WITH US AT OUR ANNUAL 'WALK TO DEFEAT MND' EVENT?

**Sunday 19 May 2024 @ Pinky Flat, Adelaide**  
**4.5km loop around the Torrens River!**

## What to expect on the day!

### Dunk Me 4 MND

Did you know we are having a dunk tank on the day? After the walk, we will have a bit of fun with special guests being dunked!!

You can actually be involved too - just contact us ASAP to express interest at [fundraising@mndsa.org.au](mailto:fundraising@mndsa.org.au), or call the office on (08) 8234 8448.

**Make sure to promote you are being dunked on your social media and share your fundraising page to increase your total raised!!!**



### Cheese & Wine Tent

For all you cheese and wine lovers out there, we have delicious cheese boxes and yummy wine available on the day!

Smelly Cheese boxes: \$20 - Includes cheese, crackers, nuts & grapes

Claymore Wines: \$9 - You'll Never Walk Alone GSM & Sauvignon Blanc

### Live Music

We welcome the talented Rodrigo Soafer, who will be playing some throwbacks for us on the day!

### Kids entertainment and more...



**Entry from 9.00am**  
**Guest Speakers from 10.00am**  
**Walk Sets Off 11.00am**  
**Dunk Me for MND 12.30pm**  
**Event Finishes 2.00pm**

**REGISTRATION PRICES**  
**ADULTS \$40 KIDS \$25**  
**INCLUDES WALK TSHIRT**

To register to join our tribe, please go to <https://my.mndsa.org.au/events/85/walk-to-defeat-2024> or scan the QR code.

# MND Client Services

## Equipment Hire

Our MNDEquip service continues to provide equipment and assistive technology to clients.

We offer an extensive range of equipment to hire for highly-subsidised costs, compared to other industry providers. We also have significantly reduced hiring rates for clients over 65, depending on their available funding. This means MNDSA clients are able to access high-quality and well-maintained equipment at a more affordable cost.

**Our subsidised fees cover delivery, pick-up, cleaning, maintenance and servicing of equipment and technology.**



**Other Industry Providers**  
\$450-\$500  
per week

+ cleaning,  
delivery and  
pick-up fees

**mnd**   
*South Australia*  
**\$150**  
per week

**For more information about equipment hire or to register:**

Please scan the QR code or call the MNDSA Office at (08) 8234 8448 Monday to Friday 9am - 5pm or email us at [equipment@mndsa.org.au](mailto:equipment@mndsa.org.au)



### MND SOUTH AUSTRALIA

66 Hughes Street,

Mile End, SA 5031

Mon - Fri 9am - 5pm

Phone: (08) 8234 8448

Freecall: 1800 777 175



[admin@mndsa.org.au](mailto:admin@mndsa.org.au)



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