

MND news

The newsletter of the Motor Neurone Disease Association of South Australia



- Launch of Parliamentary Friends of MND in SA
- Andrew Danson steps into MNDSA Chair role
- Walk to D'Feet MND & Larapinta Trek wrap-ups
- Upcoming events, new staff and much more...

Until there's a cure, there's care



Gala Dinner

17 November 2023 at 7:00 pm

3-Course Dinner, Live Music, Auctions & More

National Wine Centre

Corner of Botanic & Hackney Road

\$220 Per Person

Discount for MNDSA Clients - use code MNDSAFAMILY

\$2,400 Per Corporate Table of 10

Contact events@mnDSA.org.au for packages



Book your tickets now

Photography by John White

Welcome to the new **MNDSA Chair**

Andrew Danson



Hi everyone,

What a whirlwind the last 6 weeks have been. Firstly, I would like to thank Scott Penhall, the previous chair and board member for his contribution and service of the MNDSA board over the last 18 months. Scott's passion and commitment to MNDSA deserves recognition. We wish Scott all the very best with his next venture and hope to see him at future MNDSA events.

As the new chair, I thought it was important to introduce myself. My name is Andrew Danson. I currently run a tenant advisory business and am an advisory board member for the South Melbourne Market. I, like many of you, have had personal experience with Motor Neurone Disease with my father having lost his fight with the disease at the start of 2020. I wanted to use my skills to make a change and 'do my part' to support other families who sadly experience MND. This led me to meet Karen and the team at MNDSA and I joined the board in 2021.

The last 6 weeks have been a busy period with the team having completed the launch of the Friends of Parliament supported by the Hon Erin Thompson which is very important for the continued support of the SA Government. We also had our NDIS Audit, which the team have completed with flying colours, and further built our skills and knowledge in this area. Our Trekkers have completed the Larapinta Trail which has again exceeded our fundraising expectations. Well done to all involved!

My goals during this period are to continue to build on the great foundations that the business upholds, to continue to support and work with the state government and to foster relationships with the great corporate partners we currently have.

I am eager to continue supporting the MNDSA community as best we can.

Warm regards,

Andrew Danson
Chair - MNDSA

Message from the CEO

Winter has flashed past at lightning pace this year and what a season it's been.

It is my pleasure to announce that we have once again expanded our team of professionals in every area of the business. Our goal to not only maintain, but also to enhance the services we can provide to our clients and their families, is underpinned by our dedicated team at MNDSA. As such, we have welcomed new staff in the business services, fundraising and client service areas. To learn more about our new team members, head to page 5.

We recently said a fond farewell to our outgoing Chair, Scott Penhall and warmly welcomed Andrew Danson into the role as MNDSA Chair. Both Scott and Andrew have made significant contributions to MNDSA over the past few years and Andrew is looking forward to the opportunity of sharing his expertise to support the business and the staff, to forge ahead as we continue to expand for the benefit of our community.

MNDSA is continuously advocating to raise awareness of Motor Neurone Disease. We've been working hard to further develop our connections within government, and we were thrilled to recently launch our South Australian Parliamentary Friends of MND at Parliament House. We are grateful to co-conveners of the group, Erin Thompson MP and Penny Pratt MP. Our guests on the day were also warmly welcomed by Minister for Health and Wellbeing, Chris Picton and Minister for Human Services, Nat Cook along with many other supportive Members of the SA Parliament. One of the families that MNDSA supports delivered a powerful speech to ignite conversations about equality and quality care. An excerpt can be found on pages 8-9.

I'm very pleased to report that we have been successful with numerous funding grants to support our Client Services moving forward.

We were successful with our submissions to FightMND for two significant grants totaling \$398,042 to enhance our capabilities with Volunteer Programs and to bolster our Equipment Hire service, MNDEquip. We are extremely grateful to have received this funding which will positively impact our MND clients and their families, with immediate effect.



Fresh off the heels of another wonderful MNDSA community event at the Walk to D'Feet MND, we launched into our second Annual Trek, the Larapinta Trail. For all the highlights of these two major events read on in pages 16-19.

On behalf of the Board, Management and Staff I'd like to say a huge thank you to our tireless community fundraisers, volunteers, and business community for getting behind MNDSA, our clients and their families. The growth in our staff, support services and programs would not happen without fundraising and donations.

We've been blessed with a multitude of community fundraising events that have raised the bar with some amazing fundraising achievements. Some examples of these events can be found on our 'Thank you' pages 10-11.

We are delighted to have introduced regular Client Information Sessions and reintroduced our You, Me & MND casual gatherings at different locations around the state to support our community with social opportunities and support networks.

We continue to plan a huge line up of events and initiatives for the year ahead – assisted by our growing team of volunteers. All the latest details can be found on pages 14-15.

Wishing you all a lovely Spring & Summer ahead and hoping to see many of you dressed to impress at our 2023 Gala Dinner in November with our special discounted client ticket price - it's going to be a special night!

MNDSA works hard to ensure that our community never has to walk alone. We welcome you to our events, to engage amongst what is a generous community full of caring and resilient people.

Thank you for the part you play in that community.

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

Karen Percival

CEO

MNDSA Staff Update



Clare Dole - Allied Health Assistant

The Allied Health Assistant role appealed to Clare as she has a keen interest in working with people with MND and their families. Clare is currently studying for her Certificate IV as an Allied Health Assistant with a focus of Occupational Health. Clare brings a range of skills to MNDSA from a 25-year career working in various areas of disability. She's looking forward to supporting people living with MND and their families and carers.

Rona Dean - MND Support Coordinator

Rona has worked in the disability sector for many years in Perth, WA. She is a qualified speech pathologist and feels it is an honour to join MNDSA as a Coordinator of Supports. Rona is looking forward to working with a team of people focused on supporting people living with MND to live their best life. In her down time, she enjoys spending time with her 18-month old grandchild who is the reason behind her decision to relocate to SA!



Karen Daminato - Occupational Therapist

Born in Canada with a gorgeous accent, Karen is now happy to call Australia home. She is a qualified Occupational Therapist and has worked with the older population in Aged Care and the community for over 6 years. Karen is looking forward to working with the MND community and the MNDSA team.

Jess Alexander - Marketing & Events Coordinator

Jess joins MNDSA with experience from the NFP sector in fundraising events, marketing and partnerships. Having worked at a children's charity over the past year, Jess is aware of the necessity to maximise fundraising opportunities and the importance of supporting the community to raise awareness and funds. Jess is looking forward to contributing to our MND community in SA.



Leah Bourman - Business Support Officer

Leah has gained extensive experience in medical administration and practice management, and is looking forward to working as a part of the Business Services, Fundraising and wider MNDSA team. She enjoys travelling, seeing bands and comedians and spending time with her children and granddaughter.

Living with MND

MND is a rare condition, and many GPs may only see one or two patients with MND in their careers, hence it is easy to understand why they may think first of other conditions or causes for the symptoms.

The rationale behind the development of **MNDSA's Clinical Pathway and Referral Network** was about promoting proactive support and care to reduce the potential for families to slip through the cracks and get into crisis before seeking help.

Patients and carers have lots on their plate, time is not their friend, they may not have the capacity and/or the time to pull together complex support, so understanding what is going on, what services are able to help and how to get hold of them is critical for everyone involved. Knowing what to look out for means needs can be met in a timely and coordinated manner.

Presented as an online website, it contains printable resources and short videos about symptom management. There are links to evidence-based information on the management of symptoms and up to date direct contact information for all the providers of care along with a suite of culturally adapted information about MND (for Aboriginal and non-English speaking consumers and providers).

The final piece of the jigsaw was the development of MND, MY GP & Me – a quick reference guide to MND for GP's and other health professionals outlining key messages about caring for a person with MND and their families.

The pathway encourages a team approach engaging all the available expertise in the network to make the journey for those living with MND easier.

We can't change the outcome, but we hope with timely support and clear navigation pathways through the systems of care, the experience of the person with MND and their family will be improved as they negotiate the difficulties of living with MND. To find out more, visit: www.mndsapathway.com.au



MND Education & Research

Update from Advance



MND Research Australia produces the Advance newsletter, which is published biannually, in June and December of each year. The latest edition continues a focus on their aim to develop better tools to diagnose MND, measure progression and responses to treatments, and ultimately seek to find treatments and a cure.

To read the June 2023 edition, visit: <https://www.mndaustralia.org.au/research/research-news-updates/advance>

34th International Symposium on ALS/MND



The International Symposium is the biggest annual conference dedicated to ALS and MND research. Each year this symposium brings together researchers from around the world to share new understanding of Amyotrophic Lateral Sclerosis and Motor Neurone Disease. This year's event will take place in Basel, Switzerland on 6-8 December 2023. For more information visit: [Home - International Symposium on ALS/MND \(mndassociation.org\)](https://www.mndassociation.org) or click the QR code below:

Image Credit: reisen-magazin



Research Directions is regular update on International and Australian research, written by MND Australia's Executive Research Director, Dr Gethin Thomas. Each month Dr. Thomas explores a selection of the latest MND research.

This publication is available monthly on MND Australia's online news:

<https://www.mndaustralia.org.au/articles/research-directions-august-2023>

And via the MND Australia Facebook page: (<https://www.facebook.com/mndaustralia>).

State of Play Webinar Updates



State of Play is a Webinar Series organised by MND Research Australia (MNDRA).

The September 2023 edition of State of Play will be held Tuesday, 26th September at 7 pm AEST and features Dr Derik Steyn and Dr Brooke-Mai Whelan, who are both from the University of Queensland and are both 2023 MNDRA Innovator Grant recipients.

In this edition, hear about how researchers are targeting appetite and speech decline in MND.

To review past webinars or to register for upcoming webinars, click this link:

State of Play | MND Australia
or scan the QR Code:



Image Credits (above) MND Australia

Personal Story

A MND client and her family convey their powerful message to SA government.

Forgive me as I write both in the first person from my own perspective while often reverting back to speaking on behalf of my whole family. I am the fourth child of my parents who have been happily married for over 50 years. **Families often have diseases which are passed along generationally, in our family, that disease is Motor Neurone Disease.** We attended my cousin Melissa's funeral around a year ago, she had MND and passed away at 55 years of age. My Mother's cousin, Tony also passed away at the young age of just 37. Another cousin, George is still in his battle with MND at the age of 55 years and there is a lack of clarity around the specific cause of my Grandmother's death, but that is presumed to have been MND.

We always knew that familial MND was around like ticking time bomb, but we were never quite sure if it would come close enough to impact us. In September 2022 our world was turned upside down when that time bomb exploded on our doorstep.

My mother started experiencing some minor falls and weakness in one arm. Deep down I immediately knew and feared that it was MND.

Mum's MND progressed extremely quickly. When I say quickly, I mean that we could barely get in place the equipment necessary in her home to assist her to function before she would deteriorate again, and we would need different equipment. The rapid progression has involved all of us grieving with her as we watch her humbly relinquish her physical capabilities.

In an 8-month period she has grieved and let go of being able to walk unaided and then to not even being able stand at all. Varying lifters, walkers and finally a sling lifter being hired or purchased as we tried to keep up, as a family, with the loss and the needs and work out how to keep her safe. We watched further as all the remaining strength has now drained from her body. She once enjoyed a normal and full life, to now, only being able to move the tips of her fingers.



Her sharp mind is trapped in her lifeless body, and we are so grateful that she can still speak softly. In a matter of months so many simple things have been stolen from her; scratch her nose, pat the dog or hug her beloved grandchildren.

Now Mum requires 2 carers 24/7 and has had multiple hospital admissions over the past months. She requires a Bi-PAP machine to help her breathe most of the time. **My 82 year old father is mum's full-time carer, and three sisters share the rest of the load.** I have been unable to work for the past six months. My life has been consumed by endless emails and phone calls, coordinating care, constantly sourcing equipment, medical appointments and 70 hours a week of hands-on care. Every week brings more and more pressure to cover the hours needed, as we all grow tired and frustrated by not having enough help instead of enjoying the time we have left.

All three of the sisters own small businesses and if it were not for the fact that we have flexibility with our hours there is no possible way that we could manage the demands of keeping our Mum at home where we want her. We are stressed and anxious about how we can together manage the demands of our own families and business together with the urgent needs of our Mum. I'm personally torn between wanting to be at home to mother my own son and caring for my beautiful mum like she has done for me.

I recently called My Aged Care to ask "is there any other help that we can access", thinking surely there is something? Only to be told "no, level 4 is it or you can use residential care". **My Mum's level 4 package allows us around 8 hours of carer help per week, but there are 168 hours in a week that need to be covered.** The Package also helps with some physio and minimal equipment hire. Thanks so much to MNDSA's equipment hire program for their help or otherwise we would have even less carer hours. Basically, it is completely up to our family to make this work and give mum her very reasonable wish to stay at home.



My parents are now spending \$1300 of their retirement savings per week to top up the caring hours and you might think this sounds like a lot, but this covers only 3 night shifts a week so that we can have dinner with our families and I can see my son off to school a few days a week.

I am immensely grateful that this disease has come along so late in life for my mum. What I am at a loss to understand is how the (*Federal*) government can discriminate based on age. **This disease requires so much more than is currently covered under a Level 4 Aged Care Package which is the maximum allowable funding. Aged care funding seems very inadequate in supporting individuals with complex health needs like advanced MND.** The lack of funding is forcing families who WANT to keep their loved ones at home to instead needing to commit them to an over 65 aged care facility. **Do their loved one's matter less just because they are older? They deserve the dignity to stay in their own home, just like people who are younger with MND can.**

I understand that the funding changes might not impact my Mum and our current situation but given that familial MND could knock on any member of my family door at any stage - This must change for the future. - **Anonymous.**

Advocacy

South Australian Parliamentary Friends of MND

The South Australian Parliamentary Friends of MND was officially launched at Parliament House on June 28 2023 with the support of the Minister for Health and Wellbeing Chris Picton, Erin Thompson MP, Penny Pratt MP and many other supportive Members of the SA Parliament, together with our CEO, Board, Staff and importantly, some of our clients and their family and support networks.

The Parliamentary Friends of MND is a non-partisan forum for South Australian parliamentarians to interact with MNDSA and the wider community on issues concerning people living with MND.

The launch event will be one of many gatherings with our SA Parliamentary Friends of MND to continue the advocacy on behalf of the MND community - with the ambition to provide integrated, equitable and high-quality health care to people living with MND, regardless of their age and postcode.

The personal story (overleaf) was presented as a speech at this event and we are grateful to our MND client and her family for sharing their perspective with us and with SA government.

To support our advocacy efforts contact 8234 8448.



MNDSA Thank You

Dave Bowles Skydiving

David (Dave) Bowles is an inspirational member of our MND community in SA. In the month of June, Dave (pictured right) decided to take the leap (quite literally) out of a plane - not once - but many times throughout June, all in the name of raising awareness of MND and funds for MNDSA. Dave, his sister Connie and the team at Adelaide Skydiving teamed up to raise close to \$2,000! Thank you, Dave - we love your adventurous spirit and determination to make a difference!



Modbury Jets & Ray Coull

On 11 August, the Modbury Jets Soccer Club held a fundraising event to honour one of the Club's life-members and legends, Ray Coull (pictured left). Ray's friends, family and wider football community got behind the event, which included a huge inflatable slide with icy water, merchandise sales and a raffle. Football SA organised a live broadcast from the event, which raised over \$10,000 for the MND community in SA. Special Thanks to Jeff McCormack for organising this wonderful event.

Whyalla Sporting Community

On 17 June the Whyalla Sporting Community Club held their Annual Red & Steak Night, once again in honour of members of their community who have been impacted by MND. Long-time member of the Hockey Club, Brenda Bowey (pictured right, far left) - who is currently battling the disease - was in attendance and enjoyed the comradery on the night. As a tight-knit and supportive community, they were able to raise over \$10,000 for MNDSA. Special thanks to Angela Marino for organising this event - to benefit MNDSA - for the second year in a row.



Community Fundraising is vital to support our MND Clients all across South Australia.

MNDSA Thank You

Trinity Old Scholars FC

The Ice Bucket Challenge was a major feature of the Trinity Old Scholars Football Club fundraiser (pictured right), held on 26 August. All the players were decked out in MNDSA's new footy socks and many of the boys decided to get their chill on during half-time of the A-Grade game! Between the socks, merchandise sales and the raffle, this fun event, held in honour of the Eldridge Family, raised close to \$3,000! Special thanks to Nathan Eldridge for organising this event!



Copley Districts Gymkhana

Earlier this year, the Copley & Districts Gymkhana & Motokhana (horse and motorbike racing) was held up in the Northern Flinders Ranges. The unseasonal, heavy rain wasn't enough to keep this community away! They were still able to hold motorbike events and an auction that helped to support the MND community in SA. We are very grateful for their donation of \$3,000 this year.

Brad Ebert & Hey Diddle Wines

Brad Ebert, MNDSA Ambassador, has been a busy man of late... earning the AFL role as Carlton's Development Coach. All the while, he's been generously accumulating donations for MNDSA from the sale of the Hey Diddle Wines 'Pinot Gris for MND'. Brad recently handed over an amazing \$7,500 to help support our MND community in SA. Thank you to Brad and the Hey Diddle Wines team for your ongoing support and generosity - it is greatly appreciated. To order Hey Diddle Wines visit: <https://heydiddle.com.au/>



To hold a community fundraiser for MNDSA, visit:
<https://my.mndsa.org.au/page/81/hold-a-fundraiser>

Partnerships & Sponsors Update

SANFL & DUNK ME 4 MND

As the Tigers and Double Blues squared off in front of a record crowd in the top-of-the-table SANFL clash on the King's Birthday, June Long Weekend, personalities, including Glenelg No. 1 Ticket Holder Andrew 'Cosi' Costello, and past players took part in a 'DUNK ME for MND' challenge before the start of the game and at the first quarter and half-time breaks. Each dunk raised \$100 for MNDSA. SANFL CEO Darren Chandler said this weekend's footy fest was a great opportunity to help create awareness and support South Australians living with MND. Over \$5,000 was raised at this event!



Football SA & Larapinta Trek

Football SA have been strong supporters of MNDSA since early 2022 and to take their support one giant step further, Mark Easton, their GM for Commercial Operations (pictured right) took on MNDSA's Larapinta Trek (from 16-21 August) in support of Ray Coull. Ray is a much-loved, long-time member of the Modbury Jets Soccer Club, and is currently battling MND. We were thrilled to welcome Mark to the Trek, congratulate him on raising \$3,000, and we continue to be grateful for Football SA's ongoing support of our MND community in SA.



Paradise Mazda

We are so grateful to Paradise Mazda for their long-term and ongoing support of MNDSA.

This year, for the first time, Jeff Neale and his team (including family and friends) participated in our Walk to D'Feet MND with a Corporate Team. Their involvement was such a meaningful way to support our MND community and show them that they are not alone. There's a diverse community of supporters who care enough to walk alongside them, raise funds and raise awareness so we can grow our presence and support services to make a tangible impact. Thank you again, Paradise Mazda!



Partnerships & Sponsors

Update

SAPN Employee Foundation

The SA Power Networks Employee Foundation participated once again at our Walk to D'Feet MND this year and the Foundation dollar matched the staff fundraising efforts. We were further blown away when we were invited to collect 'the cheque' and they donated an extra \$20,000! Now that's a serious commitment to Corporate Social Responsibility. It's not every day you receive that sort of generosity – we thank them sincerely for their efforts on behalf of clients and families.



Claymore Wines

We were so thrilled to welcome this vibrant group of people into our Walk to D'Feet MND community this year. Claymore Wines sponsored our Cheese & Wine Marquee with their 'You'll Never Walk Alone' wines for us to share with our community. Then to top that off they decided to offer their team a wellbeing and community engagement opportunity by bringing a Corporate Team along to support our event. Claymore Wines had a prominent presence on the day and their support was very well received by our community of clients, families, staff and management. Thank you, Claymore Wines Team - we appreciate your support and participation!



S&S Property Developments

When we put a call out to our Business Community to seek a Corporate Sponsor for our Larapinta Trek, it was answered with enthusiasm by S&S Property Developments. Their commitment evolved into the opportunity to run a 'Dollar Matching' donation drive - which was in turn met with great generosity from our supporter community, and we were able to match their \$10K contribution with \$10K from our community! This amazing support will help us fund new Eye Gaze Communication technology for our MND Clients! Stephen Pisani (pictured left, on right), MNDSA Board Member and Co-Owner of S&S also came along on the Larapinta Trek adventure!



Events & Appeals



EOFY Tax Appeal

We know it is quite likely that you received letters and emails from a variety of organisations asking you for a donation at the end of the financial year and we are truly grateful for your support of MNDSA. Throughout this newsletter you have read about the immense care needs of people living with MND and there is no doubt that without your support we simply could not respond to the needs of clients and their families.

It's not just money... We know we cannot change the outcome, but your support helps us to work alongside families facing MND, letting them know they ARE important, that people DO CARE, and they are VALUED.

THANK YOU, Brenda (pictured above at our 2022 Festive Lunch) for allowing us to share your story, and thank you to everyone who responded. Every contribution is hugely valued.

To see all upcoming events and to register, scan the QR code or call the MNDSA Office on 8234 8448.

Adelaide Oval Corporate Box

In July we had the pleasure of hosting some of our Clients in a Corporate Box at Adelaide Oval. It was a fabulous day enjoyed by all, with great company and delicious food. The Crows won in a landslide, and it was a fantastic experience to be watching the game from an elevated viewpoint. Thank you to our clients and their families for making this a special day out, and a big thank you to Adelaide Oval for hosting us so well.



Upcoming Events



Hope & Remembrance

Our Day of Hope & Remembrance, coming up on 22 September, is an opportunity to come together with a common bond - caring deeply for our MND community and those who are committed to making a difference.

Rosa Matto, our Patron will host the afternoon and introduce our new MNDSA Chair, Andrew Danson. We'll also hear about the latest research and have moments for reflection with candle lighting, readings, poems, music followed by an afternoon tea in the gardens of Partridge House, Glenelg.

Starry Night Gala Dinner

Our Annual Gala Dinner is finally back on the calendar following a long hiatus due to covid. We can't wait to gather together as a community at the National Wine Centre on 17 November for an evening of music, awards, auctions and quality food and wines shared amongst friends. The Incredibles band will entertain us, an Auctioneer will excite us, a Wine Wall will tempt us, and our Awards will delight us. Don't miss this special night and be sure to dress to impress!



CALENDAR OF EVENTS

MNDSA Client Christmas Event
Sunday 10 December 2023

Walk to D'Feet MND 2024
May 2024 (Date TBC)

Bay of Fires Trek, Tasmania
11 to 14 October 2024

Client Events
Multiple Dates - see our website for more information by scanning the QR code overleaf

Other upcoming events...

We've got a diverse range of events lined up for our community. Keep an eye on the events page of our website for more details at: www.my.mndsa.org.au/events and/or scan the QR Code on the opposite page.

Whether you're feeling festive, looking to party, get active or keen to simply connect with others for a chat - we've got something for everyone.

Our Client Services events are expanding to include sessions in the North, South and Central Adelaide, so head to our website for more information.

Walk to D'Feet MND Wrap-Up

We were so pleased that when we asked, you answered in droves helping to support our vision for a world without MND.

In a sea of Never Give Up beanies, over 750 members of our MND community gathered on the beautiful grounds of Pinky Flat to soak up the atmosphere before and after the 5km walk around Adelaide's Torrens River.

The highlight for many was watching Premier of SA, Hon. Peter Malinauskas 'ice bucketed' by his Minister for Health, Hon Chris Picton and Member for Davenport, Erin Thompson. Many of the MNDSA Board Members also took the splash! Walkers enjoyed live acoustic music from Driving Doris, and the Caledonian Pipe Band again led walkers off after a resounding rendition of MND's anthem - Don't Dream It's Over.

The annual walk plays a major role in supporting and sustaining MNDSA's ability to react and respond to people's needs and helps us to acquire equipment to support all facets of the caring role.

We are very grateful to our sponsors; Paradise Mazda, SA Mushrooms and Claymore Wines whose support allows us to achieve a bigger audience and benefit from better publicity.

Together we raised over \$100K for our MND Community in SA. It was a massive team effort, and we can't thank our community enough for digging deep and joining our fundraising tribe!

Last but not least, a big thank you to everyone who contributed to make this event a success, especially our community of clients, families, friends, volunteers, staff, management, board, event suppliers, media, and to the SA Government, for prioritising and attending our event with fervour!



Larapinta Trek 2023 Wrap-Up

Memories by Karen Percival



Our committed Larapinta Trekkers from left to right: Hannah (MNDVIC), David Schultz, Tracey Miller, Alice Schaefer, Stephen Pisani, Erin Thompson, Cathy (MNDVIC), Sue Wundenberg, Mark Easton, Meredith (MNDVIC), Julie Dixon, Steph (MNDVIC), Declan Bell, Karen Percival, Karin Bell

The 16-21 August finally arrived, when our fearless group of MND SA Trekkers (above) flew up to Alice Springs and hit the Larapinta Trail with enthusiasm and determination.

Day 1

The MND SA's Larapinta Trek group converged on the NT from all over SA and we even welcomed a few Trekkers from MNDVIC! After arriving in Alice Springs, the Trekkers set up camp in the Mercure Hotel ready to watch Australia's Matilda's in the Women's World Cup. Excitement was a plenty for the game and the pizza!

Day 2

With an early start we met our guides and loaded on the bus for transfer to our first Trekking adventure.

First stop was Standley Chasm where we set off enthusiastically to make our way to Reveal Saddle. Angkerle Atwatye (Standley Chasm) was formed 2.2 billion years ago by ancient seabeds, and consists of quartzite walls. The North South orientation allows direct sunlight to illuminate the walls for just 90 minutes around midday giving the Chasm an impressive glow.

The unstable ground was tough on the ankles and the stones hard underfoot, this was also our hottest day at 32 degrees with no shade which felt like 37 degrees!! However there was a great sense of achievement at the end of the day when we transferred to our camp ground at Helen Gorge where we were delighted to enjoy a swim in the natural gorge before sunset.

After dinner around the campfire, we were in for a windy night ahead.

Trekking Distance 13.2km



Larapinta Trek 2023 Wrap-Up



Day 3

Finke River – Ormiston Gorge

This morning, we made our way from the Finke River to Ormiston Gorge through rolling limestone hills filled with unique plant life. The Finke is one of the oldest river systems in the world, and the local Arrernte name for this waterway – here Pinte, meaning “salty river” – gives the whole trail its name.

This leg of the trek finished at Ormiston Gorge, home to the most impressive gorge in the West MacDonnell region. A near-permanent waterhole shaded by ghost gums and towering red rock walls awaited us after a challenging trek, and we took time here to rest and freshen up with a quick dip. We then returned to our camp for an early night under the stars as we were setting off for our Mount Sonder climb at 2am the next morning!!

Trekking Distance 10kms



Day 4

Redbank Gorge – Mount Sonder

This morning, we woke at 1am to set off before the sun. We transferred to Redbank Gorge at the base of Mount Sonder (Rwetyepme or the “pregnant lady” in the local language). From here, we made a slow, steady ascent to the summit surrounded by darkness.

The journey was arduous along a rocky, often steep and loose path that occasionally disappeared into brush. Reaching the summit before sunrise it was freezing but we were rewarded with incredible 360° views of the ranges, plains, valleys and salt lakes below. Here we took time to catch our breath and bask in the grandeur of the desert landscape – and our incredible achievement.

After descending slowly, wondering how we had got up the mountain in the dark, we transferred back to our campsite for our last night camping in the Australian Outback.

Trekking Distance 15.5kms



Larapinta Trek 2023 Wrap-Up

Day 5

Ormiston Pound

Today we said goodbye to the campsite, but not before an aerobics workout with lots of laughter before boarding the bus!! There was a bit of Olivia, "Let's get Physical", Nutbush and Macarena - amazing energy from the team with their tired legs and ankles!!!

Ormiston Pound is listed as one of the best day walks in the West MacDonnell National Park - and we learnt why. The variety of scenery in one day was stunning. It was at lunchtime we came across the beautiful red cliffs and golden sands that provided the canvas for us to remember why we were all here - spelling out MND on the sand (front cover).

To finish the circuit, we all needed to cross a permanent waterhole to get back to base. We had to take our pants off, hang our boots around our necks and put our backpacks on our heads to cross over the gorge, with lots of squeals as the water was so very, very cold!

Our walk only took in the western end of the Pound and at the Ormiston Gorge ridge, we enjoyed panoramic views.

Thanks to our awesome group of Trekkers and supporters, we smashed our fundraising goal to reach over \$110K to support our MND community!



While this walk can be done at any time of the year, we were relieved to have completed it during Winter, as the summer heat would have been oppressive.

A quick stop at the Ochre Pits on the way back to Alice Springs wrapped up our Trekking in this very special part of the world. Such a challenging adventure with an amazing group of Trekkers - all to support our MND Community. **THANK YOU.**

Trekking Distance 9kms including steps underwater!!

Bay of Fires Tasmania 2024

Are you going to join us for the Trip of a Lifetime?
Challenge yourself with this stunning experience, all in the
name of supporting people living with MND in SA.

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 Cape Naturaliste, Mt
William, Boulder Point, Deep Creek, Picnic Rocks,
Eddystone Point, Ansons Bay and Humbug Point Loop.

Dates: 11 to 14 October 2024 - 4 day challenge

Fundraising Target \$3,500 per Trekker

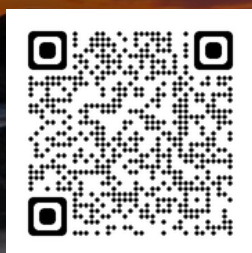
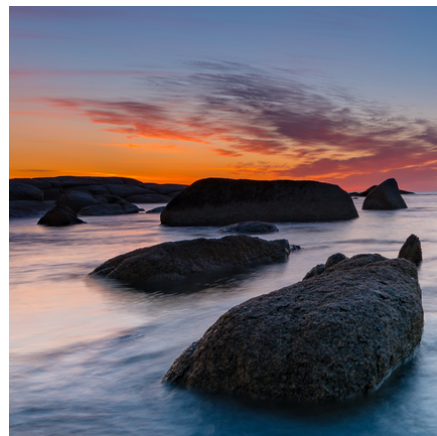
Accommodation: Twin share in a Farmstay

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/>



Discover the immeasurable beauty of Tasmania's Bay of Fires by foot and raise vital
funds to ensure MNDSA can continue to support people with motor neurone disease
and their families.

Where there's a Will, there's a way, forward.



We have listened to the views of many MNDSA clients who have shared with us that managing the practicalities of planning for life's end can feel overwhelming and complicated. Based on these views, we teamed up with Willed to provide a simple and affordable online solution to making your Will using the QR code or by visiting <https://www.willed.com.au/mndsa>



Willed is one of Australia's leading online estate planning platforms, built by lawyers and trusted by thousands of Australians. With Willed, you can write your legal Will online in less than 20 minutes from the comfort of your own home.

From just \$159 and in three easy steps you can have a Will that is legally valid throughout Australia and customised just for you.



When on the Willed website, you will be asked to create a Willed account, answer some questions about your partner and children and appoint your executors. After you have taken care of your loved ones, you might also like to consider leaving a gift to MNDSA. Large or small, when you include a gift to MNDSA in your will you are making a serious impact in the availability of care and support for people affected by a diagnosis of MND and the search for better treatments and a cure for MND *Image Credit: willed.com.au.*



Eating well with MND

Dysphagia and MND

What is dysphagia?

Dysphagia is the medical term to describe difficulty in swallowing. This includes problems with:

- sucking
- swallowing
- drinking
- chewing
- eating
- dribbling saliva
- closing your lips,

Eating and drinking is a vital part of life. Difficulty swallowing can limit what you can eat and drink, leading to frustration, stress and health problems.*



Beyond the Blender

'Beyond The Blender: Dysphagia Made Easy' is a wonderful recipe book that is all about making meals that are fresh, delicious and easy to cater to the dietary needs of people with swallowing difficulties, known as dysphagia. No longer is it necessary to blend bland and tasteless meals; with these recipes anyone can create fantastic food full of flavour.**

There are many practical recipes in this book that don't compromise on flavour and help to provide a balanced diet. There's something for everyone, including the sweet tooths!

Get in touch with your Speech Pathologist to learn more about what recipes may be suitable for your needs.



OBI Robotic Feeder

The Robotic Feeder, Obi, can be used by anyone with reduced upper limb function to improve independence at meal times. The Obi feeder allows the user to choose what they eat from the four food compartments when they want to eat.***

If you think the Obi could help you or someone you care for to eat more easily and offer greater independence, get in touch with our Occupational Therapist to find out more.



References:

*<https://www.healthdirect.gov.au/dysphagia>

**<https://beyondtheblender.wordpress.com/2018/09/14/the-dysphagia-cookbook/>

***<https://flexequip.com.au/product-library/eating-aids/robotic-feeder-obi>

YOU'RE INVITED TO

Our Day of Hope and Remembrance

JOIN MND SOUTH AUSTRALIA
FOR THIS SPECIAL OCCASION

WHEN: Friday 22nd September

WHERE: Partridge House, 38 Partridge
Street, Glenelg SA 5045

TIME: 1:30 pm arrival - service commences
at 2:00 pm with light refreshments after.

RSVP: Friday 15th September

Call our office on 8234 8448 or register via
www.my.mndsa.org.au/events

Rosa Matto will lead an afternoon of reflections, readings, music, candle lighting and afternoon tea. This is an opportunity for the MND SA Community to come together, share the past and express hope for the future.

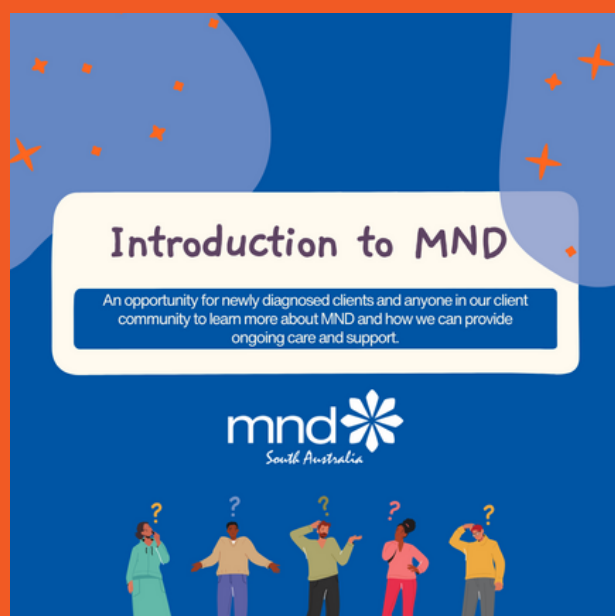
The facility has wheelchair access, with vehicle drop off and pick up points, convenient carparking, and beautiful garden for reflection before and after the service.



MND Client Services

MNDSA's Client Events

Our **Information Sessions**, held every second month, are an opportunity for people who are newly diagnosed with MND to meet members of our Client Services team, learn more about MND and how MNDSA can support families moving forward. Held on a Thursday evening from 6-7.30pm, these 'introduction' sessions are designed to be an informal gathering where our new clients can have a cup of tea/coffee get to know our supportive team, tour our facilities and familiarise with all that MNDSA can offer.



Our MNDSA Client Services Team members Denise Schoder and Leanne Shane will share information in a comfortable and informal environment. Light refreshments will be available, and we encourage partners, carers and family members to come along.

Please visit our website for a full list of events at www.my.mndsa.org.au/events



We are so pleased to have re-introduced our **You, Me & MND** gatherings. Based in the North, South and in Central Adelaide, these casual catch-up sessions are an opportunity to meet new friends, go out for coffee/lunch and be amongst people who share a lived experience with MND.

MNDSA's Equipment Hire

Our MNDEquip service continues to provide equipment and assistive technology to clients. The equipment rental service supplies and delivers, installs and collects items as well as providing information about its correct use.

We welcome calls to our Client Services team to find out more about what equipment may be helpful and how to organise support in an efficient way. Please call (08) 8234 8448 from 9-5pm, Monday to Friday to arrange equipment hire.



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



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