

MND news

The newsletter of the Motor Neurone Disease Association of South Australia



Pictured from L to R: Hon. Nat Cook MP, Ray Coull & Karen Percival

- Highlights from 2023
- What's in store for 2024?
- Latest news, research & client services
- Upcoming events, new staff and much more...

Until there's a cure, there's care

Message from the CEO

As 2023 comes to a close it is a good time to reflect on the past 12 months at the association. As part of our Annual Report I shared some of the major developments that have transpired. It has been wonderful to see MNDSA grow as an organisation and to offer increasing value and support to people living with MND. Having worked on strategies to ensure our business could be sustainable last year we saw how this played out across the year. MNDSA has not only grown in its staffing complement, but we have also expanded our service offering and community programs.

At the end of 2022/23 MNDSA had its re-registration audit for NDIS with SAI Global. Our accreditation as a Registered NDIS Provider gives our clients the comfort that we adhere to rigorous NDIS Quality and Standards requirements. I am pleased to say that our audit was a positive experience resulting in best practice recognition for two areas of our service which we are advised are hard to achieve. We were also the first MND State Association to achieve accreditation for the provision of complex support coordination.

The NDIS regulatory processes still prove to be a heavy burden with MNDSA undertaking between 20 to 30 hours of work to assist eligible clients to just gain access to the NDIS, a unique service that the majority of other providers do not offer. MNDSA provide this support for clients to ensure they get the very best first plan possible. This work is not funded by the NDIS. Rather it is funded from MNDSA donations and fundraising. We therefore hope that participants will recognise this support and choose us as their provider when they do receive the first and subsequent plans.

The SA Government support announced during the last election has entered its first year and has helped fund our equipment service and enabled the addition of five staff to provide supports to those not able to access NDIS funding. Unfortunately, approximately 50% of our clients are ineligible for NDIS funding simply due to them being diagnosed with MND over the age of 65.



With the Royal Commissions and reviews that have been underway for both the NDIS and Aged Care systems we have been working with MND Australia (our peak body) and other industry bodies to advocate for the needs of our community and to try and address some of the inequities that exist. As part of our advocacy efforts, Erin Thompson MP and Penny Pratt MP were co-conveners for the SA Parliamentary Friends of MND group which was launched in June. Great attendance from Ministers, MPs, MNDSA Board members, staff and clients helped us increase awareness of issues our community faces and contributed to a strong foundation for ongoing parliamentary communications.

As of 30 June 2023, we had 144 people registered with the Association - a considerable growth from previous years. We at MNDSA are all committed to working to support our community in various ways.

I would like to thank my amazing Client Services team on the resilience, professionalism, dedication and persistence they demonstrate each and every day to get the best outcomes for our community. To see how the team work together to come up with evidence informed solutions and the best outcomes for our community is commendable.

Lastly, I'd like to thank our Business Support team, Fundraising team, Board, Staff, Volunteers, Supporters, Sponsors and Community for making MNDSA what it is today - to support our MND Community in SA - with the best possible care we can offer.

Best wishes to all for a safe and happy Festive Season. I look forward to engaging with our entire community in 2024 through the myriad of events and programs planned throughout the year. To see how you can get involved and be a part of our wonderful community, visit our website at www.mndsa.org.au.

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

Karen Percival
CEO

MNDSA Staff & Board Update



Ass. Prof. Stacie Attrill - New Board Member

Associate Professor Stacie Attrill has been appointed to the MNDSA Board for a 3-year term.

Stacie is an experienced Associate Professor in Speech Pathology, with extensive experience in higher education, professional accreditation and clinical practice industries. Stacie brings specialised skills and knowledge in allied health. She is an accomplished and awarded university lecturer. Stacie's research encompasses health, disability and aged care areas as well as eating and swallowing for people with neurodegenerative conditions.



Nicola Buley - New Board Member

Nicola Buley has been appointed to the MNDSA Board for a 3-year term. Nicola holds a Bachelor of Arts (Psychology) and Bachelor of Laws. She has extensive commercial legal experience including business succession and risk management. Nicola has strong corporate governance, project management and business development skills that complement our existing board.



Mardi-Lee Templer - Business Support Officer

Mardi-Lee is very excited to join the MNDSA team as Business Support Officer. She's worked in Finance and Administration positions for over 30 years in Australia, United Kingdom and Ireland. Mardi-Lee is looking forward to working in a not-for-profit organisation, and meeting and greeting our clients. Mardi-Lee is keen to join in on the fundraising activities and functions with our MNDSA clients. In her spare time, she enjoys long walks with two schnauzers, cooking and entertaining family and friends.

MNDSA AGM Overview

In 2022-23 the organisation continued to adapt services to meet the further increase in demand from people with MND in SA by doing the following:

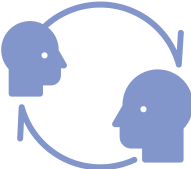
- recruitment of an in-house Speech Pathologist and expansion of our Augmentative and Alternative Communication (AAC) program,
- further increase of our Occupational Therapy staffing and allied health assistants to enable quicker prescription and training for vital equipment,
- consolidation, maintenance and expansion of our equipment pool improving turnaround and delivery times to keep people safe at home and out of hospital,
- expanding our Client Services Team with additional qualified allied health professionals,
- continued funding for the Research Fellow at the Flinders Medical Centre MND Clinic enabling clinical trials to come to South Australia,
- recruitment of a full time Volunteer Coordinator to build our suite of volunteer programs, activities and growing army of amazing volunteers,
- introduction of our Loss, Grief and Bereavement Program giving members of our community someone they can talk to who will listen and understand the challenges they are facing,
- adapting our Life Stories program to become Special Memories,
- undertaking a client survey to receive valuable feedback as part of our ongoing quality assurance processes, and
- developing our resources to ensure education can be delivered in many forms and to different audiences.



MNDSA Board Members at recent AGM (from L to R): Grant Law, Stephen Pisani, Karen Percival (MNDSA CEO), Sue Wundenberg, Ben Jordan (Treasurer), Andrew Danson (MNDSA Chair), Associate Professor Mary-Louise Rogers, Associate Professor Stacie Attrill, Dr. Peter Allcroft, Kristine Colliver and Nicola Buley. Andrew Holmes (Board Secretary) present via video call.

MNDSA 2022-23 Statistics

Number of clients engaging electronically or face-to-face



216 (2021/22 - 190)

New members with MND



99 (2021/22 - 87)

Deceased Clients



62 (2021/22 - 56)

MND Assoc FTE @ 30/6



16.4 (2021/22 - 12.4)

MND Assoc average FTE



14.4 (2021/22 - 10.2)

Regular Volunteers (including Board)



40 (2021/22 - 34)

Volunteers Hours



1775 (2021/22 - 1634)

Number of equipment items in Association equipment service



1046 (2021/22 - 1001)

Number of equipment items provided to clients



822 (2021/22 - 737)

Number of individuals who received equipment



181 (2021/22 - 151)

Advocacy In Action

We share an excerpt from Erin Thompson’s speech at our recent MNDSA Gala Dinner. Erin is the Member for Davenport in SA. She is a staunch advocate for MNDSA. We appreciate all she does to give our community a strong and consistent voice at the highest levels of Government.

“Thank you for inviting me to attend tonight’s Gala Dinner.

Officially I am here representing the Minister for Health and Wellbeing Chris Picton, but as many of you would know, MNDSA and the MND community is special to me and I’d be here either way.

I would also like to acknowledge all those here tonight who are living with MND, as well as their friends, loved ones and other members and supporters of the MND community.

In 2020 MND took my beautiful Mum, Jan.

I am familiar with the profound impact this disease has on families and communities as they witness their loved ones confronting the gradual loss of independence and the significant challenges this disease presents.

I remember when mum was diagnosed with Motor Neurone Disease, she joked that her favourite Janz Tasmanian Sparkling wine just wouldn’t be quite the same through a feeding tube.

That was the spirit of my Mum, but while she was strong, kept smiling and tried hard to stay positive, particularly in front of her grandkids, it was really difficult for her, and for all of us.

Mum’s symptoms progressed quite quickly – first she needed a walker then a wheelchair, she needed a feeding peg, there was shower equipment, speech assistance, a reclining chair and the list goes on.

If it wasn’t for MNDSA I honestly don’t know how we would have gotten through. My family will be forever grateful for their incredible support and guidance. Support can help to ease and manage symptoms, prolong independence and help people to achieve the best possible quality of life at each stage of their illness.



Advocacy In Action

Mum was 64 when she was diagnosed. But for those who are diagnosed over 65 years old, they don't qualify for NDIS support and instead need to apply through arduous and overwhelmed Federal systems such as My Aged Care.

As a result, 80% of South Australians living with MND who are over 65 pass away before receiving an appropriate level of Federal support.

This means that the support that MNDSA provides is even more vital.

This was something my mum would remind me of frequently. I wasn't yet a member of parliament when Mum was diagnosed but in my former role I did meet with politicians from time to time. And every time I did Mum would remind me to lobby them to fund MNDSA.

When I did decide to run for Parliament, I was very proud to be a part of the Malinauskas Government that has committed to providing ongoing funding to MNDSA, to help them with the incredible work they do supporting South Australians living with Motor Neurone Disease and their families.

The South Australian Government is committed to supporting South Australians living with MND.

State government funding will help MNDSA to provide specialist care, treatment and equipment.

This funding has already enabled the recruitment of five additional health professionals who are providing services to the community.

It's also provided nearly 900 equipment items to better support people living with MND.

While its great that MNDSA is now receiving some government support, they still very much rely on fundraising to be able to continue the great work that they do.

Thank you to all of you who bought a ticket to tonight's event and have been involved in the various fundraisers through the year." End.

The Gala Dinner is just one of the events that Erin has supported to benefit MNDSA this year.

She has also attended and fundraised for MNDSA's Walk to Defeat MND (including providing promotional videos to help promote the event) in April 2023.

Then in July, Erin attended and fundraised at the MNDSA Quiz Night - for a 2nd year in a row.

Following this, she laced up her hiking boots and hit the Larapinta Trail in August with 10 other Trekkers who collectively raised over \$110,000 for our Client Community.

Erin's fundraising was not limited to these events, she also spent her personal weekend time at MNDSA-Bunnings Sausage Sizzles to bolster her fundraising contributions.

In short, we think Erin is a Champion and we know her Mum would be super proud of everything she's done to honour her legacy and support others who are living with MND to support them on their difficult journey.

We are proud to call Erin Thomson one of our dedicated Ambassadors, and we look forward to being a part of her ongoing advocacy efforts for MNDSA in 2024 and beyond.



Living with MND

Spotlight on

Speech Pathology



The Speech Pathology Service at Motor Neurone Disease Association of South Australia has made significant progress during its first 9 months of operation. The service was established to address the specific speech and communication needs of individuals living with MND. The following provides an overview of the key priorities and achievements so far.

Referral Overview:

Since our dedicated Speech Pathologist, Melinda Gentle, came on board in February 2023, referral numbers have increased significantly with 70 referrals received since the internal role commenced. We have seen a growing demand for the specialised support provided by MNDSA.

Approximately 50% of these referrals were NDIS Clients, which has resulted in increased billable activity for the service. This demonstrates the effectiveness of collaboration with the National Disability Insurance Scheme (NDIS) in expanding access to Speech Pathology services for individuals living with MND.

Timely and Efficient Services:

Our dedicated resource has resulted in a faster response time with our MNDSA Speech Pathology Service ensuring that all referrals were actioned within two business days, allowing for prompt initiation of assessment and treatment.

The service has aimed to conduct initial assessments for all referred individuals within ten business days. This ensures that clients receive timely access to communication supports.

Enhanced Communication Support:

The service has enabled early access to communication supports for individuals living with MND. This is particularly relevant to those individuals awaiting My Aged Care or NDIS funding, who would otherwise not have access to communication supports until funding is in place.

Augmentative and Alternative Communication (AAC):

The service has implemented a streamlined process for AAC assessment and implementation. This ensures that individuals are prescribed AAC that is tailored to their individual needs and promotes more effective AAC implementation.

Streamlined AAC Equipment Processes:

We've seen an improvement in resource allocation with the service allocating additional resources to streamlining AAC equipment monitoring and distribution. This has ensured a more efficient and effective matching of devices to individual needs. We've also seen improvements with device optimisation, and reducing device abandonment. We've focused on maximising the use and benefits of AAC equipment. The service provides ongoing support and training to individuals and their caregivers to optimise use of AAC devices and reduce device abandonment rates.

Community Education and Collaboration:

The service actively pursued opportunities for community education, including consultations with Country Health and educational sessions for residential aged care facilities. These initiatives aimed to raise awareness about MND and the importance of specialised Speech Pathology support.

Collaboration with stakeholders:

MNDSA established collaborations with relevant stakeholders, such as Country Health and Flinders University, to promote comprehensive care and support for individuals living with MND.

We would like to make a special mention of our former MNDSA Chair, Geoff Thomas for his valuable contribution to MNDSA's Speech Pathology and AAC services. Mr. Thomas contributes \$30,000 annually (since June 2022) to help enhance and maintain our speech services. Thank you for your generous support, Geoff.

Living with MND Special Program Update

LISTENING & SUPPORT

The Talking Grief program underwent some changes this year and became our Listening and Support. We currently have approximately 18 volunteers that have completed the training and out of this group we have 10 that are actively supporting clients and family members. This support ranges from in person support, in either the clients' home or in coffee shops, to phone calls and in some cases emails. The program is structured in a way that allows for members of our community to engage in a way that they feel comfortable. Volunteers spend time with clients or family member with the conversation dictated by those we are supporting. Our volunteers are there to be someone who will listen and support members of our community through their MND journey. The goal for 2024 is to engage with volunteers in the Southeast to support clients in and around Mount Gambier. As the program expands further, we will look to offer the Listening and Support program in other regional areas of SA.



SPECIAL MEMORIES

Our Life Stories Program also underwent some changes and became our Special Memories Program. This program is about supporting our clients to put together their stories and memories in either a book or letters and then this is presented in a keepsake box to the clients. These boxes also offer our clients the opportunity to leave specific trinkets, scented handkerchiefs, a usb stick with music or recorded stories to their loved ones. This program currently has 8 volunteers that are working in teams to collect the stories, produce the books and put together the keepsake boxes.

To find out more about these programs and get involved (as a client or volunteer), please contact our Volunteer Coordinator, Olga Russo on volunteer@mndsa.org.au or call 8234 8448.



MND Education & Research



MND Research Australia (MNDRA) produces the Advance newsletter, which is published biannually, in June and December of each year.

The December 2023 newsletter has just been released and covers various research grants that are due to commence in 2024. You'll also find a summary of MNDRA's great research programs and initiatives such as MiNDAUS, MND Connect, State of Play and Research Directions - lead by Dr. Gethin Thomas.

Detailed updates in the MND research space can be found at [mndaustralia.org.au/articles](https://www.mndaustralia.org.au/articles)

To read the Advance Newsletter, scan the QR code below:



Research Directions is a 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-november-2023> OR you can scan the QR code below:



We encourage our MNDSA clients and family members / carers to learn more about MND connect and access the many resources on offer. This online resource, provided by MND Australia, has a wealth of information, in addition to guides to finding vital support and services for people living with MND.

It also has specialised information for health professionals and services providers who support people with MND.

MND Connect offers a range of in-depth factsheets on a range of MND topics.

You can access MND Connect either directly through www.mndconnect.org.au or through the Information & Support section of the MND Australia website. Scan QR code here:



State of Play Webinar Updates



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

The last webinar in 2023 was held on 14th November and focused on cognitive changes in MND.

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>

Or scan the QR Code:



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WALK TO DEFEAT MND SUNDAY 19 MAY 2024

CORPORATE TEAMS

Join our tribe and show your support for the MND community in South Australia.

SAVE THE DATE

Sunday 19 May 2024 | 9am to 3pm
Walk starts at 11am | Pinky Flat, Adelaide
4.5km loop around the River
Food & Drinks | Entertainment
All welcome for this community event
Registration essential | Teams of 4+

MAKE A DIFFERENCE.



RALLY YOUR TROOPS FOR A CORPORATE TEAM TO SUPPORT MNDSA.

MNDSA's annual flagship event welcomes over 800 people who join forces for the common goal of raising over \$100K for South Australians living with Motor Neurone Disease.



FOR MORE INFO:

E: fundraising@mndsa.org.au
Call: 08 8234 8448

People living with MND should never walk their journey alone.

Personal Story

Meet Ray Coull, MNDSA Client, and learn why he is affectionately known as...
Cool Ray.

Since being diagnosed with MND in January 2023, Ray Coull has been actively engaged with MNDSA and has made a huge effort to help raise awareness and much needed funds to support the wider MND community in SA.

We asked Ray to share what motivates him to be so involved with MNDSA's events and fundraising, and indeed take on external community fundraising events organised by his many mates in the Football community in SA.



Top image: Ray Coull with the Body Fit Training (BFT) Team. Bottom image: Ray representing the Modbury Jets Football Club.



Ray & Tam at MNDSA's Gala Dinner

Q. MNDSA's Walk to Defeat MND was your 1st fundraiser this year. Why did you register to participate (just a few months after your diagnosis) and what did you enjoy most about the event?

A. Along with family members and friends we decided to take part in the Walk to Defeat MND because I felt the need to get on the front foot and be positive about taking this beast on. The thrill of seeing so many people take part and seeing many people going through this at the event and talking to many of the MNDSA staff on the day, making it so special, was awesome.

Q: How long have you been connected to the Modbury Jets Football Club?

A. Along with our club president and close mate Jeff McCormack I have been involved with Modbury Jets Football Club for 18 years, starting coaching u/15s and progressing through to assisting coaching roles in our senior teams for the past 6 years.

Q: How did you feel when your Modbury Jets FC community staged a major fundraiser for you and MNDSA earlier this year?

A: It was a very overwhelming feeling that night in August when a huge crowd rolled up and shared in the outstanding job Jeff & the committee put on in conjunction with Football SA. To see people from many different clubs there and the staff from MNDSA selling their socks, beanies and also the club selling the fancy Coull beer was a fantastic sight. It was a great night and the funds raised were huge!

Q: When Football SA's GM for Commercial Operations, Mark Easton took on the MNDSA's Larapinta Trek in your honour – did you realise how far reaching your community support is?

A. Meeting Mark and talking to him regarding the trek at one of our games recently was great. It really hit home that not only myself but many others are going through the journey of MND. Mark taking on the trek was an outstanding honour, and I am extremely thankful to Mark for his unreal effort.

Q: What did it mean to you to win a Community Award at the recent MNDSA Gala Dinner?

A: That night at the gala ball will go down in my memories for life. When asked if I would be interested in attending the ball, at first I wasn't really sure. After speaking to several people, I decided to go and the guests at our table had a fantastic night as did Tam & I - dancing after the award ceremony. I spoke to several people I had never met before, and it was an awesome feeling being able to chat to them. It meant a lot to me to have those close to me there - that had a big impact in helping me achieve this award.

Q: What are you looking forward to this festive season?

A: This festive season will be very different for many reasons, the first year with this disease and my condition, the first in our new home, and I guess looking forward to catching up with family members and many friends for a quiet drink and delicious foods!

Once again, we thank Ray for his ongoing support of MNDSA and willingness to engage with our whole team to not just receive support but to give a huge amount of support back to MNDSA and the MND community across South Australia. Ray won the Multi-Event Fundraising Award recently with more than \$20,000 raised so far in 2023.

We admire Ray's courageous approach to battling MND and his selfless efforts to contribute time, energy and funds back into MNDSA to support others who are on a similar MND journey.

Thank you Ray for your amazing courage.

Community Fundraising

3 easy steps:

Choose your event:

Hold a raffle or sausage sizzle at your local sport club, host a morning tea, take on a physical challenge and ask your friends to sponsor you - to name just a few community event ideas to help you raise funds.

Set up a fundraising page online:

Visit MNDSA's website and follow the prompts to create your own fundraising page. You can then create a QR code or copy the website link and share it.

Share the event & donation details:

Via social media, email and text, you can share the website link with all your friends to get maximum support for your efforts.

To enquire about Community

Fundraising, contact 8234 8448 or email us at fundraising@mndsa.org.au



Ray Coull & Jeff McCormack at the Modbury Jets Fundraising event.

MNDSA Thank You

Supporting Kids during MND

Year 9 Students, Emily (R) and Anne (L) from Pedare Christian College, completed a Community Project earlier this year in June, which saw the pair undertake quite a time consuming, but rewarding project to create a special book and gift pack for children who have been affected by a family member's diagnosis with Motor Neurone Disease. Both Students visited the MNDSA office to deliver these gift baskets, that were full to the brim of all the things children love (including soft toys and crafts), but most importantly a book to help understand an illness in the family, from a child's perspective. Thank you for your wonderful efforts, Emily & Anne and congratulations for receiving an Excellence Award for this project.



MGA Whittles BBQ

In October this year, MGA Whittles hosted a community BBQ on premise at their Darwin and Dulwich offices to raise vital funds for MNDSA. The BBQ was well attended by staff and families to help fundraise and raise awareness of Motor Neurone Disease. Special thanks to Susan Brennan (MGA Whittles) and Sue Wundenberg (MNDSA Board) for helping to arrange this event and make a strong contribution of \$4,000 for our MND community in South Australia.

Limestone Coast Line Dancers

In early December the Limestone Coast Line Dancers held an MND Dancing Day with 40 dancers in attendance. The dancers all took part in a fundraising drive via entry fees, raffles and donations and managed to raise \$2,335 in honour of Richard Von Duve who passed away from MND. Richard's sister Julie Ricketts was instrumental in organising this wonderful fundraising initiative. Thank you Julie, and all the Line Dancers for your generosity.



MNDSA Thank You

Kooyonga Golf Club

The Kooyonga Golf Club hosted an 'Evergreen' Ladies Christmas Luncheon in December in honour of Colin Heath, who lost his battle with MND and who was an active member of the Club.

Determined to do something positive and help raise funds, Colin's wife Liz planned for this event to be a fundraiser for MNDSA with all donations made on the day to benefit current and future MNDSA clients. Over \$2,400 was raised! We are so grateful to each and every lady who made a contribution. Thank you, Liz and thank you, Kooyonga Golf Club.



B, L & G Umpires Association

In September this year, the Barossa, Light & Gawler Umpires Association held their Grand Final Dinner at the Vine Inn Barossa and chose MNDSA as the charity to fundraise for. This is the 2nd year in a row that MNDSA has benefitted from the generosity of the Association's members, who also donate a portion of their Umpire fees to MNDSA. Thank you BLGUA - we greatly appreciate your support of our MND community in SA. Congratulations to Secretary, Tim Asher (R) for receiving his Life Member Award on the night!

Body Fit Training (BFT)

Steve Jadon and his team from the BFT gyms worked together to rally their gym members for ongoing support throughout the whole month of September this year to help fundraise for good mate, Ray Coull (featured in our Personal Story). Members were offered a set of physical and fundraising challenges to create a fun way to raise money for MNDSA. Then in October, BFT held a fundraising event in Civic Park to draw their community together and show support for Ray and others living with Motor Neurone Disease. Over \$7,000 was raised! MNDSA is extremely grateful for these creative and dedicated efforts to support our community!



Partnerships & Sponsors

Gala Dinner Champions

TLM Insurance Solutions

Tracey Miller, Managing Director of TLM did not hesitate to come on board as one of MNDSA's Major Event Partners for the Gala Dinner this year. No stranger to MNDSA events, and our highly engaged community, Tracey decided to invest with us further, following a huge commitment in successfully completing the Larapinta Trek and associated fundraising milestones. We offer an enormous thank you to Tracey - so much more than MNDSA's Insurance Broker, she's a partner who is enthusiastic about supporting our MND community, and this is invaluable to us.



S&S Property Developments

Stephen Pisani of Pisani Property Group accepted the Corporate Supporter Award on behalf of he and Steven Vacca at our Gala Dinner recently, and deservedly so. Not only did they enable us to run our first ever 'donation matching' fundraising as part of the Larapinta Trek campaign, they also announced at the Gala that S&S Property Developments would be donating \$200,000 to MNDSA from the sale of one of their stylish new townhouses on Anzac Highway at Kurralta Park. This significant donation will enable MNDSA to develop stronger connections in Regional South Australia to ensure that all our clients continue to receive quality and consistent care, regardless of where they live in SA.



Link Assistive

Link Assistive participated at our Gala Dinner this year as dedicated Event Partners which included bringing a table of the Link Assistive team to engage at the event. We are grateful for their support, and we are proud to be associated with their team as their values closely align with our own at MNDSA. CEO, Bas Tijdhof and his team live their vision to contribute to independence and the ability to live an inclusive and connected life and deliver their mission to help people to communicate, connect, learn, and participate by providing high quality personalised, assistive and interactive technology solutions.



Partnerships & Sponsors

Gala Dinner Champions



Evolving Pathways

The innovative team at Evolving Pathways joined us at our Gala Dinner in November as generous Event Partners helping to raise funds at the event. We loved welcoming their team to this vibrant community event and look forward to engaging with them in the future. Evolving Pathways can provide extensive support to our MND community, including registered nurses, counselling and psychology, support workers, chefs, house keepers and cleaners - to name a few of the valuable supports they are able to offer.



VIVA Mutual

We were so thrilled to welcome the team from VIVA Mutual to our Gala Dinner this year. Their presence as a new Event Partner was welcomed by MNDSA staff, management, board, clients and the wider business community. It was such a great opportunity for VIVA to engage with MNDSA and visa versa and we look forward to many more event collaborations in future. The VIVA Mutual team provides high quality support services, they demand strong, engaged relationships between workforce, clients and community and deliver exceptional support for their community and ours.



Guardian Insurance Group

A big thank you to Evan Jackson, Managing Director of the Guardian Insurance Group for supporting MNDSA over the past 12 months with valuable (free-of-charge) exposure on their large LED promotional screen on Henley Beach Road, Mile End. When we put the call out to welcome Guardian to our Gala Dinner, they accepted with a unique offer to provide a table of 10 guests to be used by our MND client community with complimentary tickets to this special event. This generous gesture provided the opportunity for 5 of our clients to attend the dinner with their loved ones to create special memories and enjoy a night out - something that is so valuable to our community.

Upcoming Events in 2024



Walk to Defeat MND Sunday 19 May 2024

As MNDSA's largest community event, the Walk to Defeat MND brings our entire, resilient community together. Our clients who are living with MND (and their family/friends/carers) are at the heart of this event and we surround them with friendship, support and hope. The walk itself is a 4.5km track around the picturesque Torrens River with a festive gathering at Pinky Flat before and after the walk. Close to 800 people attend this annual event and collectively help to raise over \$100,000 for our community.

Hope & Remembrance Friday 26 July 2024

Our Day of Hope & Remembrance 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. We'll also hear about the latest research and have moments for reflection - for those who are battling MND and those we've lost - with candle lighting, readings, poems, and music followed by an afternoon tea in the tranquil gardens of Partridge House, Glenelg.



Annual Trekker Quiz Night Friday 23 August 2024

Now a permanent fixture on our event calendar, the Trekker Quiz Night is a night of camaraderie, hilarity and super-fun fundraising to help our Trek team bolster their fundraising efforts before they set off on the Bay of Fires Trek in Tasmania in October 2024. Our quiz nights are attended by almost 300 participants and they sell out fast due to the evening being highly entertaining and quite a riot with special quiz rounds including food tastings, arts and crafts (like newspaper couture pictured left), music, dancing and much more.

Upcoming Events in 2024



Bay of Fires Trek

10-15 October 2024

MNDSA is once again rounding up a brave team of dedicated trekkers to take on our annual fundraising trek. It's not for the faint hearted, but it can be achieved by people of all fitness levels - with some pre-departure training of course! It has been described as "the trip of a lifetime" and "the best thing I've ever done", by previous trekkers who have made lifelong memories and friends by undertaking our trek and raising vital funds to help maintain our client services, support and equipment. Head to our events page to find out more... and we'll see you in Tasmania!

Gala Dinner

Friday 1 November 2024

Our 2023 Gala was a huge success with over 230 guests enjoying the finest in South Australian produce and wines and the opportunity to party the night away. We raised over \$44,000 for our community from a range of fundraising initiatives and outstanding support from our wider community. Stay tuned for the 2024 Gala Dinner venue and keep your eyes on our events page. We can't wait to gather together as a community once again in 2024, dressed to impress and entertained all night long with an event that truly brings our whole community together.



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

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 Defeat MND - Join us on Sunday 19 May 2024

We are so pleased to announce the date for our annual flagship community event, the Walk to Defeat MND.

Every year we welcome a sea of blue t-shirts and Never Give Up beanies, with close to 800 members of our MND community who gather at the beautiful grounds of Pinky Flat to soak up the atmosphere before and after the 4.5km walk around Adelaide's Torrens River.

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

We are actively seeking partners and sponsors for the 2024 event to make it bigger and better than ever, with fantastic entertainment, food and activities for the whole family to enjoy.

Together we aim to raise over \$100K for our MND Community in SA. Community fundraising is always a massive team effort, and we can't thank our community enough for digging deep each year and forming our fundraising tribe!

We can't wait to bring everyone together to make 2024 a great success, especially our community of clients, families, friends, volunteers, staff, management, board, event suppliers, media, and SA Government!



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

Dates: 10 to 15 October 2024 - 4 day challenge

Fundraising Target \$3,500 per Trekker

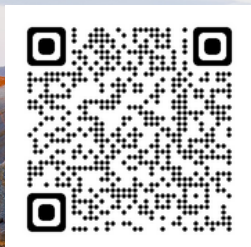
Accommodation: Twin share in a Farmstay

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/>



mnd 
South Australia

INSPIRED
ADVENTURES

2023 Gala Dinner Highlights



An opportunity to leave a lasting legacy.

Planning for life's end is not a pleasant exercise and can be an emotionally overwhelming experience. However, it is important that all of us have a valid will in place to ensure that our loved ones are not left with the burden of managing our estate or that it becomes the responsibility of government.

MNDSA has teamed up with Willed to provide a simple and affordable online solution to preparing your Will which you can access via 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.



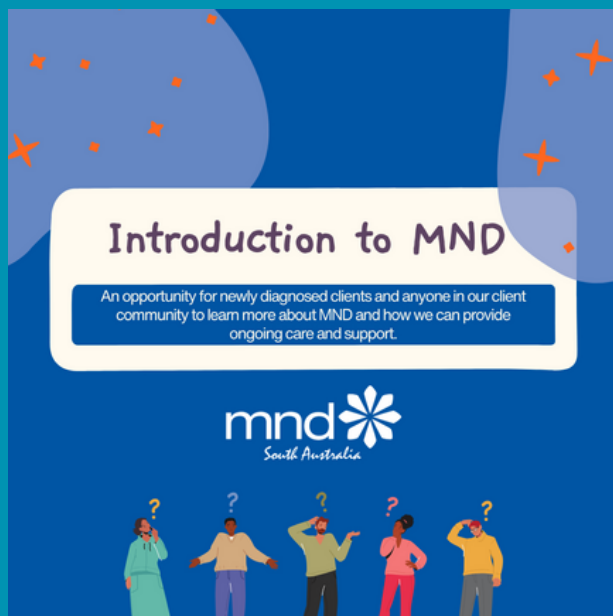
When on the Willed website, you will be asked to create a Willed account, answer some questions about your partner and children and appoint your executors. After you have taken care of your loved ones, you might also like to consider leaving a gift to MNDSA. Large or small, when you include a gift to 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.

The banner features a dark red background with white snowflake patterns. In the top right corner is the MND South Australia logo. In the center is an oval photograph of a woman wearing green and red glasses, a man in a maroon shirt, and Santa Claus. Below the photo, the text '2023 Christmas Appeal' is written in a large, gold, cursive font. At the bottom left, the text 'Help us support families living with MND this Christmas' is written in white. To the right of this text is a QR code. Further right is a white curved arrow pointing left, with the text 'DONATE HERE' in white capital letters below it.

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 member, 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. We've recently received a range of new equipment stock. 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



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