

MNDnews

The newsletter of the Motor Neurone Disease Association of South Australia

We support those affected by
Motor Neurone Disease

THE COUNTDOWN
IS ON FOR THE MOST
LOVED EVENT ON THE
MND SA CALENDAR



Until there's a cure, there's care

MESSAGE FROM THE CEO

2021 marks the 35th Anniversary of MND SA providing services to the community in South Australia impacted by MND.

Until recently, we have very much operated on the “pay it forward” model within our community to ensure we could continue to provide supports. In recent years, we have seen major changes in the disability and fundraising landscapes that have meant we have needed to adapt to help you all access supports in appropriate timescales, and for us to survive to do that.

We have come into 2021 with the opportunity to chart a new course, following a strategic review in 2020 necessitated through the challenging funding landscape and changes impacting our business. The relocation to new premises on a new site with warehousing for our equipment and training facilities, along with achieving some major grants, has seen us embark on a number of business improvement initiatives that are well underway and will be further announced as the year progresses.

We are a small organisation, yet we offer a very broad range of services and interventions in support of people living with MND. To deliver these services efficiently requires experienced and dedicated staff, and I am delighted to announce that our team has been strengthened by a number of new appointments detailed on pages 1 and 2. As the only organisation of our kind in South Australia which provides dedicated support for people living with MND, we are committed to attracting the very best talent to ensure that we are delivering the highest standards of service.

MND SA has invested heavily in staff, resources and processes over the last few years, to ensure that we meet all the requirements to become an NDIS Registered Provider. This is important because it provides clients and carers with a level of accountable and responsible service quality, assessment against controls, standards, and assurances, that non-registered providers cannot warrant and are not audited against. It has also provided us with a much-needed income stream at times when fundraising is more challenging.



We are the only provider in South Australia that is connected to the MND Clinic at Flinders Hospital and has the backing of our national MND network with all the resources on offer. By choosing MND SA for NDIS services, every dollar claimed enables the provision of services for our entire MND community (including those over 65 who do not benefit from NDIS funding).

MND SA strives to ensure that all of our clients benefit from the best services on offer through our valuable connections, resources, network of support, information services, social events, educational sessions and advocacy.

Our campaign to “Make Aged Care Fair” still continues, as does our lobbying to secure funding for our over 65s who are unable to access the NDIS because of their age.

We all await the outcomes of the Royal Commission, and MND SA will be working with our National network to ensure any recommendations which will benefit our MND community are progressed.

In the meantime, we will continue to fundraise, and hope that you can all join us at the National Walk to D’Feet MND being held on 2nd May 2021. Details on pages 7 and 8.

If our staff can be of any assistance, please don’t hesitate to give us a call or even drop in to see us. We look forward to improving the services we can provide in the years ahead.

**Karen Percival ,
CEO**

MND SOUTH AUSTRALIA SAYS **THANK YOU**

STAFF FOCUS

We are very fortunate to have a number of new staff members joining us at MND SA. Meet the new additions to our team!



MATTHEW MASSY-WESTROPP
Client Services Manager

Matthew brings a wealth of clinical and management experience as the former General Manager of the State Domiciliary Equipment Service (DES).

He spent his early career as an Occupational Therapist and attained a Master of Health Services Management degree from Flinders University before moving into management roles. Matthew is also a director of Home Modifications Australia, the national peak and industry body that represents and promotes the benefits of home modifications for older people and people with disability. Matthew has extensive knowledge of both the NDIS and My Aged Care systems and how to apply them to achieve the best outcomes for beneficiaries.

We are also very excited to bring Matthew on board as he has experience in working with key stakeholders in the Department of Health and State government to advocate for the needs of those with disabilities in this state. This will be of great benefit to our ongoing lobby to expand funding for people with MND who are over the age of 65.



PAM TURNER
Occupational Therapist

Pam joins us with a solid track record and extensive experience. She has worked in a variety of hospital settings as well as in community rehabilitation, including chronic conditions management, complex home modifications and hospital avoidance programs. In addition, she has worked in both residential and community settings in Aged Care, and most recently was a team leader assessor for My Aged Care.

As a founding member of the team to develop a Palliative Care Occupational Therapy role within the Northern Adelaide Palliative Care Service in 2012, Pam was co-author of a local poster presentation at the National MND conference that year. She aims to provide care with the support to promote client independence with dignity and choice.



MEGAN MITCHELL
**Allied Health Assistant
(Part-time)**

A number of you may have met Megan when she came to MND SA for work experience. We are delighted that she has now come on board as a team member with her friendly and can-do attitude, dealing with all things equipment.



DONNA SCRIVENS Occupational Therapist/ Support Coordinator

Donna has extensive experience from the UK from both NHS and the Social Services community, working with exposure to complex needs, palliative care and acute medical situations. These roles encompassed prescription of aids, home modifications and meeting complex care needs. Since moving to Australia, she has enjoyed working in aged care facilities, providing rehabilitation and functional assessments, as well as preparing care plans.

Donna has a very bubbly personality and is focused on person-centred intervention to provide quality client-focused outcomes. She is looking forward to working as part of the team and specialising in MND.



CRYSTAL GUO Occupational Therapist (Part-time)

Crystal has extensive experience in conducting home visits for NDIS participants, including equipment prescriptions and complex home modifications.

Adding to this experience in the Commonwealth Home Support Program and Home Care Packages, Crystal is excited to put her skills to use for the benefit of our entire MND community. She has previously supported clients with MND and is looking forward to meeting our clients as part of the team.



THANK YOU SA POWER NETWORKS EMPLOYEE FOUNDATION

Vicki Shearer, Belinda Bryan and their staff have championed the MND SA cause for some time, and we want to say a BIG THANK YOU.

The regular voluntary salary contributions that were made to the SAPN Employee Foundation from management and staff during 2020 totalled a mighty \$19,000. With these funds, we purchased a much-needed forklift for our warehouse, enabling us to lift equipment from the ground to the mezzanine floor for safe storage.

Thank you SA Power Networks Employee Foundation. We greatly appreciate your support!



Volunteer with MND SA

Volunteers are an essential part of a number of community-based organisations, just like us here at MND SA. Cliff and Andrew (pictured) are our wonderful Volunteer Coordinators who have been volunteering with us for just over a year. They are very excited to help us expand our volunteer program to offer more ways in which people can make a difference to the lives of those living with MND.

If you are interested in becoming a volunteer, please contact us at: volunteer@mndsa.org.au

PERSONAL STORY

For many, the MND journey can be a rollercoaster and, for Peter Chambers, his journey was no different. Pete had symptoms for around 18 months leading into his diagnosis in December 2019. And, as he explains, no stone was left unturned when investigating the cause of his symptoms.

"There were three or four things the neurologists were looking at and had to exclude. MND was always in the background, but it was never the likely diagnosis during that 18 month period," he says. "When it was finally diagnosed as MND, there were tears, but it didn't come as a complete and utter shock. I was kind of prepared for it, but when you hear those words, it's not what you want to hear".

Not wanting his diagnosis to define him, Pete has used it as the catalyst for his positive mindset and desire to help others.

"I wanted a legacy that is not negative. There's no way I want people to look at me and remember me as being someone who couldn't cope with this.

I looked at my kids and my wife, and I wanted the legacy of 'this is how you battle a disease such as this. This is how you face and cope with adversity'. I was driven by that really early on to say I know what the end result will be, but it's not going to get me. It's not going to define me."

MND Victoria have been with Pete every step of the way since his diagnosis, providing him and his family with care and support.

"We didn't know MND Victoria existed so, to find it really quickly, to make a phone call, and to receive a phone call back in a matter of hours, and then for Fran [his MND Advisor/Support Coordinator] to be on our doorstep 48 hours later, 3 days before Christmas back in 2019, was extraordinary. To know that you've gone from finding something that you didn't know existed to all this physical support really quickly is fantastic."

Pete has now started what he calls his 'MND Career'. He is using his voice to create a platform to advocate for others living with motor neurone disease.

"It means everything to me, that I can help others with my platform," he says. "You see all the positive responses come in and it's great to know people are thinking of you, but it also reinforces that what I'm doing is being seen by people, and people are seeing it as a really positive thing for the community in general."

"I want to make a commitment to give back for what I'm receiving. To be able to contribute in any way is not only an extension of what I'm doing, it's an extension of what's driving me to be an advocate for the work of MND Victoria and the recognition of the disease itself."

Part of his MND Career has included a recent appearance on Nick Bracks' podcast, "Move Your Mind", to discuss 'Dealing with Adversity'. Throughout the episode, Pete shares the life lessons that have come from learning to live with MND and focusing on the important things in life. "It was a tough gig at the time, but it's incredible how the mind works", he says. "I have my down times of course, but you've got support around you. MND Victoria look after me - I've got an Advisor, OT's, Physio and a support network of carers who do a wonderful job of taking the stress out of my life. It means I can get on with things and lead as normal a life as I can."

Pete has created his own campaign, Pete's Legacy, where you can follow along with his journey. Visit: www.mnd.org.au/campaign/2/petes-legacy

Like all other Australians living with MND, Pete receives services from his local MND Association. Please contact your local State Association for more details on the services they provide.



LIVING BETTER

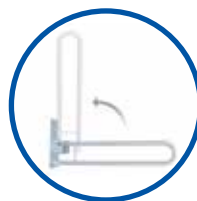
Toilet Talk

One of the key areas that people express concerns about is their ability to use the toilet safely and independently. Using the toilet is typically a very private and personal affair; so when someone experiences problems with toileting, it can be stressful and impacts on confidence and dignity.

In this article, I would like to highlight some of the most frequently requested assistive technologies and other strategies that can be used to overcome practical difficulties and enhance safety and independence.

Issues with mobility and fatigue can interfere with a person's ability to:

- * get to and from the toilet
- * sit down and stand up from the toilet
- * maintain a stable sitting position
- * manage lower-body clothing
- * manage personal hygiene tasks



Grab rails: If you find yourself grabbing at furniture or fixtures to assist with getting on and off the toilet, then this is an indication you may need grab rails. Rails come in a range of shapes, materials and sizes and are used to provide assistance with lowering and standing. Drop down rails can be stored upright when not in use. Rails should be installed by a qualified tradesperson. An occupational therapist can advise on the type and positioning of rails to optimise their effectiveness.



Toilet surround: This is a height-adjustable frame that fits around most standard toilets. It provides armrests to grasp for assistance with lowering and standing. This can be a handy alternative to installing permanent rails.



Over toilet frame (OTF): Like the toilet surround, this provides armrests to assist with transferring. An OTF also has an in-built toilet seat which sits higher than a standard toilet seat.



Toilet seat raiser: As the name suggests, this raises the height for sitting. Some models have cutouts at the front and rear of the seat to enable easier access for cleaning. If raising the height of the toilet seat, ensure your feet are still able to reach the floor as this provides greater stability than if your feet are floating.





Toilet seat raiser with arms: This piece of equipment combines the use of a raised toilet seat with armrests to assist with transfers. The armrests can swing up out of the way if you need to transfer onto the toilet from the side. What I like about this item is that it keeps the floor clear of clutter.



Commode: Commodes can offer a higher level of support and come with a wide range of features to suit different needs. For wheelchair users, if there is not sufficient space to transfer between wheelchair and toilet, it can be more effective to transfer onto a commode and then wheel into position over the toilet. Commodes can also be used to sit on during showering. Dual-purpose items such as a commode can help reduce the amount of equipment required within the bathroom.



Urinal bottle: Urinal bottles are a portable option and come in styles for men and women. Some prefer to use urinal bottles overnight to avoid the disturbance of getting out of bed and to the toilet. These can be convenient for their reduced energy expenditure requirement.



Bidet: Bidets are becoming increasingly popular for automated cleaning and drying. They direct a gentle stream of water to assist with cleaning and can be operated with a control. These are particularly helpful for people with limited use of their arms and hands. Electric bidets require a power source and different models have particular installation requirements that should be considered before purchasing.

Other ideas:

- * **Flushing controls:** For someone with hand weakness, a lever may be easier to use than a button, or alternative controls can be integrated.
- * **Adapted clothing:** If managing your clothing is difficult, consider wearing clothing that is easy to remove and adjust (e.g. loose-fitting fabric, elasticated waistband, magnetic closures).
- * **Door:** If the toilet is located in a small space, consider changing the swing of the door so that it opens outwards, or switch to a sliding door if possible. This increases the circulation space available in the room and enables a helper to access the room if you were to have a fall behind the door.
- * **Remove trip hazards:** Ensure you have a clear path to get to the toilet. Avoid having a pedestal toilet mat as these can present a trip hazard.
- * **Lighting:** Ensure you have adequate lighting to guide you to the toilet. A night light or sensor light can be handy if you tend to get up in the middle of the night to use the toilet.
- * **Carers:** If you require a carer to assist with toileting tasks, it is important that you are afforded as much choice and control as possible. Carer assessment and education can be helpful to guide caregivers on dignified ways to support you to participate with as much independence as possible.

When assessing toileting skills, the main goal is always to respect a person's right to **dignity** and to optimise **privacy, safety and independence**. There are many factors to consider when selecting equipment, so it is recommended that you get in touch with a physiotherapist or occupational therapist who can provide assessment and advice on strategies and technologies to suit your individual needs.

Sophie Nunn,
Occupational Therapist,
MND WA

MND RESEARCH

CHCB Neck Weakness Research

Neck weakness is a symptom of MND that can have a big impact on the quality of life of the person living with MND. However, there is a lack of good quality research about the characteristics of neck weakness in MND or the best evidence-based strategies to help support the head and neck.

The Physiotherapy Department at Calvary Health Care Bethlehem (CHCB) in Victoria want to change this and have teamed up with MND Victoria to commit to further research into this subject.

What has been done so far?

At the 2019 Allied Professionals Forum in Perth, the Physiotherapy team presented about their experiences in helping people to manage neck weakness and head drop.

To help guide their research, they then conducted a survey with 33 of their patients who have developed neck weakness. They found that neck weakness occurs across all types of MND and typically results in the head dropping forwards, or a combination of forwards and to the side. The most common strategies these patients used were:

- * Postural support from their recliner chair or wheelchair
- * A neck collar (79% of the patients used some form of collar) – a soft collar or Aspen Vista collar were the most commonly used
- * For 43% of the patients who use a neck collar, the team had made custom modifications to their collars to improve comfort and tolerance.

Other strategies currently used were:

- * Pillows, cushions and rolled up towels
- * Specialist headrests for wheelchairs
- * Various forehead supports or straps

So.....what's next?

The team are now collaborating with MND Victoria in a new research study to look at:

- * How common it is to develop neck weakness in MND
- * At what time period neck weakness symptoms usually develop
- * How head support strategies may change over time
- * The relationship between neck weakness and respiratory function
- * The relationship between neck weakness and walking

All this research aims to develop evidence-based guidelines/framework to help people with neck weakness improve their quality of life, and their therapists to improve the quality of care.

The authors for the research (questionnaire) are:

Timothy Sheehy – CHCB, Karol Connors – CHCB and Dr Christine Wools – CHCB.

For the second project, the following people are involved:

Timothy Sheehy – CHCB, Trinh Nguyen – CHCB, Rosanne Gibb – CHCB, Stephanie Zhao – CHCB, Sally Mathieson – CHCB, Anna Smith – CHCB, Dr Christine Wools – CHCB and Prof Prue Morgan - Head of Physiotherapy School of Primary and Allied Health Care, Monash University.



UPCOMING EVENTS

Adelaide Walk to D'Feet MND

The Walk to D'Feet MND symbolises the hope that one day we will defeat this dreadful disease, whilst it serves as a memorial to those whom we have lost.

Register now and join us on Sunday 2nd May as we walk 4.5km around the beautiful Torrens River Precinct, celebrating our community's strength, courage and unity.

When: Sunday 2nd May 2021 | 9:00 am - 2:00 pm (The Walk starts at 11:00 am)

Where: Pinky Flat (Opposite Adelaide Oval), War Memorial Drive, North Adelaide SA 5007

There is plenty of car parking available and public transport is also a great option.

TICKETS

Each ticket includes a free t-shirt delivered straight to your door.

Individual - Adult: \$40

Individual - Child: \$20

Family of 3: \$90

Family of 4: \$100

Register online at:

<https://my.mndsa.org.au/events/1/walkto-dfeet>

What's in store for 2021? We have some significant and exciting changes to share with you...

- * For the first time, all the MND State Associations in Australia will be Walking to D'Feet MND on the same day, which also aligns with the start of National MND Week.
- * We have a new, user-friendly and much-improved fundraising platform to use for registrations and fundraising pages.
- * Registration costs are significantly lower this year than in the past and your t-shirts and merchandise orders will be posted out at no extra charge.
- * The highest fundraising team/family/individual will be given the honour of pole position as the Walk commences, being led by the Caledonian Pipe and Drum Band.





Special Guests and Entertainment

We have the well-known and much-loved sports and media identity, **Chris Dittmar**, donating his time as our Master of Ceremonies. Chris has assured us that he is truly 'hands-on' and will be mingling and getting to know our community before and after his MC duties.



The Blackwood Ukulele Group (BUG) are back for their third year, rocking the morning with their electric and acoustic ukulele's. (9:00 am - 10:30 am)



Jamie Newton mesmerised us last year with his beautiful rendition of the MND SA Anthem 'Don't Dream It's Over'. We are thrilled to say that he had no hesitation in accepting our invitation to join us again. (10:55 am)



The Moon Dance (5 piece) Band will be playing all the songs that we know and love from the '70s until now, while you relax and enjoy the beautiful ambience of Pinky Flat after the Walk. (11:30 am until 2:00 pm)

Our friends at the YMCA will be there to entertain the kids with games and activities.

Food and beverage vans will be open from 9:00 am onwards. There are a number of delicious options available, including egg and bacon rolls, sausage sizzle and soft drinks, barista coffee, and our signature blue and white iced cocktail donuts.

Over the years, hundreds of thousands of dollars have been raised and used to provide vital support services to South Australians and their loved ones whose lives have been affected by MND. Our goal for this year's Walk to D'Feet MND is to raise \$125,000, so let's all get behind it with heart and soul by registering and sharing your fundraising page with all of your social networks.

We hope to see you all there!

TelethonSA

We are happy to announce that MND SA has been selected as one of the participating charities in the TelethonSA Home Lottery this year.

TelethonSA is regarded as an iconic South Australian brand, proudly supporting South Australian charities. It is a humble and affordable way that South Australians can support not-for-profit South Australian charities like MND SA, and help

us raise much-needed funds. From only \$10 a ticket, you could win some amazing prizes, including a brand-new Melisi Projects Home at The Square at Woodville West.

The proceeds from each ticket purchased through us will go directly to providing care and support to South Australians currently living with MND.

Get yours today: www.telethon.com.au/charity/motor-neurone-disease-sa

MAKE YOUR HEART SING

TICKETS STILL ONLY \$10

NOW ON!

Telethon HOME LOTTERY
Celebrating 60 years of Telethon in SA

Tickets available now from participating charities and telethon.com.au

TelethonSA Melisi Projects Home Lottery at The Square at Woodville West is your chance to win great prizes while supporting 23 amazing charities who each has their heart in SA.

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MELISI PROJECTS the sq at woodville west RenewalSA Government of South Australia

NEWSPOT Taste Furniture

TelethonSA

GIVING



\$35 for 35 Years: Become A Regular Giver

For 35 years, MND SA has provided the best possible care and support for South Australians living with MND. The level of support, the quality of information and the access to vital assistive equipment has increased greatly since 1986 and is allowing those who are diagnosed with MND to live as well as possible for as long as possible.

The only way the above is possible is because of our generous fundraisers and donors who contribute funds that the Association requires to deliver all of its vital services.

MND SA is looking to establish a community of donors who wish to support the Association on a regular basis. Our \$35 for 35 years of service campaign is an opportunity for you to commit to donating \$35 per month to recognise the critical role MND SA plays in the lives of 150 people currently living with this disease. **To become a regular giver, visit:** <https://my.mndsa.org.au/campaign/1/35-for-35>



Bequests

Leaving MND SA a gift in your Will (a bequest) is a tremendous and thoughtful way of supporting our work.

By remembering MND SA with a bequest, you are making a unique commitment. Your legacy to MND SA will help us to continue to provide the best possible care and support for those living with MND.

MND SA cares, and with your help we always will.

Please contact Karen Percival, CEO if you would like more information on how to leave a bequest to MND SA.



MND SA 2021

YOU, ME & MND

Education | Information | Friendship | Support

Join us for these informative and social sessions that are designed for MND clients, their carers, family and friends. Each session is held at our new premises in Mile End from 11:00 am - 1:00 pm. Following the educational aspect of each session, light refreshments will be served and there will be the opportunity to mix and mingle with other guests and MND SA staff.

Please visit <https://my.mndsa.org.au/events> to register



2021

- Thu 15 April**
Voice and Message Banking
Sandra Stewart
- Thu 13 May**
Rehabilitation and Palliative Care
Dietician
Liz Kapur, Flinders Medical Centre
- Thu 10 June**
Exercise Physiologist
(To be advised)
- Thu 8 July**
Remedial Massage
Judy Valero
- Thu 12 August**
Occupational Therapist Focused
MND Small Aids
Pam Turner
- Thu 9 September**
Aged Care Alternatives
Mark Trebilcock
- Thu 14 October**
Eye Gaze Demonstration
Sandra Stewart
- Thu 11 November**
Leisure, Holidays and Travel with
MND
MND Staff
- Fri 10 December**
MND Client Christmas Lunch
Festival Function Centre, Findon