

MNDnews

The newsletter of the Motor Neurone Disease Association of Tasmania



**Thank you to all of our
amazing volunteers
and donors!**

MESSAGE FROM THE PRESIDENT

We have many reasons to be thankful for all of our amazing members and volunteers in these past few months. We had a big 2021, and we are looking forward to putting into action everything that we have in store for 2022.

Our next Annual General Meeting will take place on Sunday 27 March 2022 at 10.30 am. We are trying something new this year due to the continuing COVID-19 restrictions, people's hesitance to travel long distances, and wanting to keep our members safe. We will hold our AGM online via MS Teams; invitations will be sent to our members with all of the information on time, date and how to connect. We hope to see some faces there so that we can have a cup of tea and talk about how MND Tas can continue to support you, and/or how you can get involved.

We have now completed the redevelopment of our website and it is live with a fresh look and feel, and it is much easier for you to find the information you need. It is your 'all-in-one' destination to access information, support from the Advisors, latest news, donations and fundraising appeals, as well as specific information for Health Professionals.



Please let us know if you have any suggestions about how we can make this better and provide the resources you need. No suggestion is too big or too small, we would love to hear from you.

Please write and share your stories, opinions, questions, or any thoughts about this newsletter. Write to me at info@mndatas.asn.au and see our contact details on the back page.

Kate Todd
President

MND TASMANIA SAYS **THANK YOU**

Thank you, William Fraser!

MND Tasmania would like to thank and acknowledge William Fraser for his amazing fundraising efforts!

Once again, William was able to display his beautiful Christmas lights while fundraising hundreds of dollars for MND Tas. The Ulverstone Municipal Band played Christmas Carols with the beautiful Christmas lights in the background, and over 400 gifts and books were given away to children 6 years and under. It was a lovely experience for his family and neighbours! Fundraising for MND is a cause close to William's heart and we thank him for all of his support; not only for MND Tas but for our broader community too.



Thank you, Rosie and Indie!

Rosie and Indie, daughters of one of our long-time supporters, decided that they would have a fundraiser stall in Orford over the holidays and they raised over \$6k in donations to MND Tas! They sold crafts like painted shells, pinecone pin cushions, and other beautiful items.

We are all amazed by Rosie and Indie's efforts and the support that we received from their family and from Orford's generous community, and we thank you all very much!



MND TASMANIA SAYS THANK YOU

Meet an MND Researcher

Everyone at MND Tasmania is passionate about MND research. One of the most difficult things about MND is that there is no known cause, treatment, or cure, so research into these areas is essential. Sharn Perry is a Neuroscientist and Lecturer at the Wicking Dementia Research & Education Centre. Here is a short interview we conducted with her about her research.

When did you start working on MND and why?

I have always been fascinated in understanding how our nervous system communicates for us to produce movement. My PhD focused on understanding how different nerve cells in the spinal cord communicate with each other to generate locomotion - walking, swimming, and running. During this research I became interested in a particular spinal cord population, known as Renshaw cells, which are thought to be involved in amyotrophic lateral sclerosis (ALS). At the end of my PhD, I started working at the Wicking Dementia Research and Education Centre where I could apply my knowledge of spinal cord cell populations to MND research.

What is the current focus of your research?

My current research focuses on investigating how spinal cord motor circuits change throughout ALS disease progression. We use experimental models of ALS to try and understand what changes occur to spinal cord nerve cell populations during ALS, and how these spinal cord changes affect motor neurons and motor behaviour.

What are some of the recent findings from this work?

In a research project in collaboration with my colleague Professor Anna King, we have found that there are changes to the messages motor neurons receive from surrounding spinal cord nerve cell populations as ALS progresses, and that some proteins might be involved in protecting these messages.

What is the most interesting aspect of this work?

I think the most interesting aspect of this work is that we never stop learning – every new piece of information we uncover about MND leads to more questions to answer and more problems to solve. We are constantly finding out new information about spinal cord nerve cells and how MND affects these different populations, which means we are continually expanding our understanding of this disease.



What other research-based activities are you involved with?

I have a collaboration with my colleague Associate Professor Anthony Cook, where we are using human stem cells to make nerve cells to try and understand how nerve cells recover from too much activity, a process that damages nerve cells in ALS. I am also working with a collaborator at the University of Leeds UK, Professor David Hogg, to see if we can use automated computer vision technology to detect early signs of motor dysfunction in experimental models of ALS.

What do you enjoy doing in your spare time?

In my spare time I like to bake and keep active by walking my dog and spending time at the gym!

Thank you for your support!

We are thankful for the Social Club at Dept. of Treasury and Finance for organising a fundraising 'November Dress Down Day' and donating the proceedings to MND Tasmania.

We are also grateful for the support we received from The Paddy Wagon Hotel, Hydro Tasmania, Don Market and Moto Vechio.

We have gratefully received continued support from Margaret Eldridge, Shane Ling, Doug Bester and Kevin Burgess, and donations in memory of David Greenwood.

MND RESEARCH

**MiNDAUS
PARTNERSHIP**

MiNDAUS Partnerships

New MND Registry

Many of you have taken part in the Australian Motor Neurone Disease Registry (A MND R) and this is a precious resource that may be useful for future generations.

A MND R has now been replaced and updated as part of a National Health and Medical Research Council funded project called the MiNDAUS (pronounced MindOZ) Partnership. This partnership consists of a broad Australia wide membership between Clinicians, Clinics, Researchers, and support organisations such as MNDA, MNDAV, other state organisations, and FightMND.

This project has created the MiNDAUS Patient and Clinical Registry which not only replaces A MND R but offers something completely new as well.

MiNDAUS Patient & Clinical Registry

We hope that this new Registry will be of direct and immediate benefit for people living with MND and their Carers, as well as important for Neurologists, Researchers, and Health Professionals, to increase the understanding of MND.

The new MiNDAUS Patient Registry allows you to control and update your own information, keep track of your care team, and share your information with the MND Clinic, MNDAV

Advisor, care provider or a new doctor.

The new MiNDAUS Clinical Registry will hold information collected during clinic visits about your journey with MND so that, in the future, we can try to find out more about:

- * What causes MND?
- * What are the different types?
- * How can we best treat the symptoms?
- * How we can discover effective treatments?
- * Can we find a cure?

A MND R data

The records held in A MND R are retained and will be analysed in the future alongside the newly collected information. Assoc Prof Paul Talman, chair of A MND R, would like to gratefully acknowledge all of the people with MND who took part, and also acknowledge the tireless work of the doctors and nurses at the clinics who contributed data.

To find out more, visit www.mindaus.org (or scan the QR code on the right), contact your MND Advisor, or contact Catherine Hansen, MiNDAUS Operations Manager at e: catherine.hansen@deakin.edu.au or ph: 0467 523 911.



Research at Calvary Healthcare Bethlehem - invitation to get involved

Dr Susan Mathers, Director of Neurology at Calvary Health Care Bethlehem, is undertaking a research project titled "Identifying and Responding to the Health Literacy Needs of People Living with MND/ALS (Finding Clear and Useful Health Information about MND/ALS)". The project aims to find out how easy or difficult it is for people with MND to find, understand, and make use of information about managing their life with the disease. Specifically, what help do these people, together with their families or carers, need to make the decisions which are best for them?

In this project, Dr Mathers hopes to recruit up to 350 people (including those living with MND and their families or carers) to complete some short online questionnaires.

To complete this survey, please visit hsu.imb.uq.edu.au/mnd-health-literacy or scan the QR code on the right.

For more information, contact either: the CHCB Study Research Nurse at ruth.krasniqui@calvarycare.org.au or ph: 03 9595 3294; or MND Victoria Education Team at e: info@mnd.org.au or ph: 03 9830 2122



LIVING BETTER

Carers' Tips and Tricks

We all care for others, don't we? But when do we become carers? Possibly when we're doing things for our loved ones that other people don't have to do, even when we're doing it willingly and out of love. And that's when it's good to recognise the change in role and seek some support for this new role.

Top 10 Tips

- 1. Be kind to yourself** – take that opportunity to catch up with a friend for coffee, do that art class, go to the gym. Whatever it is that fills your cup, do it; and if you find you can't, reach out for some support.
 - * Check out the funding for Carer Respite - fancy words for taking a break.
 - * Come to a Carers Wellness Relaxation Day.
- 2. Look after yourself** – make sure you keep on top of your own health needs with regular check-ups.
 - * Book an appointment with your GP if you haven't seen them in a while.
- 3. Learn to say "No"** – it's okay to say no, but we need to practice. Say no to the extra things, the things that deplete you. Can someone else do the thing you're saying "no" to?
 - * Talk to your MND Advisor/Support Coordinator about the tasks you can't do in caring for your loved one.
- 4. Learn to say "Yes"** – accept help. I am sure that, in the past, you have helped and supported others, now it's your turn to accept the help and support in return.
 - * Talk to your MND Advisor/Support Coordinator about the help available.
- 5. Find your people** – where do you get support? We all need someone to listen to us when we need to vent, someone to advise us, someone to pick us up and get us back on track. Look for the people to do these things for you. Sometimes a counsellor or psychologist can be just who you need.
 - * Come to a Kitchen Table Conversation online or by phone.
 - * Join the MND Carers Facebook group, with other carers from around Australia – search for 'MND Carers Australia' on Facebook or visit www.facebook.com/groups/1408400102747388
 - * The Carer Gateway has loads of resources including counselling - call 1800 422 737

Carer Wellness Relaxation Days

Planning has commenced for arranging three separate days to provide carers with a well-earned break and a bit of relaxation.

- Wednesday 6th April in Mornington, Victoria
- Sunday 10th April (online), or
- Saturday 7th May in Ballarat, Victoria

Come together to explore the art of caring for yourself as well as being a carer, the art of relaxing and a bit of art itself.

Visit www.mnd.org.au/events or scan the QR code below, to register and select the date on which you'd like to attend.



Kitchen Table Conversations

Join in these monthly online conversations which will be guided by whoever joins in. Ask a question, share something you have discovered, learn from each other and support each other.

- 1st Friday of each month at 2:00 pm
- 4th Tuesday of the month at 7:00 pm

Come once or come every month. This is a safe space to share or listen, and to have a laugh or a cry - just like we would if we were sitting around a kitchen table.

Hosted by Andrea Salmon, Carer Project Coordinator at MND Victoria & Lynette, past carer

6. **Take a walk outside each day** – notice 5 things you can see, 4 things you can feel, 3 things you can hear, 2 things you can smell, and 1 flavour you can taste.
 - * Download Smiling Mind, an app full of short meditations and support tools to help manage stress.
7. **Allow yourself to lament (have a good cry)** – you are allowed to feel sad, but if the sadness is overwhelming and ongoing, that's not good for you. Some people write journals, some light a candle, some people seek counselling.
 - * Grief counselling is for everyone - ask your GP or MND Victoria for more information.
8. **Be prepared** – find out about the things that are concerning you, ask questions, get answers, know more about what to expect so that you feel better prepared.
 - * Contact us at e: info@mnd.org.au or phone: 1800 777 175 and ask your questions.
9. **Take Control** – in a practical sense. You may need to find out more about financial or legal matters, wills, or powers of attorney. There's no such thing as a silly question - if you've thought it, you should ask it.
 - * Visit www.chronicillness.org.au/workwelfarewills/ and use the drop-down menu to find what you're looking for.
10. **Take a deep breath** – breath in for the count of 3, hold for the count of 4, and breath out for the count of 5. Practise deep breathing a few times each day - while you're waiting for the kettle to boil, the phone to be answered, or the shower water to heat up.



Wisdom from other Carers

"Treasure every moment and be open to all the support that MND Victoria has to offer."

"Everything won't happen tomorrow. Your relationship with the illness is different to your partner's. Be conscious of your own needs."

"Take care of yourself, and don't be afraid to ask for help."

"It's okay to be sad, scared or angry."

"Make time for yourself and don't feel guilty about it. Don't beat yourself up if you aren't perfect at being a carer all the time."

"Nothing that you do is right or wrong, just find what works for you."

Andrea Salmon

Carer Project Coordinator, MND Victoria

PERSONAL STORY

One Day at a Time Colin Wilkinson

Colin Wilkinson is a real family man. He has a fierce love for his wife - Sharon, his children - Glenn and Fiona, and his grandsons - Austin (8) and Isaac (6).

"Sharon and I have been married for nearly 39 years. We met at a party when we were about 18 or 19. We met, got together, went out for about 3 years, and got married because I wanted to have children. Shaz got pregnant straight away. And when we decided we wanted another child, she got pregnant straight away again. And that was it. It just worked well and everything fell into place for us. We were blessed there."

Colin loves to spend as much time as he can with his children and grandchildren. They live close by, and he and Sharon often mind the grandkids a couple of times a week. "We just want to do it as much as we can. I can't go and play sport and wrestle with the kids anymore, so now our thing is PlayStation and Nintendo. We mainly play car racing games which I like because I can beat them at those. I can't beat them in the other ones. They've got all their favourites as well but they just blitz me all the time. But that's part of the fun. They teach me, and I teach them as well."

Before his retirement, Colin was an auto-electrician and ran his own business. "I started my own business when I was about 20, and I ran that for about 20 years, sold that and then became a trade teacher, quit that and started a caravan electrical business for another 20 years. I got to the end of that and that was when we decided to retire, sell the business, and go caravanning. But that's when I got crook. So we sold everything off and took a whole different avenue and went in a different direction."

Colin first noticed something wasn't right in December 2019. He usually had a great sense of balance, but suddenly found he was tripping over out of the blue. "I'm like a mountain goat, I never fell over anywhere. I was the

stable one. Shaz was always tripping over things and we'd just laugh about it.

But we'd be walking along, holding hands, and I'd be back on the nature strip, laughing 'What happened?' We laughed about it half a dozen times before thinking that something was going on here. And then we might have a couple of drinks on a Friday night, and after two or three cans I could hardly talk. My speech was totally slurred. Shaz was going 'What's wrong with you? You can't handle your beer anymore.' It was just weird. So we started doing some checks and finally found out what was going on. It took something like six months to diagnose and then they say this is what you've got. You've got MND. Having survived a Non-Hodgkin's Lymphoma in 2009, I really thought I'd had my share of bad luck. But apparently not."

"2020 was a big year. It all happened very quickly. But it was a case of 'had to'. We had to change. COVID meant we couldn't go caravanning and then, with my diagnosis, we had to change everything. We were living in a house with three levels, so we sold the house, sold the business, sold the car, sold everything, and then moved into a retirement community in January 2021."

"It took a while for us to get used to it. Now it's the best thing we did - we don't have to do anything. It makes life easier - there's nothing to worry about for Shaz. She doesn't have to do any work at all. We can spend our time together. That was the whole plan - to spend as much time together. We've always been joined at the hip, but now, we're even more joined at the hip. I'd be lost without her, completely lost. She does everything."

"We've got a lot of support from OTs, physios, our MND Advisor and everyone else. They help you get through each day, especially with all the equipment that's needed. But the biggest thing is family and friends. I've got great family and friends. Without the love and support of our family, we would not be able to make it through this struggle. Fiona and Glenn, their partners Jacinta and Richard, my sister Deb and her husband Rod have been completely supportive and caring all the way through this journey, despite their own despair at what I am going through. We have always been a close family but now we are even closer as each day passes and we focus on all of the important things that matter to us. Our family is our strength. They are our heart and soul. Our wonderful friends ring all the time and drop in when they can. You know you had a great network before, but this just reinforces it. Everyone is there for you."

"My diagnosis has taught me not to take life for granted. I always thought I was bulletproof, but you don't know what's around the corner. Tomorrow, that's the next thing on the list. Getting up and doing it all again for as long as I can. We've got each day to look forward to."



UPCOMING EVENTS

MND Tasmania's Annual General Meeting (AGM)

The MND Tasmania Board has great pleasure in inviting our members to attend our upcoming AGM on Sunday 27 March 2022 at 10:30 am.

The MND Tasmania AGM is always a great opportunity to meet our Board Members, know more about our work, meet other members in attendance, and hear from a specialist researcher in the field of MND.

At the meeting, we will report to members on the Association's performance during the year to December 2021 and our outlook for the coming year.

Due to the continuing COVID-19 restrictions, and to keep our members safe, this year's AGM will be held online via MS Teams. This will allow members from across the State to attend and participate in a safe way.

If you wish to attend, please contact us via email to info@mndatas.asn.au and we will be happy to provide you with the link to attend, and further information.

We look forward to seeing you at the meeting!

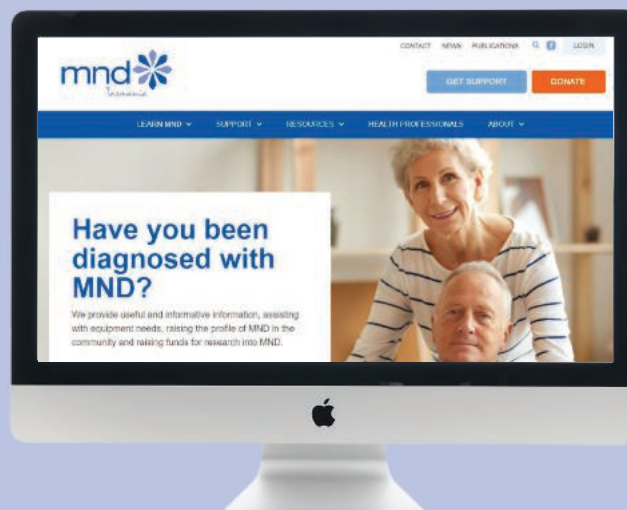


MND Tas Website

We hope that you have visited our new website and that you are loving it as much as we are! It not only has a fresher look and feel but it also makes your experience while using it much easier. It is an information hub for members as well as a supporter hub with specific information and resources for Health Professionals.

You can find us at www.mndatas.asn.au

Please let us know your feedback and suggestions by sending us an email at info@mndatas.asn.au



UPCOMING EVENTS



MND Support Groups

The MND Support Groups in Tasmania are independently run by community members for community members. We appreciate their willingness to devote their time in volunteering for such a worthy cause.

North West MND Support Group

The NWSG in Ulverstone invites all MND Tasmania members and supporters to its meetings.

WHEN: At 11 am on the first Wednesday in the month, except January

WHERE: Ulverstone Returned Servicemen's Club Back Room, 21 King Edward Street, Ulverstone

CONTACT: Junene Stephens is the secretary and can be contacted on 0428 252 763 or email: jstephens@berendsen.net.au

Northern MND Support Group

This is an informal coffee and catch-up style group, where members come together to talk all things MND and Kennedy's Disease, as well as share experiences and helpful tips.

WHEN: Every second Tuesday at 10 am

WHERE: Selah Café at the Door of Hope, 50 Glen Dhu Street, South Launceston

CONTACT: Deb Beyer is the coordinator and can be contacted on 0418 462 369.



Drink Tea for MND

Calling upon our TEA-riffic community! "Drink Tea for MND" is a fun (and delicious!) way to raise awareness and funds to support MND Tasmania.

Your DT4MND event can be held ANYTIME, ANYWHERE that suits you! You can host your tea your way, on the date of your choice. It could be a morning tea at work, a virtual afternoon tea, a luncheon - the ideas are endless!

Please register online at www.drinkteaformnd.org or scan the QR code on the right.



Raise awareness and funds for Motor Neurone Disease while catching up with friends...

GIVING

How you can make a difference

There are many ways to make a positive difference for those living with MND. Some are bigger than others, but there are a lot of little things that you can do which have a larger impact.



Have a conversation

Chatting about MND with a friend, acquaintance or even your local barista will help to raise awareness of this horrid disease and the work of MND Tasmania.



Run your own fundraiser

There are so many different ways you can fundraise, both virtually and in person. From hosting a movie night or free dress day at school/work to shaving your head or running a marathon, no idea is too small or too crazy. Reach out to us if you're interested in creating your own event – we will be there to help you every step of the way. Email info@mndatas.asn.au or visit www.mndatas.asn.au for more information.



Donate

The funds required to deliver our vital service come from the generosity of our fundraisers and donors, so every dollar really does make a difference! Plus, any donation over \$2.00 is tax-deductible. Visit www.mndatas.asn.au/donations to learn more or scan the QR code below.



Volunteer your time

We couldn't do what we do without the help of our incredible volunteers. Whether they're helping out at community events or volunteering their time as Board members, their work and dedication truly makes a difference. Please contact info@mndatas.asn.au for more information on how you can help.



MND ADVISORS AND NDIS SUPPORT COORDINATORS

Client Numbers

We are currently supporting 45 registered members:

North West Region Tasmania	8
North Region Tasmania	18
Southern Tasmania	19
TOTAL	45



CURRENTLY
SUPPORTING
45
REGISTERED
MEMBERS



DELIVERED
505
HOURS OF
SERVICE
in the last quarter

MND Advisors and NDIS Support Co-ordinators

Northern Tasmania: Emma Forsyth (Mon-Thur):

p: 0456 182 551 or e: eforsyth@mnd.org.au

Southern Tasmania: Jenny Fuller (Tue, Wed, Fri):

p: 0412 599 365 or e: jfuller@mnd.org.au

Team leader: Eric Kelly (Mon-Fri.):

p: 0421 323 850 or e: ekelly@mnd.org.au

FREECALL 1800 777 175

This number is answered at the MND Victoria office (Monday - Friday, 9 am - 5 pm). To assist the volunteer receptionist, please say that you are calling MND Tasmania. If you wish to speak to a Board member or an MND Advisor, you will be asked for your contact details, and your call will be returned by that person as soon as possible.

Above: Emma Forsyth
Left: Jenny Fuller



MND Tasmanian Board Members:

MND Tasmania has a volunteer Board and no paid staff.

President: Kate Todd

Senior Vice President and Fundraising: Michelle Macpherson

Vice President & Public Officer: Chris Symonds

Secretary: Lucy Polizzi

Treasurer: Julie Driessen

Member Support: Elisa Howlett

Ordinary Directors: Tracey Dickson, Steve Issac

Ex-officio Support: Libby Cohen



We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands in which we live, work, and learn. We recognise and respect the enduring relationship they have with their lands and waters, and we pay our respects to Elders past, present, and emerging.

MND TASMANIA

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