Summer 2022/23

MNDnews

The newsletter of the Motor Neurone Disease Association of Tasmania

A Walk to D'Feet to Remember!

mnd
Tasmania

Until there's a cure, there's care

MESSAGE FROM THE PRESIDENT

We had another fantastic day at our annual "Walk to D'Feet MND" on 16 October 2022, and we are so grateful for the wonderful support we continue to receive from individuals, teams, and local businesses. It was a fun packed morning, and we've raised over $30,000 of funds that will stay in Tasmania to support Tasmanians! Thank you all so much!

In November, we had a strategy session to renew our strategic plan for coming years to ensure that we can provide the right services for our community. If you have any views you'd like to share, I would love to hear from you.

We have now started to plan our next Annual General Meeting which will take place in March 2023. We will be sure to send out the details with all the information on time, date, and location to our members. The Board of MND Tasmania always looks forward to the meeting, and to the opportunity to discuss how we can continue to support you as well as we can.

Coming into the holiday period, things can get busy, but please take a chance to rest, relax, and enjoy time with family and loved ones.

We love to hear from our members, so 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

Another Walk to D'Feet to Remember

The annual "Walk to D'Feet MND" was a great success, with more than 100 people attending. The Walk is our biggest fundraiser of the year - we've raised over $30,000! We are grateful to everyone who supported the event.

The Walk was held on Sunday 16 October at the Domains Athletics Centre in Hobart. It was a beautiful day filled with laughter, past reflections, and new memories. We had a fun-packed event with face-painting, sausage sizzle, coffee and snacks, and various games on the oval.

Thank you so much to all MND Tasmania families, volunteers, participants, and to the wonderful businesses which donated the amazing raffle prizes. All funds will stay in Tasmania to care for, and support, those individuals and their families living with MND.

We are forever grateful to **Hobart Wrest Point Casino, Local Loot, Anytime Fitness, Pennicott Wilderness Journeys, Shambles, Blundstone, The Old Woolstore Apartment Hotel, ZooDoo, Harvey Norman, Tupperware, Hill Street, Elite Appliances, Fuller Bookshop, Daci & Daci and The State Theatre.**

TG and JM Matthews Foundation

In 2021 we were successful in receiving a grant from the TG and JM Matthews Foundation to purchase a robotic feeding device - the 'Neater Eater'.

The Neater Eater is now in our equipment loan library. One of our members, who has the device on loan, has commented: "it gives me the freedom to eat while carers continue with other tasks" and it is an "excellent tool… great for my independence".

We are very grateful to the TG and JM Matthews Foundation for funding this device!

Hobart Repertory Theatre Society

We are very grateful to the Hobart Repertory Theatre Society community for their efforts in raising $4,000 in funds for MND Tasmania. The funds were raised through their performance of 'The Last Resort' Play during October.

Hobart Repertory Theatre Society is a volunteer organisation, just like MND Tasmania, and they are often able to support various charitable and community organisations.

They have just launched their 2023 season and we can't wait to see their upcoming shows!

We truly thank you for your wonderful efforts and for donating to MND Tasmania.

Latrobe Primary School

Chris Symonds, our Vice President & Public Officer, was delighted to participate in the Latrobe Primary School Big Chill MND Fundraiser organised by the Year 5/6 Student and Sports Leaders. Chris was able to turn his speech into a physical education session for the 300 students and teachers who attended, before they went under the ice bucket!

We are very thankful to the Latrobe Primary School community for raising awareness and funds for Tasmanians living with MND!

Bunnings Father's Day – 'Grill and Drill'

Kate Todd, our President, participated in the Bunnings Father's Day "Grill and Drill". She loved the opportunity to promote our Association, get in touch with the community, and to network with other organisations.

Donation Tins

You may have seen our donation tins around the state at various businesses. We are so very appreciative of all these businesses which help and support us by raising awareness of MND and funds for MND Tasmania. The latest business to take a donation tin was the Kmart Plaza Newsagency in Launceston - thank you!

New Members

We welcome new members living with MND and their families to the MND Tasmania community, network, and services. Please feel free to contact our MND Advisors for Tasmania (see contact details on the back page). The MND Advisor service is managed on our behalf by MND Victoria, with MND Advisors who travel State-wide as required to support our members on a needs-basis.

Thank you for your support!

We are grateful for the support we received from Devonport High School, Archbishop of Hobart's Charitable Foundation, Margaret Eldridge, Hotel Tasmania, Doug Bester, Port Sorell Primary School, Scottsdale Primary School, Evandale Primary School, and the continued support we receive from Kevin Burgess.

We have also received donations in memory of Alison Nation.

UPCOMING EVENTS

Carer Support - because we need to care for the Carers too!

Providing care for a person living with MND can be physically, emotionally, and psychologically difficult. Whilst many carers highlight the privilege and reward of being able to care for a loved one, it is important that carers also receive the information, support, and assistance they need to manage the caring role.

We have a number of Carer Support Programs available, including the “Kitchen Table Conversations” and “Wellness and Relaxation Days” (see further details on the next page). To see the full list of programs, please visit www.mnd.org.au/page/114/carer-support or scan the QR code on the right.

> “You gather bits of information in all sorts of places and pick out the bits that work for you, and keep the memory bank open as other bits of information may be useful later.”
>
> **2022 Carer Survey, Carer Project**

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...

MND Kitchen Table Conversation for Carers

1st Friday and 3rd Thursday of every month!

Both conversations are hosted by Andrea Salmon, Carer Program Coordinator at MND Victoria, alongside a past carer and volunteer.

These conversations are run monthly via Zoom on the:

- 1st Friday of the month at 2pm (next session is Friday 6th January 2023)
- 3rd Thursday of the month at 7.30pm (next session is Thursday 15th December 2022)

Come once or come every month! These Kitchen Table Conversations encourage carers to learn, listen, and to have a laugh or a cry – just like we would if we were sitting around a kitchen table.

Contact the MND Victoria office on 1800 777 175 or email **info@mnd.org.au** to register and get the join link.

Some people come each time and others come just once. The numbers vary between 5 and 7 carers and the topics vary from going on holidays and managing emotions to adapting clothing.

A recent comment from a carer who attended was: *"I do appreciate you and MND hosting these programs because they are very informative and we really get the feeling that we are not alone."*

Carer Wellness and Relaxation Days

"Carer Wellness and Relaxation" Days gives carers the opportunity to take some time off, to connect with other carers, and to learn some skills for caring for someone living with MND and for themselves.

They usually include talks with experts, skills such as transfer techniques, or activities along the lines of art, mindfulness or "come and try" Pilates.

The programs usually include an overnight stay, but are flexible to allow carers to come for one session or the whole program - whatever is possible. Support for the person at home can be arranged.

Stay tuned for details of the program being planned for Devonport and Hobart.

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 and volunteer 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 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. The group have currently ceased in-person meetings and are instead communicating via a private Facebook group. You can request to join at **www.facebook.com/groups/337315731509176** or scan the QR code on the right.

GIVING

CHRISTMAS APPEAL 2022

The *best care* until the world is free of MND

For most people living with motor neurone disease, the focus is always on appointments and issues around their disability and declining health. We now have the opportunity to help shift that focus - with your help.

MND Tasmania has been providing vital services to those living with MND since 1986. Over the past 36 years, services have expanded thanks to many wonderful donors and fundraisers who understand how their support and involvement directly helps those living with this horrible disease.

Until a cure is found, MND Tasmania will continually look to provide services and programs that offer a better quality of life for those living with MND.

That's why we are asking for your generous support this Christmas time.

Last Christmas, MND Victoria and MND Tasmania launched a new initiative known as "The Bucket List Wish Program". This program was funded entirely by donations through our Appeal this time last year. Through the funds raised, 18 wishes have been granted for people living with MND. Wishes such as one final holiday with the family, the completion of a large tattoo, tickets and an on-ground experience at an AFL final, a family getaway from the daily struggle of MND to luxurious accommodation on the beach, and many, many more.

Thanks to the support of a fantastic corporate partner and our amazing donors throughout the year, MND Tasmania has also been able to offer a program in recent years known as "Take a Break". This is a program that can fund small but useful items, services, experiences, or subscriptions that just make life that little bit easier for someone living with MND. Ultimately, it's about taking a break from MND. It might be tickets to a concert, a gardener to keep on top of someone's pride and joy, a pay tv subscription, it might even be for a handy kitchen tool. There is absolutely no limit on what someone might need to "take a break" – except for the funds available.

These two programs are small but mighty and have an incredible impact. As the number of people living with MND increases, so too does the funding that's needed.

Every day, we continue striving to provide essential and high-quality support to all Tasmanians living with MND.

But this Christmas we are asking for your help.

Help us grow our new services for people living with MND so they have the opportunity to "take a break" from the daily impact of the disease, whilst we continue to provide the best possible care and support every single day.

Bernard and his wife, Catherine, were thrilled when they were told their wish of spending a few nights together in Portarlington could be made possible by MND Victoria. Whilst Bernard is still able, the couple wanted to create as many memories as possible. Catherine said: "it was the most glamourous accommodation we have ever stayed at." Catherine and Bernard had lots of plans to do things but ended up immersing themselves in the opportunity to be in each other's company in front of the fire with books and magazines.

Margaret has had a long-time wish of spending a few days on a luxury houseboat. She has been living with MND for 12 months and figured it was now or never. She applied for funding through "The Bucket List Wish Program" and within a few weeks, we were able to fulfill this dream for her. Margaret, her family and some friends spent a week on a spectacular houseboat cruising down the Murray River. Margaret said they were able to create memories none of them will ever forget.

Christmas time can be immensely hard for families going through the MND journey. Your gift might just be that pick me up someone needs at this time of year. Visit www.mnd.org.au/christmas2022 or scan the QR code below.

Every dollar matters and will help improve the quality of life of someone who needs it.

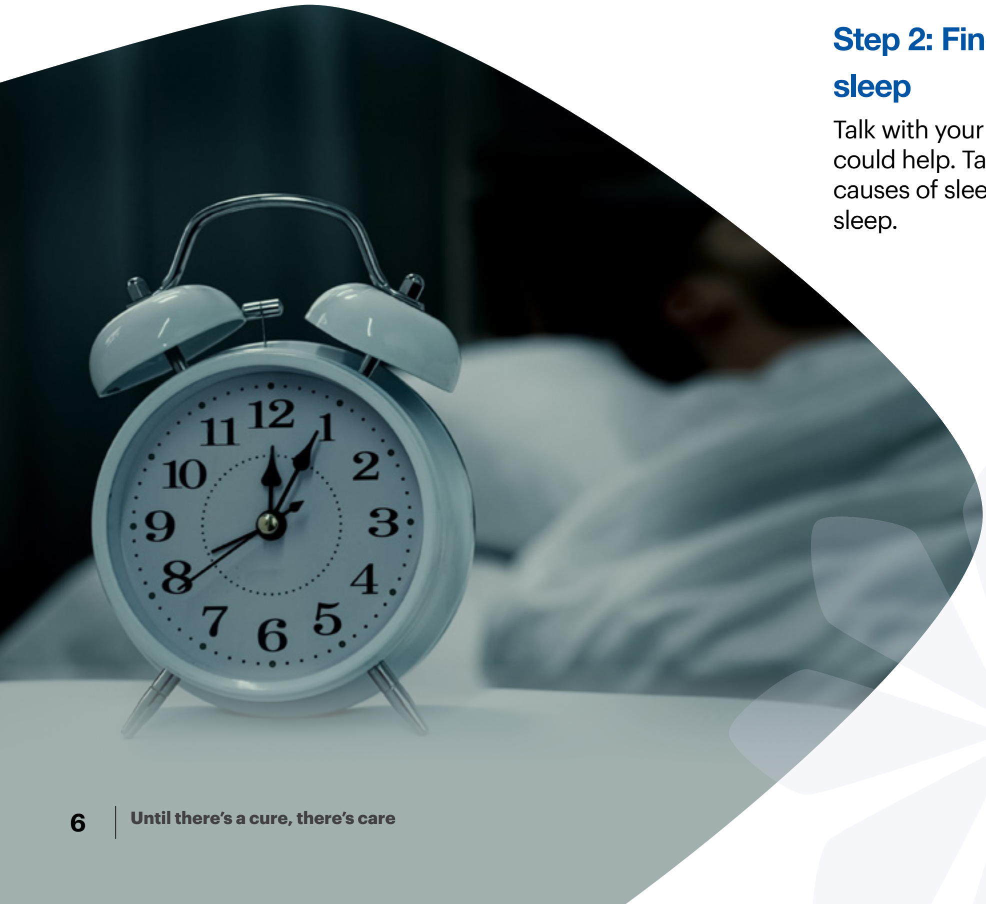
LIVING BETTER

Sleeping Better

Getting a good night's sleep can help to improve your quality of life, provide relief, and make it easier to cope with the many challenges that MND brings.[1]

It is common for MND to affect sleeping, for both the person diagnosed with MND and their carer. Difficulty getting comfortable, muscle weakness, pain/cramps, restless legs, difficulty changing your position in bed, changes to breathing, dry mouth or increased saliva, and stress/distress/anxiety/depression can all take a toll on sleep. If MND is affecting the muscles that control your breathing, carbon dioxide levels can increase in your body and this, in turn, can cause waking throughout the night.

Fortunately, there are things that may help to improve your sleep.



Who to talk to about sleep problems?

Health professionals including your GP, Neurologist, Physiotherapist, Occupational Therapist and, where relevant, Respiratory (breathing) Specialist, Psychologist/Counsellor, and Palliative Care Physician, can all play a part in working with you to improve your sleep.

Step 1: Find out the cause/s of sleep problems

As there are different causes of sleep difficulties in MND, an important first step is to understand what is causing the difficulty sleeping. For some people there will be a combination of factors.

This will guide which health professional/s to talk with. It is common for high levels of stress/mental health difficulties to affect sleep for families affected by MND. It is important not to be shy about talking about these difficulties if you think they might be contributing to sleep problems.

Step 2: Finding solutions to improve your sleep

Talk with your health professional/s about what treatments could help. Table 1 below summarises some common causes of sleep problems and things that can improve your sleep.

Table 1

Difficulty getting comfortable/changing position in bed	Tips and equipment can help you to get comfortable, change your position, and rest your arms and legs in bed at night. Sometimes different supports/equipment can be used over time - it is always worth asking for support if you are uncomfortable in bed.
Changes to breathing at night - frequent waking	There are different causes of disordered breathing at night in MND. Some people experience sleep apnoea.[2] If you have breathing difficulties, non-invasive ventilation (wearing a mask that connects to a machine that helps your lungs to fill at night) can drastically improve your sleep, reduce morning headaches and fatigue, and improve your quality of life. If you notice changes to your breathing, regular check-ups to monitor your lung function, and working out a plan for your situation, are important. Some hospitals can offer a sleep study. Sleep studies involve going into hospital and having specialists study your sleeping to understand the types of changes to your sleep, and to plan treatments to improve your sleep.
Pain	While MND does not cause pain, some of its symptoms can lead to pain. Medications prescribed by your Neurologist/GP/Palliative Care Specialist, and positioning support from a Physiotherapist or Occupational Therapist, can help to manage pain and improve sleep.
Dry mouth or excess saliva	Your Neurologist/Palliative Care Specialist, Speech Pathologist, and sometimes Physio/ OT, can try a range of treatments to help manage dry mouth or drooling at night.
Worry/Distress/Anxiety or Depression	There are a range of treatments available including: ❋ Relaxation. ❋ Counselling, including strategies to manage troubling thoughts. ❋ Talking with your support network -close friends or family - about your worries and concerns. ❋ Medications. ❋ Seeing a Psychologist or Psychiatrist.

What is sleep hygiene?

Sleep hygiene is about forming habits that help to reinforce when it is time to sleep. It is one of many approaches used to help people who have chronic health conditions and/or mental health conditions to sleep better.

Sleep hygiene habits include:

- Getting into bed at the same time each night and/or getting up at the same time each morning.
- Avoiding looking at mobile devices/computer screens for 1-2 hours before bedtime.
- Trying to do something that makes you feel calm before you go to bed at night. A warm bath/shower, listening to music, nature sounds, podcasts, meditation, prayer, listening to relaxation tapes, hugging/relaxing touch, relaxing essential oils, or reading are some things that people use to wind down in the evening.
- Make sure the temperature in your bedroom is right for you and try to make your sleeping area a restful place to be.
- Try not to get stressed about not sleeping! Avoid clock watching at night, and remember that lying down and meditating/ doing gentle breathing exercises in bed is still giving you some rest.
- Some people find it helpful to declare an MND-free zone in the evenings – this means time off from talking about MND or stressful worries related to MND after dinner time. You can schedule in time to think about/talk about MND earlier in the day if you need to do this.

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1 *Boentert, M. 2020. "Sleep and Sleep Disruption in Amyotrophic Lateral Sclerosis." Curr Neurol Neurosci Rep 20 (7): 25–25. doi: 10.1007/ s11910-020-01047-1.*

2 *Aiyappan, V. et al. 2020. "Sleep-disordered breathing in patients with motor neurone disease: one size does not fit all." Neurodegenerative Diseases 20: 131-138*

PERSONAL
STORY

Last year *with* Grandma

By Georgia Ross

In February 2020, a fit 73 year old Diann Ross came home from her regular midweek ladies tennis, disappointed in her game and concerned she'd let the team down: "my serve is terrible, I can hardly toss the ball to serve". And so began her journey to understand what was "wrong". With the introduction of COVID and all its confusion about access to doctors, visits and appointments, coupled with some delays, it wasn't until August that Diann's MND diagnosis was formalised. A cruel message delivered as such: "it's just bad luck…". It was shattering advice.

One of Diann's nine grandchildren, Georgia Ross, as a year seven student, completed an English essay based on observations of her Grandma (Gma), including sharing her diagnosis and the last year of her life as she was cared for by her family.

The Ross family share this piece with you in memory of Diann, who passed away on 12 March 2021. The matriarch of the Ross family, a much-loved wife, mother, mother-in-law, grandmother, aunty and friend, who was active, fit, kind, supportive and a wonderful human. We miss her so much and continue to hope and work towards a cure for this insidious disease.

The annoying sound of the phone ringing on the wall startled Grandma, the call that she had been waiting for. Multiple pains and aches over the past few months caused her to go to many doctors and specialists. Pains in her joints that stopped her doing everyday things, aches in her muscles and tendons that made it difficult to do the easiest things. Why was she finding standing up from the couch such a hard and exhausting task? Things like reaching the top shelf were something she could no longer do. She knew there was something very wrong. This phone call could finally give her the answers she had been searching for. No one expected this to happen to Grandma. That day in mid-2020 Grandma was diagnosed with motor neurone disease (MND). MND is a cruel demon that possesses your mind and stops your body from working, gradually getting worse and worse. Grandma was shocked, partly relieved that she knew what was happening to her, but sadness started filling her body.

I remember so vividly when she called my parents and told them. I opened the door to their room, and I could see tears rolling down their faces. I had never seen my dad cry this much in my life. "I hate to ruin your day, but I have MND" my grandma had said to them. I could feel my eyes start to water and my stomach felt sick. My parents and I then told my two siblings, and as soon as we said those 3 letters M N D they burst out into tears. We were already familiar with what MND was because of the AFL and Neale Daniher, so we knew the horrible effects of it.

The next time we saw her, we were all so sad. Grandma and Pa live on a farm in Main Ridge or 'The Farm' as we call it. My cousins and I would always go there every Christmas and Easter, my whole family loves going there, but this time we weren't going there to celebrate anything. My family, my cousins, my aunties, and uncles all going with Grandma on our minds. One of my aunties and her family live in far north Queensland and immediately booked the soonest flights possible to be with Grandma and the rest of the family. It was so special to feel how connected our family was, we were all bonding over wanting the best for Grandma. As

her symptoms were getting worse by the day, we instantly organised plans for a wheelchair, to make the house wheelchair accessible, and a car suitable for a wheelchair. All for Grandma, we wanted her to be as comfortable as possible and not to be put through any pain. We started donating to charities in support of the awful disease and we signed up for events to raise money for it as well.

As the weeks went by, each time I saw grandma, she was in much worse shape than the time before that. People with MND usually live for another 3 years after first experiencing symptoms but, in some people's cases, they can live for up to 10 years. So we still had hope that she would be around for a bit longer. In Grandma's case, her symptoms were progressing fast and the glimmers of hope we had were disappearing. It really is so hard to see someone you love so much basically deteriorate. Our family could not stand to see her in such a state, and we hated more than anything knowing that she would leave us.

Usually, on Christmas, we have a big family feast with all the Christmas foods you could want, and it's all thanks to Grandma, she normally organises everything and cooks all the food, she was the backbone of the family. But this wasn't a normal Christmas. Grandma was stuck in her wheelchair unable to do anything. She couldn't even cut up her food and could barely put her food on her fork and put it in her mouth. We all knew this would be the last Christmas we would have with her, so it was very emotional. My dad, his three sisters and my Pa were the saddest, being Grandma's children and Husband. I can't explain how bad I felt for Pa, you could tell how upset he was, he was usually so talkative and cheerful, but he was silent, you could see the sadness through his eyes. Grandma though, was always in great spirits, she was always so optimistic, and had such a positive view of life.

At the beginning of March 2021, Grandma choked on some water in the middle of the night, Pa called an ambulance because Grandma was coughing heaps too. She was rushed to the hospital where the doctors found out that she had pneumonia. I can't imagine how Pa would've felt in that situation. I don't want to imagine it. We thought that Grandma still had a few more months left in her, but the doctors told us otherwise. My Dad and his sisters got to the hospital ASAP, where they would live for the next week, Grandma's last week. My siblings and I back home had no idea how quickly it all happened, and we weren't ready to say goodbye yet.

I remember when Mum called me while I was at school. Crying, she said to me "George, I'm going to have to come pick you up. Grandma's not doing well". As soon as she called, I knew what was happening. When we got to the hospital, my siblings, my mum, and I were all crying our eyes out. I remember seeing Grandma lying on the hospital bed. Lying there helpless with tubes up her nose to keep her alive. She could hardly even talk to us. She could barely force out a word at a time before she would be out of breath. My siblings and I had never felt this type of pain before. It felt like I was being stabbed in the heart. My head was pounding from crying so much. As we gave Grandma our final hugs and kisses, I remember feeling the saddest I had felt in my life. We had to say goodbye.

Grandma was such an inspirational woman and I aspire to have her attitude and her positive, never give up mentality. She brought my whole family closer together and she will be forever missed.

MND ADVISORS AND NDIS SUPPORT COORDINATORS

Client Numbers

We are currently supporting 49 registered members:

North West Region Tasmania	9
North Region Tasmania	19
Southern Tasmania	21
TOTAL	49

CURENTLY SUPPORTING **49** REGISTERED MEMBERS

DELIVERED **1,021** 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: Kim Hamilton (Tue - Fri):
p: 0422 149 445 or e: **khamilton@mnd.org.au**

FREECALL 1800 777 175

This number is 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.

Right: Emma Forsyth
Below: 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

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