

MNDnews

The newsletter of the Motor Neurone Disease Association of Tasmania

Our favourite event of the year:
Walk to D'Feet MND!



Until there's a cure, there's care

mnd 
Tasmania

MESSAGE FROM THE PRESIDENT

Our 'Walk to D'Feet MND' on 15 October 2023 was a fantastic day for us and for our members! We are so grateful for all the support we received from the participants, volunteers, and local businesses. It was a fun-packed morning, and we've **raised over \$35,000** of funds that will stay in Tasmania supporting Tasmanians. We couldn't do it without you - thank you!

We are planning our next Annual General Meeting which will take place in March 2024. Once we have confirmed the date, time, and location, we will send all the details to our members. The Annual General Meeting is always a great opportunity to get to know the Board Members, as well as to discuss how we can continue to support you and how you can get involved.

We are so grateful for all the support we receive from all of our members and from our amazing community! And in this edition, our member and collaborator, Paul Kelly, is providing insights into the key moments that defined MND research.

As we are heading towards the holiday period, we would like to thank all of our MND Community for your continued support. Things can get very busy around this time of the year, but please take a chance to rest, relax, and enjoy time with family and loved ones.

We welcome new members to the MND Tasmania family. We are here for you and will support you on the journey ahead. Please reach out to us through the Board and through our wonderful MND Advisors.

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 or see our contact details on the back page.

Kate Todd
President



LIVING BETTER

A Brief History of MND – 15 key moments that defined MND

By Paul Kelly, our contributor currently living with MND

- 1 1874:** French neurologist, Jean-Martin Charcot, identifies and describes the clinical features of MND (Amyotrophic Lateral Sclerosis). The condition is dubbed Charcot's Disease.
- 2 1939:** Star baseball player, Lou Gehrig, delivers his famous farewell speech at Yankee Stadium, bringing public attention to MND and raising awareness about the disease. Many will come to know the condition as Lou Gehrig's Disease thereafter.
- 3 1944:** Dr. El Escorial criteria are established, providing a standardised method for diagnosing MND.
- 4 1963:** A young Stephen Hawking is diagnosed with MND at the age of 21. His exceptional achievements as an astrophysicist while living with the disease will inspire millions and raise awareness about the condition. Later, the film, 'The Theory of Everything' (2014), is based on his life.
- 5 1991:** The World Federation of Neurology publishes the first international guidelines for the diagnosis and management of MND.
- 6 1993:** Mutations in the superoxide dismutase 1 (SOD1) gene are identified as a cause of familial MND.
- 7 1995:** Riluzole becomes the first FDA-approved drug for MND treatment, offering modest benefits by delaying disease progression.
- 8 1998:** The ALS Association launches the "Walk to Defeat ALS" fundraising event, raising awareness and funds for research.
- 9 2006:** The gene, C9orf72, is linked to MND, providing further insights into the genetic causes of the disease.
- 10 2008:** Researchers discover a link between MND and the TARDBP gene, expanding our understanding of the genetic basis of the disease.
- 11 2014:** The ALS Ice Bucket Challenge goes viral, raising millions of dollars for MND research and increasing public awareness.
- 12 2015:** The AFL, in conjunction with Neale Daniher's Fight MND, launches the charity event, 'The Big Freeze', which continues to raise awareness and millions of dollars for MND initiatives.
- 13 2017:** The FDA approves Edaravone as a treatment for MND, the first new medication for the disease in over 20 years.
- 14 2022:** The FDA approves AMX0035 (Relyvrio) for the treatment of MND.
- 15 2023:** The FDA approves Tofersen for the treatment of SOD1 mutation MND.

CORRECTION

In our previous newsletter, the article 'Deciding on a PEG Tube: Options for Enteral Feeding', by Paul Kelly, mentioned that "no chewing or solid foods can be consumed orally while the tube is in place". While this is true for the writer who has kindly shared his experience and knowledge, it is not the case for everyone. Thank you for bringing this to our attention! If you have any questions or concerns, we encourage you to speak to your health professionals who will be able to comment on your individual circumstances.

MND TASMANIA SAYS THANK YOU

Perth Primary School

In Term 3, students at Perth Primary School organised a Footy Colours Day that raised funds for MND Tasmania. Thank you to everyone who organised and supported the day - you're all amazing!



Order of the Eastern Star

The Hobart Chapter 162 of the Order of the Eastern Star came together in early October for their annual Installation Dinner at the Tasmanian Golf Club.

Their current Worthy Matron, Mrs Margaret Campbell, and Worthy Patron, Mr Gerald Upchurch, have chosen MND Tasmania as one of their charities to support at the end of their term of office. Their term of office ended in early October at the Installation Meeting to install the new

Pictured here with MND Board member Steve Isaac (far right), is Margaret Campbell - Immediate Past Worthy Matron, Gerald Upchurch - Immediate Past Worthy Patron and Sam McLean - the Chapter Chaplain.

board of office-bearers for next year, followed by the Installation Dinner.

We are extremely grateful for the ongoing support and being presented with a cheque for \$3,500 towards care and support services to the Tasmanian MND/KD Community. It was humbling to hear Chaplain McLean give a moving talk of his family's own experience of being affected by MND. It was a wonderful evening, and we are truly grateful for your support, OES Hobart.



Hobart Hash House Harriers

Once again the wonderful Hobart Hash House Harriers H4 and Hobart Hash House Harriers and Harriettes (H5) supported MND Tasmania in 2023.

We are so grateful to Chris "Fuggles" Fuglsang and the HHHH/H cohort for inviting MND Tasmania Board Members Lucy and Saga along to one of their charity runs. We are also grateful for their continued support to the entire Tasmanian MND/KD Community! A \$2,000 cheque was donated with a choir of wonderfully cheeky songs!



Carers Day recently run in Hobart

As part of the 2021/22 MND Victoria Carer Respite Project, a Hobart Carer Wellness Program was held at The Old Woolstore in early October.

The Program was developed in collaboration with Jenny Fuller and Emma Forsyth, MND Advisors, and a range of activities and speakers were carefully selected.

It was a great opportunity to connect with others in a relaxed atmosphere. The program had the support from a range of specialists and researchers, with activities ranging from Tai Chi, art and relaxation, to conversations around nutrition and advances in MND research.

Thank you so much to all that attended and made this program a success!



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 WLF Accounting and Advisory, Perth Baptist Church Hearts and Crafts, Stepping Stones Margate, R Meredith 6ty Pty Ltd, Department of Home Affairs, DHA Morning Tea, James Miller, Christain Miles and Peggy Roberts.

We also acknowledge the ongoing support received from Kevin Burgess.

We have received donations in memory of Margaret Paterson and Maxwell Robson.

PERSONAL STORY



www.mnd.org.au/ChristmasAppeal23

When Bruce was diagnosed with MND in 2021, his youngest child, Shauna asked, “Are you going to die?”. There aren’t many questions tougher to hear, let alone answer. Bruce simply responded with “No, I’m not going to die now. There’s plenty of wiggles in this worm left. There’s plenty of good living to happen.” – And that’s exactly the attitude Bruce, his amazing wife, Natalie and their two children, Lincoln and Shauna, have lived with ever since.

Two and a half years on, the family have remained committed to supporting each other and living in the moment. Bruce says, “All the plans of working hard towards retirement and travelling, the thinking changed. It’s more about day-to-day for me now. It’s getting the most out of each day and doing what I can. Keeping in a routine.”

For MND Victoria’s 2023 Christmas Appeal, the family wanted to share their story to hopefully inspire others to live every day with a positive outlook and highlight the importance of “support, care and love”. **Bruce and Natalie know that without the huge amount of support they have around them, life would be so much harder.** As well as the many incredible

friends, family members, neighbours, colleagues, and many others who they have met within the MND Community, **Natalie is immensely thankful for all of MND Victoria’s services** because, as a family, they have utilised each one.

One of our newest services are our Carer Support Programs. At MND Victoria we realise that **it’s not just the person living with MND going through the journey - it’s also their loved ones** who provide varying levels of care and support, depending on how advanced their MND is. The programs provide carers with the information, support and assistance that they need to manage the caring role.

As Bruce says in the video:

“Caring for me as an individual, and caring for my family who are my carers, I think is a real thing that MND Victoria does that sets them apart.”

Natalie absolutely adores caring for her husband; however, she understands the importance of taking a break and treating herself to something that fills her cup - and that’s what our Carer Programs enable. Natalie recently attended one of the programs funded by our Carer Programs initiative and said, “I went to the Carer Wellness Program in Mornington, and it was fantastic. I met four other ladies, and we got a WhatsApp group going. We check in on each other every now and again.

We did painting, relaxing, sharing and some laughing – and I did some crying. It was a great day, really powerful. I could see it was a relief for the other ladies to just come and do something and meet people who do understand what it’s like to care for a loved one with this disease. Because if you’re not going through it, you don’t understand.”

If Natalie and all the other carers (who certainly didn’t ever imagine themselves in this position) aren’t supported or don’t have an avenue to look after themselves, it makes it so much harder on the person with MND, and the family and friends around them.

Along with the support Natalie provides Bruce, he says he couldn’t live as well as he is without MND Victoria being in his corner each and every day. He says, “It’s a really critical service. Understanding what we need and how we like to roll, and then being able to fit in with that and get the right person or service for me or the family, is pivotal.”

Bruce has his own MND Advisor & Supporter Coordinator who walks the journey with him. **He is also a huge fan of our world-class Equipment Service that allows him access to all the various assistive equipment that he will require as the disease progresses.** At the moment, he loves his recliner chair and special table that allow him to continue working from home whilst remaining as comfortable as possible.

As stoic and inspirational as Bruce is, he says he has learnt a lot about perspective. “I’ve always been someone who looks at things from someone else’s perspective. So, the key thing I’m concerned about is: ‘What’s my impact on other people?’ But then it really boils down to that thing that I’m no longer a burden. I will ask for help. I’m on this journey and there’s a whole lot of people on the journey with me, and they’re supporting me and lifting me up and carrying me. We’re on the journey together. But I’ve also got to be careful and understand that not everyone can do it all.”

We asked Bruce why he wanted to share his and the family’s story for MND Victoria’s Christmas Appeal to help raise funds for others impacted by MND and he said, “It’s the services. It’s the individual care. It actually impacts my life and changes it for the better. The other fundraising around finding a cure is important and great to have, but MND Victoria actually impacts the day-to-day lives of people living with MND. They change it to a positive. A cure may come, and we need to spend money on it, but we also need to spend money on the well-being of people with MND and what we can do now.”

Support, Care and Love

Bruce and Natalie’s Story

LIVING BETTER

Sexuality and Intimacy in MND

This article has been adapted from the MND Australia factsheet 'Sexuality and Intimacy in MND'.

MND Victoria recently hosted a webinar on 'Sex and Intimacy in MND'. An article about the webinar, which includes detailed discussion and practical tips, can be found at <https://qrco.de/beZ1Uh> or by scanning the QR code below.



About intimacy and sexuality

Intimacy and sexuality are important to quality of life and emotional well-being, and remain important to people living with motor neurone disease (MND) and their partners, regardless of age and level of disability. For some people, sex becomes more important following diagnosis, for others it becomes less important. Close physical contact, touch, and time together, become more important as a person's condition deteriorates.

What you should know

- MND can affect intimacy and relationships but the condition itself has no direct impact on sexual function, arousal or needs.
- Having a partner who is also acting as a carer may impact relationships.
- Intimacy and sexuality may be experienced through sexual and non-sexual touch.
- Talking with a GP, MND Association Advisor, neurologist, nurse, or allied health professional regarding intimacy and sexuality may be beneficial.

Impact of MND on intimacy and sexuality

Understanding how living with MND affects expression of sexuality and intimacy is an important first step in addressing problems that may arise. It may be reassuring to know that MND itself does not directly impact sensation, sexual function, arousal, fertility, or the ability to have an erection or orgasm. However, people living with MND and their partners report experiencing barriers to physical expressions of intimacy in their sexual and non-sexual relationships. Physical, emotional, psychosocial, and cognitive-behavioural features of MND, lack of social support, and use of assistive technology, may indirectly affect intimacy and sexuality. The need for partners to take on a caring role can also create barriers.

Talking about intimacy and sexuality – it's not just about sex

As MND progresses, things will continue to change, and it is important to try to maintain open communication with your partner and/or loved ones about the impact of these changes, and to seek help as required.

Research highlights the need for healthcare professionals working at MND clinics to give people living with MND and their partners the opportunity to talk about intimacy and sexuality, if they wish to, as part of the assessment process. Some professionals, however, will find it difficult to raise and talk about this subject and may instead invite the person with MND and/or their partner to telephone or email with any concerns that they may have. Either approach opens the door for people with MND and/or their partner to talk about the impact of MND on their sexuality and relationships. If the

subject is not raised at clinic visits, ask for help if you and/or your partner are struggling with the impact MND is having on intimacy and sexuality. Your GP, MND Association Advisor, nurse, palliative or allied health care professional will be able to talk through your concerns and refer you to the right person. Not all barriers can be overcome but it is possible, with support, to adapt and make changes to maintain intimacy.

What can help?

Depending on the stage of the disease, you may need to change how you do things to maintain intimacy and sex. It may take some time to adjust and feel comfortable with these changes, and it is therefore important to try to:

- Be open with your partner: talk about how you are both feeling and communicate what you can and can't do as the disease progresses, and what does and doesn't work for each of you.
- Be flexible: make changes to consider the physical impact of MND such as tiredness and fatigue, by having sex at a time when you are least tired or by trying massage and relaxation techniques.
- Be creative: try different sexual positions, ask your partner to take on a different or more active role, or consider using sexual aids (available online or from specialist shops).

MND may affect speech, however sex is often a time when people can express themselves without having to talk. You may already have a special way of communicating with your partner using signs and signals such as blowing a kiss, but you may need to try new ways of communicating and signalling how you feel. Whatever you try, a willingness to laugh together while you experiment can help to maintain intimacy.

Who can help?

Not everyone requires help or advice when they experience barriers to physical and sexual intimacy. It is important to be aware that some of the features of MND can be managed to minimise impact on intimacy and sexuality. Talk about any worries you may have with someone from your healthcare team who you trust and feel comfortable talking to. You can do this as a couple, or separately. They will be able to talk through your concerns and, if needed, refer you to the appropriate health professional.

How to bring it up with healthcare professionals?

Conversations about sex and intimacy are not always easy to initiate and can feel awkward. If your healthcare team does not start the conversation, you might like to ask:

- Can we talk about something personal?
- Do other people with MND find that...?
- Can we talk about how MND affects...?

MND EVENTS



MND Tasmania Walk to D'Feet MND

We had another phenomenal day with more than 100 people attending our 2023 Walk to D'Feet MND. Thank you all for the outstanding support we have received from our volunteers, registrants, fundraisers, and event supporters! We have raised over \$35,000 of funds that will stay in Tasmania to care for, and support, individuals and their families living with MND.

The Walk was held on Sunday 15 October at the Domains Athletics Centre in Hobart. It was a beautiful day filled with laughter, past reflections,

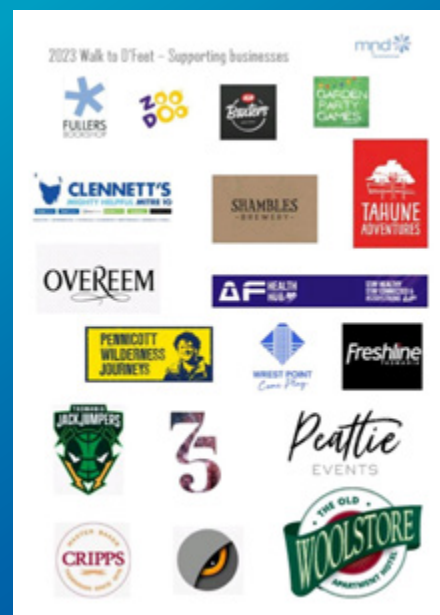
and new memories. We had a fun-packed event with face-painting, sausage sizzle, coffee and snacks, and various games on the oval.

A big shout out to our generous event day in-kind businesses who provided invaluable support. The day is a success with your amazing kindness and contribution:

- Olive Tree Catering
- Bunnings Warehouse Glenorchy
- Cripps
- Freshline Hobart

And a special mention to Blundstone Australia for their continued, super generous support.

NEVER
GIVE
UP



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 of 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 are once again catching up in person, which will coincide with the MND Clinic dates.

When: Wednesday 20th December

Where: Selah Café, Door of Hope, Glen Dhu Street, South Launceston

Contact: Emma Forsyth on 0456 182 551 or email eforsyth@mnd.org.au

FUNdraise for MND Tasmania

Are you interested in becoming a community fundraiser for MND Tasmania? You could host an event, get active, set a challenge, celebrate an occasion, have a bake sale... ideas are only limited by your imagination!

When you sign up to fundraise for us, you'll receive your own online fundraising page to help spread the word about your activity and to receive donations. Get in touch with us by emailing info@mndtas.asn.au



MND INFORMATION

Client Numbers

We are currently supporting 54 registered members:

North West Region Tasmania	9
North Region Tasmania	21
Southern Tasmania	24
TOTAL	54



**CURRENTLY
SUPPORTING
54
REGISTERED
MEMBERS**



**DELIVERED
325
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: Tracey Dickson

Vice President & Public Officer: Chris Symonds

Secretary: Lucy Polizzi

Treasurer: Julie Driessen

Member Support: Elisa Howlett

Fundraising: Saga Hassinen

Ordinary Directors: Steve Isaac

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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