

MNDnews

The newsletter of the Motor Neurone Disease Association of Tasmania

**OUR BIGGEST
FUNDRAISING EVENT
OF THE YEAR -
WALK TO D'FEET MND
WAS A SUCCESS**

**NEVER
GIVE
UP**

**NEVER
GIVE
UP**



Until there's a cure, there's care

MESSAGE FROM THE PRESIDENT

We had a fantastic day at our annual Walk to D'Feet MND on 31 October 2021, and are grateful for the support we received from teams, individuals and local businesses. Thank you all again for coming along for a great day and supporting MND Tasmania.

We are planning our next Annual General Meeting which will take place in March 2022. We'll send out the details with all the information on time, date and location to our members. We hope to see a number of faces there so that we can have a cup of tea and talk about how MND Tas can continue to support you, and 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. Let us know if you have any suggestions as to 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.



As we head into the busy holiday period, we'd like to thank all of you for your continued support and involvement in the MND community. Take care and we look forward to a great 2022.

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

MND TASMANIA SAYS THANK YOU



FightMND Care Grant

MND Tasmania would like to thank and acknowledge FightMND as a major donor to the equipment library.

The FightMND Care Grants have allowed us to regularly update and improve the equipment available to our members.

We were fortunate to be one of the successful applicants this year after FightMND received 47 applications worldwide for their grant round. Funds were granted to a clinical trial, drug development projects, and others, including state-based MND Association applications for equipment.

TG & JM Matthews Grant

We have been successful in the TG & JM Matthews Foundation grant application, completed earlier this year by Gethin Thomas from MND Research Australia. It includes three robotic feeding devices (two for Victoria and one for Tassie).



The Neater Eater Robotic (pictured right) is of great assistance for people with significant arm impairments as a result of their MND. This assistive eating technology device allows them to maintain independence when it comes to eating.

A personal story: Margaret Eldridge

Margaret's history with MND began 15 years ago when Kate, a very dear friend, was diagnosed with familial MND in her late 40s. Another friend set up a 'Share the Care' group to support Kate and a number of friends helped in any way they could - from daily tasks, cooking, doctor's appointments, home modifications, organising social events and eventually liaising with palliative care professionals.

Margaret made a promise to Kate that, for as long as she was able, she would help raise money for research so that one day there would be a cure for MND. Kate died at 50 and not long after, another of Margaret's friends was diagnosed with familial MND. Margaret set up the 'Share the Care' group which supported Doreen.

The annual 'Bring and Buy' events continued, as did jewellery-making. In addition, Margaret writes jingles for her aquarobics group which has been very supportive. Now Margaret's granddaughter, Caitlin, helps with the jewellery making and they often have afternoons together making earrings, necklaces and bookmarks.

In 2007, Margaret was awarded the Order of Australia (AM), for her work with migrants, refugees and international students. This year she was added to the Tasmanian Honour Roll of Women. A third friend was diagnosed with MND in her eighties, so Margaret has good reason to continue fundraising. You are a true friend Margaret, and we thank you for all your support.

Thank you, Ashlin Hagan!

During a 'Genius Hour', an event at Taroona Primary School attended by guests of the children, Ashlin Hagan focused on promoting awareness about MND and raised over \$100 in donations to MND Tasmania.

Jenny Fuller, MND Advisor, visited the school to talk to Ashlin and her classmates about MND and to collect the donations. Doris Hagan, Ashlin's grandmother, has recently died of MND.

Thank you Ashlin for your wonderful effort in fundraising and increasing awareness of MND.



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. Andrew Phipps is a PhD Research Fellow at the Wicking Dementia Research & Education Centre. Here is a short interview we conducted with him about his research.

When did you start working on MND and why?

I am new to the field of MND research! I started my post-doctoral research fellow position with Prof. Anna King at the Wicking Dementia Research and Education Centre in 2021. I have always had a strong interest in understanding the causes of neurodegenerative disease, and I believe that we can make a difference for people living with MND by working together with the excellent team of researchers here in Tasmania.

What is the current focus of your research?

The focus of my research is to understand how motor nerve fibres are vulnerable and degenerate in MND, and if there is anything we can do to protect them. I am currently working with a fantastic team of researchers at the University of Tasmania, including chemists, pharmacists, clinicians and neuroscientists. We are performing a pre-clinical drug trial for a new treatment to protect the long nerve fibres of motor nerve cells.

What are some of the recent findings from this work?

We are currently testing the drug in different models of MND. It is still early in the project, so we are currently collecting data. We have some early data that suggests the drug reduces inflammatory cells in the spinal cord during MND.

What is the most interesting aspect of this work?

I really enjoy the hands-on lab work and microscopy - being able to see the intricate nature of the nervous system is always fascinating. This year I have also spent time learning about drug activity while working with my colleagues in health sciences, chemistry, and pharmacy.

What other research-based activities are you involved with?

Alongside my current MND research, I am interested in the study of how ageing and disease change the way our genes work in the nervous system, and I completed a PhD studying this in 2019. I am now looking at new ways of incorporating my molecular skills to understand more about MND,

and if there are molecular pathways that account for the vulnerability of nerve cell fibres.

What do you enjoy doing in your spare time?

In my spare time, I am a professional photographer/cinematographer and picture framer, so I spend a lot of time out in Tasmania's beautiful wilderness capturing images and doing documentary work of Tasmania.

Thank you for your support!

This quarter we are grateful to the Hotel Valern for organising a walk between the Elwick Hotel and the Hotel Valern. Fundraising activities were undertaken in both venues, raising over \$2,000 in donations!

Thank you to the Hobart **Hash House** Harriers for organising a fundraising run and donating over \$2,000 to MND Tasmania!

We are also thankful to the Launceston Preparatory School for organising a fundraising event and donating the proceeds to MND Tasmania.

We have gratefully received continued support from Margaret Eldridge and Shane Ling and received donations in memory of Dr Rick Lette, Gavin Flack and Doris Hagan.



LIVING BETTER

Physical Activity and MND

Finding ways to enjoy physical activity with MND can help, even as it gets harder to keep your body moving.

Why does physical activity help with MND?

Generally, activities like walking, gardening, yoga, stretches and others that involve physical movement can help support your physical abilities by strengthening healthy muscles whose nerves have not yet been affected by MND. Physical activity can also help maintain joint range of movement, reduce stiffness and pain, and support overall wellbeing and enjoyment of daily life.

Many people living with MND feel that it's important to enjoy physical activity. Recent research finds that personal enjoyment of general physical activity is more motivating for some people living with MND than a more formal exercise program. So you may want to think about the activities you enjoy doing, and how your healthcare team can best support you to do them.

What you need to do first

It's best to talk to your neurologist, GP, physiotherapist and others in your healthcare team about physical activity and how to manage:

- * fatigue
- * getting plenty of rest
- * pain and stiffness
- * aerobic, strength and endurance exercises, if they're suitable
- * assistive technology for maintaining independence, mobility and comfort, if suitable.



Fatigue is an issue

It's important not to push yourself to exhaustion while exercising and to get plenty of rest after physical activity to reduce fatigue. Even daily tasks like washing and dressing can drain energy, and you may need to rest and take time to recover. Physiotherapist and occupational therapist assessments and regular reviews can help to guide you.

What can I try?

- * Walking outside the home, housework, gardening
- * Yoga, stretching limbs with a physiotherapist, hydrotherapy (activities in a pool of water)
- * Exploring best ways with a physiotherapist to do physical activities while sitting in a bed or chair
- * Talking with your health professionals regarding medications that may help with discomfort
- * Stable and supportive shoes, walkers, braces, orthotics
- * If active movement is no longer possible, active-assisted physical activity may help, such as active-assisted arm or leg cycling, or various team sports with your local electric wheelchair/powerchair sports association.

Being active for wellbeing

Physical activity may help you to focus on things that you enjoy. You can have a break from other worries, build your confidence and sense of control, and spend time with others and feel supported by them.

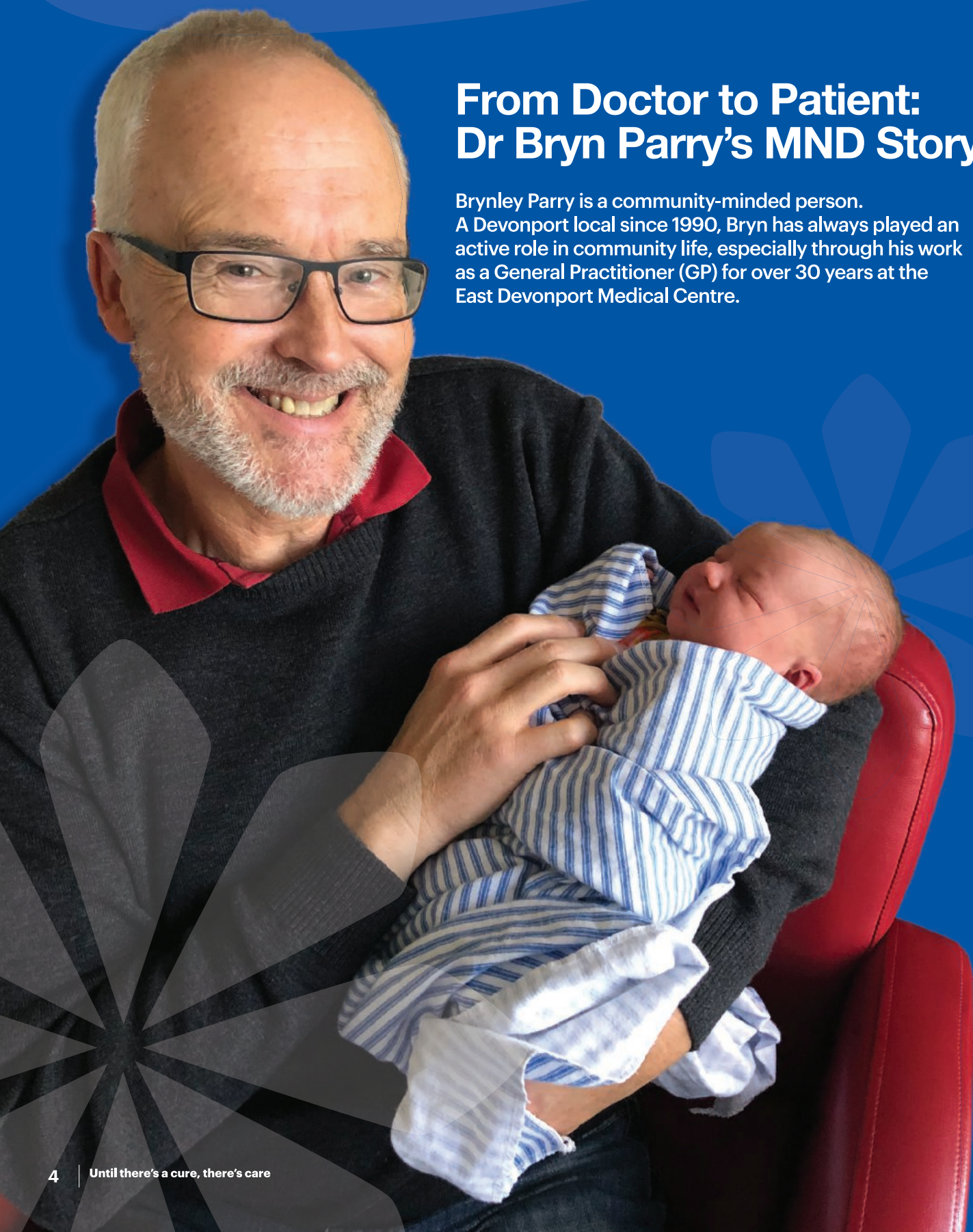
This article has been adapted from the MND Australia factsheet 'Physical Activity and MND'. For more information, visit <https://www.mndaustralia.org.au/mnd-connect/information-resources/physical-activity-and-mnd> (or scan the QR code on the right), contact your local MND State Association or call the MND Info Line on 1800 777 175.



PERSONAL STORY

From Doctor to Patient: Dr Bryn Parry's MND Story

Brynley Parry is a community-minded person. A Devonport local since 1990, Bryn has always played an active role in community life, especially through his work as a General Practitioner (GP) for over 30 years at the East Devonport Medical Centre.



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



Bryn and his wife, Clare, had not planned to settle in Devonport, but the longer they stayed, the more they felt it was a great place to bring up children and raise a family. Dedicated to his community as well, Bryn signed on as a Partner at the East Devonport Medical Centre in 1992. This was the same day their first son, Lucas, was born. Their next son, David, soon followed and then sixteen years later, their daughter, Myf, was born, completing their family.

During his career, Bryn had only encountered one patient with motor neurone disease (MND). In early 2020, he first started to notice his right foot was dragging when he jogged, but MND was not something that had really crossed his mind. By April, this slight drag was enough to get caught on uneven surfaces, and Bryn fell over a traffic hump when running down to the pool with Myf. It was then that he realised this developing foot drop was not going away and decided to investigate what was going on.

It can often take a long time to get a confirmed diagnosis of MND. For Bryn, it was no different and the impacts of COVID-19 only prolonged the process. His doctor referred him for a nerve conduction study, which was where the delay started. "There is a lack of availability of nerve conduction studies as Tassie, at least in the North, has been reliant on fly-in neurologists to perform nerve conduction studies."

By June, diagnostic progress was still at a halt and his right leg was continually weakening. Being a proactive GP, Bryn referred himself to see a Sports Medicine Physician who specialises in feet and a Neurosurgeon in Hobart. They then referred him for a number of tests to investigate the cause of his symptoms. Although Bryn was not in pain, the results indicated that it was nerve related. He was encouraged to start advocating for himself and push to get the nerve conduction study done.

"It's funny because I was used to advocating for my patients, but it hadn't occurred to me that I should jump up and down on my own behalf. It was interesting as a doctor, having the experience from the opposite side."

Bryn eventually had his nerve conduction study done through the Launceston General Hospital in July, which was then followed by a lumbar puncture. "By the time I had the lumbar puncture and all the results, it was another seven weeks before the formal diagnosis. The diagnosis didn't happen until late September."

He does not see the date he was officially told he had MND as anything in particular. "It was almost just like another day. I think I had virtually accepted that that was going to be the

diagnosis by then. We'd eliminated everything else. Perhaps that was one of the advantages of such a drawn-out process."

One of the hardest things for Bryn was learning of the prognosis of the disease. Typically, the average person lives with MND for 27 months, and that news left him dismayed.

"My son Lucas is actually a GP, so he's well aware of what MND is. When I told my second son [David], I watered it down a bit. I didn't want to shock him. He and his wife were living in Melbourne at the time and within 24 hours he'd phoned to say they were moving back to Tassie. It was a real shock and surprise, but I realised that Lucas has been in his ear telling him about the prognosis of MND."

Myf was only 12 years old when Bryn was diagnosed, so he and Clare gave her the "PG version" of his diagnosis. "We didn't really want to confront Myf with that information, but it was inevitable that she must now have had some idea about it. Our main emphasis has been to try and keep things as smooth, even and normal for her for as long as we can."

Bryn is very thankful for the care and support he has received from MND Tasmania. His MND Advisor and Support Coordinator, Emma Forsyth, has been very helpful every step of the way, personalising everything for Bryn to ensure that all of his needs are being met.

"When you're battling with this illness and coming to terms with a life-limiting prognosis, you don't want to be spending the time you have left in some sort of bureaucratic maze. The service that MND Tasmania offer really converts what could be a terribly difficult, stressful, miserable time into something that is more like it should be – a positive, helpful step. I can't imagine how much more difficult it would have been without them."

Bryn is not letting his diagnosis get in the way of giving back to his community - he is currently a Board Member of the Mersey Colts Cricket Club and part of the Pastoral Leadership Group at the Lifeway Baptist Church. This is his way of supporting the "good people doing good things in the community."

"While it can be difficult on a day-to-day basis to stay positive, one of the big things to remember is that the mind is still able to function. I'm just working on maintaining the right attitude and approach to dealing with the ongoing challenge of MND."

MND RESEARCH



To learn more, visit
[www.mndaustralia.org.au/
research](http://www.mndaustralia.org.au/research) or scan the
QR code above.

MND Research Australia (MNDRA) supports high-quality MND research to discover the causes, improve care, and find treatments and ultimately a cure for MND. They have recently revamped their website to make it even easier to keep up to date with the latest research information in MND.

How to get involved with research

There are a number of **clinical trials** and **non-clinical research** currently happening all across Australia, and people living with MND may be eligible to take part in them.

A **clinical trial** tests new treatments and interventions in people to find out if they are safe and/or effective – you will need to speak to your neurologist first to assess your eligibility. **Non-clinical research** looks at other, non-medicinal factors – these are sometimes open to family members of those who have been affected by MND.

A full list of current clinical trials and non-clinical research opportunities can be found on MNDRA's website (see details above).

Research news and updates

MNDRA are frequently uploading publications, updates and webinars on the latest advances in MND research in Australia and internationally to their website. These updates include:

- * Advance – a biannual research newsletter, detailing the latest on MND research in Australia.
- * State of Play Webinars. Developed in 2020 and set to return in 2022, these webinars are open to the whole MND community and are designed to provide an introduction to the advancements of the research community in Australia.
- * International Research Update – produced quarterly.
- * Updates from the International Alliance Scientific Advisory Council (SAC) - a centralised resource to review and provide a global perspective on scientific and biomedical announcements, information and opportunities relating to ALS/MND.

MNDRA's research

Since 1987, MND Research Australia has funded over \$46 million in research grants. A number of these grants are funded by the State MND Associations through the generosity of their supporters and donors. A full list of the current recipients of Research Fellowships, Innovator Grants, MNDRA PhD Scholarship Top-up Grants and currently funded multiyear grants from previous years can be found on MNDRA's website (see details above).

GLOBAL MND NEWS! A truly monumental day for MND research

The UK Government have announced that they will commit £50 million (AUD\$92.5 million) over five years into targeted motor neurone disease research.

The **United to End MND** campaign started two years ago, with a group of five people living with MND who were determined to accelerate research in the cause, treatments and ultimately a cure for MND. They joined forces with MND Scotland, MND Association, and My Name's Doddie Foundation, as well as leading researchers, neurologists and others living with MND, to call on the Government to fund a virtual centre of excellence for MND research, providing the infrastructure needed for accelerating treatments for MND.

Research into the cause, treatments and ultimately a cure for MND is a joint effort from the brightest minds right across the globe. This investment will accelerate the fantastic work already underway.



UPCOMING EVENTS



Our BIGGEST fundraising event of the year - Walk to D'Feet MND was a success!

The annual Walk to D'Feet MND Tasmania was attended by 196 participants who helped smash our \$25,000 goal. We have raised over \$34,000 and we can only say thank you to everyone who supported the event!

The Walk was held on Sunday 31 October at the Domains Athletics Centre in Hobart, and once more we had a fun-packed morning with face-painting, sausage sizzle, and various games on the oval.

All funds raised will stay in Tasmania to care for, and support, those individuals and their families currently living with MND.

We also want to say thank you again to all of the businesses that donated the wonderful prizes! We would like to send out a special thanks to Blundstone Footwear, Elite Appliances, Edge Running, Anytime Fitness, Daci & Daci, The Woolstore, Bream Creek Winery, Shambles, Spencers, Pennicott Tours and Harvey Norman for their continued support. We are also very fortunate to be supported this year by Spa180, Peattie Events, Glaetzer-Dixon Family Winemakers, Hill Street Grocer, Michael O'Keefe Photography and Zoo Doo.



MND Tas Website

Our website has gone through a complete redevelopment! We hope you will love it as much as we do. It is easier to find all the information you need, and it has a fresher look and feel. Our main focus when updating the website was to not only give it a fresher look and feel, but to also make your experience easier while using it. It is an information hub for members as well as a supporter hub with specific information and resources for Health Professionals.

Please let us know if you have any suggestions for the website 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.



GIVING



Christmas Appeal 2021

This year, our Christmas Appeal is a bit different... All proceeds raised through this Appeal will fund a wish for someone living with MND through our new BUCKET LIST WISH PROGRAM.

Living with motor neurone disease is incredibly hard for those diagnosed, and for their loved ones. This new initiative and pool of funds will be able to provide experiences, gifts or services to help make a wish come true, and give families a chance to create memories they can cherish together during an incredibly difficult time.

This is where we need YOUR help. The more we raise through our 2021 Christmas Appeal, the more wishes we can grant.

MND Victoria and MND Tasmania have focused on care and support programs to improve the lives of thousands of Victorian and Tasmanian families impacted by MND for the last 40 years. We are the only not-for-profit organisation providing direct care for

all Victorians and Tasmanians living with the devastating disease, at no cost to them. We are proud of the vital care, support, information and assistive equipment which we have provided to thousands of people living with MND over that time.

But there is one thing we are yet to tick off our list...

We kindly ask you to consider a donation to MND Victoria and MND Tasmania this Christmas. Your gift will help to make a wish come true, and give families a chance to create memories which they can cherish during an incredibly difficult time.

Help us to add another layer of support to the services we have been providing since 1981.

Visit www.mnd.org.au/christmaswish or scan the QR code above, top right.



We often hear "I wish I could..."

"I wish I could go skydiving." David

"I wish I could watch my footy team play in luxury." Peter

"I wish I could have a night to remember at Hamer Hall." Catherine

MND Victoria and MND Tasmania's Bucket List Wish Program will be able to provide experiences, gifts or services that will put a smile on faces and allow some solace from the daily burden of MND.

Proceeds raised through this Christmas Appeal will fund a wish for someone living with MND

MND ADVISORS AND NDIS SUPPORT COORDINATORS

Client Numbers

We are currently supporting 40 registered members:

| | |
|----------------------------------|----|
| North West Region Tasmania | 7 |
| North Region Tasmania | 16 |
| Southern Tasmania | 17 |
| TOTAL | 40 |



**CURRENTLY
SUPPORTING
40
REGISTERED
MEMBERS**



**DELIVERED
686
HOURS OF
SERVICE**

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



Above: Emma Forsyth
Left: Jenny Fuller

MND Advisors and NDIS Support Co-ordinators

Northern Tasmania: Emma Forsyth (Mon, Wed, Thurs):
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.






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

PO Box 379, Sandy Bay,
TAS 7006 Australia

Freecall: 1800 777 175

Charity ABN: 21877144292

 info@mndatas.asn.au
 www.mndatas.asn.au
 www.facebook.com/MNDTas