MND ADVISOR AND SUPPORT COORDINATOR SERVICE

Emma Wilkinson-Reed (based in Launceston) supports people living with MND in the North and North West Tasmania regions.

Jenny Fuller (based in Hobart) supports people in the Tasmania South region.

They both work in the role of Regional Advisor & Support Coordinator and continue to work very hard to support their members, providing information, support and advice, and connecting them to supports and services. They are also in regular contact with local health, disability and community service professionals and agencies to provide information and support for them as they work with people living with MND. Emma and Jenny are working hard to create supportive and collaborative relationships.

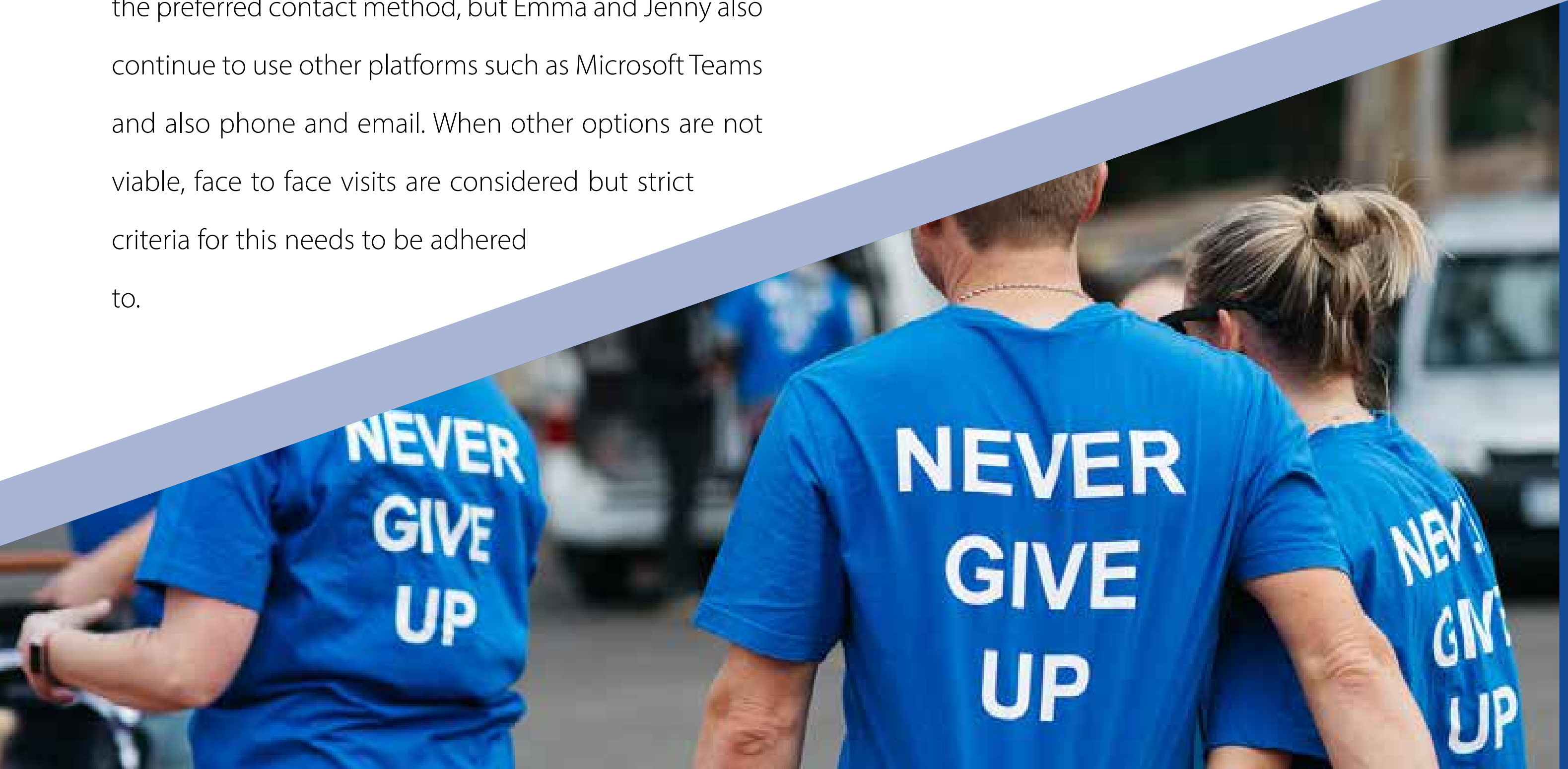
COVID-19

Emma and Jenny continue to work from home during the COVID-19 pandemic. Zoom with clients is currently the preferred contact method, but Emma and Jenny also continue to use other platforms such as Microsoft Teams and also phone and email. When other options are not viable, face to face visits are considered but strict criteria for this needs to be adhered to.

During COVID-19, MND Victoria have held a weekly live streamed event to their Facebook page on each Thursday evening called 'Zooming with Dan'. On June 19th, Emma featured on this with a client's son, Ben, from Flinders island. During this event both Emma and Ben spoke of supporting people who live in remote locations and who are using platforms such as Zoom. Ben also spoke of the difficult time in the lead up phase to getting MND diagnosis confirmed. This event really highlighted some of the work and support that both Emma and Jenny do every day, in support of people living with MND and Kennedy's disease in Tasmania.

Jenny and Emma are continuing to work on projects as requested. There has been ongoing work with the Keeping Connected project and with Multidisciplinary Teams in Tasmania. The Keeping Connected Project continues to explore how we can better support people with slower progressing MND or Kennedy's Disease in a meaningful way. We are working to develop a model for working with multidisciplinary teams for people living with MND.

Eric Kelly, Team Leader, Regional Advisor & Support Coordinator



CONTACT DETAILS

Emma Wilkinson-Reed

(photo top right)

Email: ewilkinson-reed@mnd.asn.au

or phone: 0456 182 551

Days of work: Mon, Wed, Thurs

Jenny Fuller

(photo bottom right)

Email: jfuller@mnd.asn.au

or phone: 0412 599 365

Days of work: Tues, Wed, Fri

Eric Kelly

Team Leader MND Advisor & Support Coordinator

Email: ekelly@mnd.asn.au

or phone: 0421 323 850

Days of work: Monday to Friday

CLIENT NUMBERS

We currently support 35 registered members in Tasmania:

North region—12

North-west—9

South—14

MND TASMANIA

PO Box 379, SANDY BAY, 7006

Charity ABN 21877144292

Telephone: 1800 806 632 (MND Victoria office so leave a message)

Email: info@mndatas.asn.au

Website: www.mndatas.asn.au

BOARD

MND Tasmania has a volunteer Board and no paid staff.

A member of MND Australia and of the Neurological Alliance of Tasmania.

President: Michelle Macpherson
Vice President and Secretary: Kate Todd
Public Officer: Chris Symonds

Treasurer: Julie Driessen

Ordinary Directors: Libby Cohen & Joyce Schuringa

MND ADVISORS & NDIS SUPPORT COORDINATORS

Northern Tasmania, Emma Wilkinson-Reed (Mon, Wed, Thurs): 0456 182 551, ewilkinson-reed@mnd.asn.au

Southern Tasmania, Jenny Fuller (Tues, Wed, Fri): 0412 599 365, jfuller@mnd.asn.au

Eric Kelly, Team Leader MND Advisor & Support Coordinator (Mon – Fri): 0421 323 850, ekelly@mnd.asn.au

FREECALL 1800 806 632

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

SHARING YOUR STORIES

We're hoping to use the voice of our members more in our communications and social media to raise awareness and help future supporters and ambassadors understand what it is like to live with MND, and what support from the community means for those diagnosed with MND or Kennedy's disease.

If you are happy to be interviewed to share your story or provide a few quotes that we can use from time-to-time, please contact us by writing to the Editor or send us a note via our email address and we'll get in touch.

If you would like to share a story in the next issue of the newsletter, please get in touch by 24 August 2020.

MND TASMANIA NEWS | July-August 2020

FROM THE PRESIDENT, MICHELLE MACPHERSON

Hi everyone,

Whilst our return to normal life feels imminent, though as mentioned by the Chief Medical Officer, COVID-19 will be with us long term, ensuring our members stay safe, now and into the future, is critical. Our wonderful advisors will continue to support members to stay as healthy as possible.

Ramping up our fundraising and online presence will be a key focus for the Board over the coming months as we recover from our postponed events during COVID-19.

COVID-19 has seen a national discussion on isolation and how to connect people during the pandemic. We know MND is isolating by nature, so we have taken this time to think about how we can better connect our members, so that you know you are not alone.

With so many amazing people living with MND, we want to connect you, through your stories. Members will be contacted over the coming weeks and be given an opportunity to share their stories via a short questionnaire, with an option to be contacted by Mary-Ellen, (our newsletter editor), and interviewed to share more.

We are always looking at ways to improve our member services and we will provide a summary from the recent survey results in our next edition. We were very pleased to know that Jenny and Emma are much loved by our members for the support they provide.

If you think there are other things we can do to build a stronger network or provide a better service, we would love to hear from you at **info@mndatas.asn.au**.

Michelle Macpherson, President

We hope this newsletter finds you safe and well

At the time of its printing, Tasmania had reached 40 + days without any cases of COVID-19, so we hope when this goes to print, we have further built on these great figures and continue to return to 'normal' life.

The response to the online Move for MND campaign has been staggering, with over $200,000 raised nationally! This has given us some ideas about how we could run online campaigns in the future to complement our traditional fundraisers.

Global MND Awareness Day took place on 21 June and, whilst we weren't able to run some events, we had some great support online and in State and Federal Parliament.

The pandemic has given us time to think about how we can better connect our members by sharing your stories; to create a community of MND Fighters, so you know you are not alone.

Thanks to members who responded to the survey on support provided. Responses were overwhelmingly positive, particularly in regard to the support provided by our two MND Advisors, Jenny and Emma (we aren't surprised!). In this edition, we have also included a reminder about the equipment and communication library available to our members.

North-West families

FUND-RAISING

Local fundraising events will ramp up from late July with restrictions easing. Whilst we have had to postpone some of our bigger events, we have raised around $13,000 since the last edition via the national Move for MND campaign – a great effort given the circumstances.

A key focus for us over the coming months will be to do more social media and build our online community of supporters, and 'regular givers' to supplement the generous donor support we already receive. If you aren't online, then hassle your kids, grandkids and anyone else in your network to follow us on Facebook.

The online campaign – Australia Moves for MND – has raised over $200,000 during the pandemic. This has been a sensational event for MND Australia and no doubt more campaigns like this will be seen in the future. A Tasmanian family raised over $8,000 of that total, following a diagnosis, and their story was featured in the Advocate – congratulations and thanks to the Hamilton family of Shearwater.

AWARENESS-BUILDING

Whilst social distancing stopped us having a formal event in Tasmania, there was a lot of online support to recognise MND Global Awareness Day on 21 June.

Members of Parliament from both State and Federal Government showed their support by wearing our cornflower. The Minister for Primary Industries and Water, Mr Guy Barnett, recognised the International MND Day in the Tasmanian Parliament on 24 June, recognising the impacts of MND on the broader community and the need to find a cure.

EQUIPMENT SUPPORT FOR MEMBERS

People who have MND may discover a rapid change in their need for Assistive Technology (AT) which can be complex, unexpected, expensive and previously unheard of. Advances in AT allow people to optimize function and independence. Funds donated to MND Tasmania provide a financial contribution for the provision of essential equipment and home modifications.

A new benefit is now offered to members to provide a financial contribution for other specific purposes that may be recommended by a Health Professional or the MND Advisor. MND Advisors can provide information and advice on what may be eligible for this assistance.

MND COMMUNICATION EQUIPMENT LIBRARY

When a person with MND is experiencing difficulties with speech, an early referral to a Speech Pathologist or an Occupational Therapist with expertise in 'Communication' is important.

The MND Tas Communication Equipment Library, established in 2017 in collaboration with Fight MND, is managed by ILC Tasmania, a state-wide organisation. A variety of communication devices are available for loan to members from the library. The library works with the referring Speech Pathologist to provide the most suitable equipment for each person.

For further advice on any of these Member Supports or the most suitable Health Professional for you and your needs, contact the MND Advisor.

RESEARCH

In the next edition, we'll feature the Menzies Centre MND Research team. Having this amazing team in our own backyard gives us unique access to the research. As mentioned in the last edition, the team generously gave up their Sunday to talk to us at the AGM and the insights were fascinating, so we're eager to share more of this with you.

The research arm of MND Australia is focussing on building stronger collaborations across all research facilities, (both nationally and internationally), to ensure there is no duplication of effort. Planning is underway for a National MND Summit in conjunction with FightMND; with the Annual MND Research meeting taking place in Brisbane later this year.

MND Australia also sent a letter to the Minister for Health, the Hon. Greg Hunt, to highlight the issues faced by MND researchers in Australian universities in light of the COVID-19 pandemic, and the support that is urgently needed to continue MND research. Great to have MND Australia advocating for us.

IMPORTANT INFORMATION

NORTH WEST TASMANIA MND SUPPORT GROUP

The contact person is Junene Stephens at 1800 806 632 (message) or email info@mndatas.asn.au

NEW MEMBERS

We welcome new members living with MND and their families to our community, network and services. We encourage you to contact any of the MND Tasmania team, including the board and our MND Advisors (who are also our NDIS Coordinators of Support).

VALE

We extend our heartfelt condolences to the family and friends of those who have recently passed away, including Peter Gaffney, Oliviero Venettacci and Alain De Sousa. A generous donation was sent by the East Launceston Bowls Club in honour of Alain.

DALLAS HANSON'S STORY

MAKING THE MOST DURING COVID-19 TIMES

Dallas was diagnosed with MND on February 16. We had just returned from three weeks of swimming and body surfing in Port Macquarie.

As we both enjoy swimming, we started going to the open pool in Glenorchy, Tasmania, every second day. We used to walk three or four times a week but that has become impossible. Swimming is a form of exercise which Dallas can still enjoy. We knew the pool would be closing at the end of March, as it did every year. But this year the coronavirus closed it even earlier.

We decided to start swimming in the sea. The water was fresh but after the first ten or twenty seconds, once our bodies acclimatised, the experience was lovely. We both just loved being back in the sea and so we continued to go swimming every second day. Of course, in the process we have acquired a lot of cold-water swimming gear. Dallas loves gear, particularly gear with 5-star reviews. Dallas now has a watch with a thermometer - so that he can measure the temperature every time we swim. This has fast become one of his favourite activities. So far, the coldest we have swum in is 12.1 degrees. It will get colder. We swim for around 20 minutes. If we swim for longer, our feet and hands turn numb and it becomes exhausting.

A good wetsuit and hat, and gloves, and boots are essential in cold water. There's a huge variety of wetsuits now because of the popularity of triathlons (where the swimming component is often the hardest). Dallas bought an Orca wetsuit - one called '3.8' that supports the legs and torso with some fancy air bubble product. But he is now aspiring to a 'Blueseventy thermal reaction' that is designed for very cold water, and that has furry pink stuff as lining. Dallas figures he can still swim, sort of, when/if the legs totally collapse. The hat of choice is 3mm thick and is called 'flash bomb'. He now also has new booties that are 5mm - very thick- and, so far, they keep his feet really warm.

Our friend Annie now joins us. As do Dallas' son, Jamie, his partner, Gabrielle, and their 4-month old son, Wulfy. Dallas, Annie and I swim first, then we look after Wulfy while Jamie and Gabrielle have their swim.

Post swim, the key is to change into dry, warm clothes as quickly as possible. Then we hang around just a little bit longer to have cups of hot tea from a thermos and unlimited chocolate biscuits. Swimming is now one of the highlights of our week. Of course, it is easier to love when it is a still, sunny day, as it was when the photo below of Dallas and me was taken. But we love our cold water swims no matter what the weather is, and we hope to continue with them for as long as we can. I have said that 10 degrees might be my limit... but we will see.