

CLIENT SURVEY REPORT

MND Tasmania, in partnership with MND Victoria, delivers an Advisor and Support Coordination Service for people living with Motor Neurone Disease and Kennedy's Disease in Tasmania.

Information and advice about these diseases, supports and services, are available through the Tasmanian Advisors based in Hobart and Launceston, who are supported by the Information Service based in Victoria.

The Tasmanian Annual Quality Survey seeks feedback from current clients to help further develop and improve the delivery of services. In May the survey, consisting of twenty-six questions, was sent to all current Tasmanian clients. In total thirty-six surveys were sent out and eighteen (50%) were completed.

The Board of MND Tasmania were very encouraged to read that there was an overwhelmingly positive response to our quality survey with 'satisfaction with services' rated as good, very good or excellent across news, website, information and Advisor Service. All those who use the NDIS Support Coordination Service were happy with this service and frequency of contact.

The purpose of this survey was to identify and classify any areas where services could be improved, such as better awareness of our Communication Library. The results from the survey will enable the

MND Tasmania Board, the team from Tasmania and Victoria to identify and implement strategies to enhance these services.

Here are just a few of the comments received commending our wonderful Advisors;

"Brilliant contact service; very personable with excellent communications ability"

"Super friendly, helpful and makes you feel you are a person with a difficulty, not a statistic"

"Feeling that my family will have the support they need when they need it and just knowing someone is able to guide me on my journey"

If you would like information on any of the resources provided, please contact the MND Victoria office (contact details on the back page).

IMPORTANT INFORMATION

Northern MND Support Group/Coffee Club – This new group meets at 11am on the first Monday of each month (or the second Monday if a public holiday falls on the first) at Selah Café – Door of Hope – 50 Glen Dhu Street, South Launceston. Please let Emma Forsyth know if you will be attending so a suitably sized space for the group can be reserved on the day. eforsyth@mnd.asn.au or 0456 182 551

North West 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 Supports).

VALE

We extend our heartfelt condolences to the family and friends of those who have recently passed away including Allan (Bill) Radcliffe, Roslyn Beaumont and Stephen Collins.

CLIENT NUMBERS

We currently support 41 registered members in Tasmania

✿ NORTH REGION-15

✿ NORTH-WEST-9

✿ SOUTH-17



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. The association is 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 Forsyth (Mon, Wed, Thurs) phone 0456 182 551 email: eforsyth@mnd.asn.au
Southern Tasmania: Jenny Fuller (Tues, Wed, Fri) phone 0412 599 365 email: jfuller@mnd.asn.au
Eric Kelly, Team Leader MND Advisor & Support Coordinator (Mon – Fri) phone 0421 323 850 email: 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 an MND Advisor, you will be asked for your contact details and your call will be returned by that person as soon as possible.

SHARE A STORY

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



MND TASMANIA NEWS | September-October 2020

FROM THE PRESIDENT, MICHELLE MACPHERSON

Hi everyone,

We hope this newsletter reaches you safe and well, as always.

COVID has been a harrowing time for everyone, so we thought it a good time to point you in the direction of a suite of new mental health resources created by the University of NSW. Funded by a grant from MND Research Australia, these are now available on their website and we recommend that you, or your loved ones, take a look: https://www.3dn.unsw.edu.au/sites/default/files/documents/FactsheetMND_plainenglish.pdf

One of our advisors, Emma, recently visited Flinders Island. Emma and Mimi, who is an OT and often works with Emma, delivered an information/education session at the hospital which was received with a great deal of positivity. Great to see them going above and beyond (quite literally) to get out and support our community.

Last month we also saw the continued Royal Commission into Aged Care confirming the shocking tale of discrimination and neglect of people in the

Aged Care system and the unfolding misfortune in residential aged care. MND Australia called on the Government to end discrimination and urgently invest to support older people with disabilities. A copy of the statement can be found on our website and it is anticipated that the final report of the Aged Care Royal Commission will be handed down next February.

We will continue to ramp up fundraising and our promotion program over the coming months as life, hopefully, returns to normality for us. Keep an eye out as we are planning a virtual Walk in the next few months and remember to spread the word! We were successful in receiving a FightMND grant of over \$5,000 that went towards equipment for our members, so that is great news.

We have also received the results from our Annual Quality Survey sent to all our members living with MND or Kennedy's Disease. The results were very encouraging and further details are included in this edition.

As always, 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

FUNDRAISING

MND Tasmania has received a FightMND equipment grant of \$5,685! This generous donation will go towards the purchase of devices and other items that will expand the range of equipment in the Communication Equipment Library. Items to be added to the library are:

- Small communication devices
- Falls detector/alarm devices
- Hard cases for high end communication devices
- Amazon Echo device – assists making video calls while using a text to speech communication device

The key enabler to establishing the MND Tasmania Communication Equipment Library was the initial FightMND grant in 2017. Both organisations work collaboratively in providing a range of communication devices that will cover the needs of our members living with MND.

The Independent Living Centre Tasmania (ILCTas) manages the library on behalf of the association. Speech Pathologists and Occupational Therapists with expertise in communication, are the health professionals who provide assessment and trials with the most suitable equipment for a person with communication difficulties. Your health professional or MND Advisor can give information and advice on who to go to for the correct assessment and management.

Thank you to FightMND for continuing to work with MND Tas in delivering the best support for people living with MND.

During August we received a donation of \$1825.00 from the East Launceston Bowls Club. This group holds a fundraiser yearly in honour of their life member Alain DeSousa who was diagnosed with MND and unfortunately that brought an end to him

playing the game he loved so much. On 27th May this year Alain passed away after fighting a long and strong battle with MND and we sincerely thank all the people that supported this fundraiser which will enable us to continue to help others living with MND in Tasmania.

AWARENESS-BUILDING

We, like so many other non-profit organisations, have been restricted in getting out and about as much as we would like to raise awareness of MND. As the majority of COVID-19 restrictions have been removed, we will be ramping up over the coming months!

During August we wrote to the Health Minister, Sarah Courtney, to request further information regarding the timeline for the promised and much needed extra palliative care beds in the North-West. We will hopefully have more information to follow in our next edition.

RESEARCH

The North West MND Support Group has made a generous donation of \$3,000 from their local fundraising efforts. As requested by the group we have forwarded this amount directly to Menzies Institute of Medical Research for MND Research. We are extremely thankful for the hard work this group do in our community and for their continued support.

We are still looking to get inside the lab at the Menzies Centre to talk with the team about their MND Research. When confirmed we will provide an update in one of our 2021 Newsletter editions.

MND ADVISOR & SUPPORT COORDINATION SERVICES

Emma recently travelled to Flinders Island. Along with Emma was Mimi, an Occupational Therapist. Whilst on the Island they delivered an information session at the hospital to help them consider strategies that they could implementing in the future to support people living with MND and Kennedy's Disease.

Picture below of Emma and Mimi as they board their scenic flight home which took them over snow-capped mountains (glad they aren't worried about small planes).



AN UPDATE FROM ERIC AND THE TEAM!

COPING WITH COVID!

Emma and Jenny continue to work from home during the COVID-19 pandemic. Zooming with people living with MND and Kennedy's disease is currently the preferred contact method, but Emma and Jenny also continue to use other platforms such as Microsoft Teams and phone and email. They can visit clients if strict COVID-19 criteria are met.

As shown, Emma has recently had a work trip to Flinders Island to support a person living with MND, their family and the local health workers. It is very exciting to be reaching into these remote locations.

The recent Keeping Connected working party, on which Jenny was a key worker, has now completed and recommended that a Keeping Connected MND Advisor Support Coordinator position be advertised. This person will work across both Victoria and Tasmania to support people over 65 years, with slower progressing MND as we continue to explore how we can better support people with slower progressing MND or Kennedy's Disease in a meaningful way.

This person will work with Emma and Jenny. There will be more news to follow when an appointment has been made.

Jenny and Emma are continuing to work on projects as requested, including ongoing work with Multidisciplinary Teams in Tasmania. There has been ongoing work with Multidisciplinary Teams in Tasmania. Jenny and Emma have surveyed Health Professionals in the 3 regions of Tasmania to ascertain how to best provide multidisciplinary care and support. Work is ongoing in this space.

EQUIPMENT SUPPORT FOR MEMBERS

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 Tasmania Communication Equipment Library, established in 2017 in collaboration with FightMND, is managed by ILC Tasmania, a state-wide organisation. Members may access a variety of communication devices on loan from the library. The library works with the referring Health Professional to provide recommendations on 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 your MND Advisor.



NATIONAL SUPPORT SERVICES (NSS) MEETINGS



Photo of some of the 60+ NSS MND staff from across Australia. Jenny is, far right second row and Emma, far left bottom row

During August there was a series of meetings with all the MND support service staff from across Australia. These meetings took place as 4 x 2 hour Zoom meetings, which discussed professional development, resource sharing and linking with and supporting each other across Australia. Both Emma and Jenny were active participants in these meetings. General topics discussed included:

- Update from Carol Birks, MND Australia.
- MND NSW Ask the Experts: Live streamed on Facebook with a focus on MND research
- External Speaker: Jodie Cooper, Positive Psychology, Focus on Resilience, Self-care; Complexities surrounding Working from Home in the Current Climate
- Group Discussions re: Holistic MND – Head to Toe Perspective; and Travelling with MND – Holidays & Permanent Moves

Eric Kelly,
Team Leader, Regional Advisor & Support Coordinator

If you need further information about access services or information contact either Emma, Jenny or myself or email the information team at info@mnd.asn.au