



September - October 2018

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MND Tasmania 1986-2018: *supporting people living with MND in Tasmania for 32 years*

Advocacy

In this month's edition of the newsletter in 2017, we published a report on our advocacy. One of the "things we do" as MND Tasmania and as stated in our external strategy paper is to "engage in advocacy/lobbying". A copy of that newsletter and more information can be found on our website and at www.mndatas.asn.au/files/MND_Tasmania_External_Strategy_2018.pdf

It is interesting to see the four sub-headings (1 – 4) of a year ago and what has changed and stayed the same!

1. State-wide Neurology Services

Rumours of neurologists being appointed have abounded since Dr Koshy's departure in 2017 but at the time of writing in August we are still waiting for confirmation of the promised appointments of two or three neurologists in north/northwest Tasmania.

2. Neurological Nurses

Two additional specialist neurological community nurses to support people with neurological diseases in Tasmania have been appointed by the Tasmanian Health Service this year. Although they accept referrals to assist people with MND, their time is largely allocated to the needs of the many people with Parkinson's disease.

3. MND Advisor

This role continues to be indispensable in assisting and supporting people with MND.

Although NDIS and MyAgedCare funding should enable appropriate services address the needs of

people with MND and their families, we are still here to try to fill the many gaps.

Our MND Advisor service has been provided through a Memorandum of Understanding (MOU) with MND Victoria since 2007 and has been funded by grants, philanthropic funds and donations.

A new 2018-2021 MOU has been signed in August by the CEO of MND Victoria and the President of MND Tasmania. This forms a new milestone in our partnership as we have agreed to double the hours of the MND Advisor service in Tasmania for the next three years. The donations to MND Tasmania and fundraising achieved during the past 10 years are vital to the ongoing existence of this service which is invaluable to our members who have MND and their families.



As a key purpose of the Board is "to support people living with MND, to share their experience and understand the challenges they face" (External Strategy paper – see above for

website address), MND Tasmania has established a Care Foundation to underpin ongoing funding for the State's MND Advisor position.

As our Association is run by volunteers, we are grateful for the support of the Council and staff of MND Victoria who assist with providing ongoing support for people with MND in Tasmania, their families and their health and support workers.

4. Legislative Council Inquiry into acute health services in Tasmania

In 2017 the Neurological Alliance of Tasmania (NAT) submitted a paper to this Inquiry and MND Tasmania contributed case studies to illustrate how the issues affect people living with MND requiring hospital services. The outcomes of the Inquiry have not yet been released.

5. New issues a year later:

5.1 National advocacy—As MyAgedCare and NDIS have largely taken over responsibility for funding services for people with disabilities and are funded by the Commonwealth government, the role of lobbying on our behalf has been led by MND Australia (MNDA). Carol Birks, CEO of MNDA, has met with the Board of MND Tasmania twice during the last 12 months and has frequent meetings with the relevant Ministers and public servants based in Canberra to inform them of the special and unique needs of people with MND, to provide specific educational material about MND and to push for funding for appropriate and timely care and support.

5.2 State advocacy—MND Tasmania through its participation in the NAT has continued to communicate with the Minister for Health and meet with his staff to address the significant gaps in services, particularly as State services are withdrawn in the expectation that the private sector funded by NDIS will provide appropriate services.

5.3 NDIS participants—Our MND Advisor service's role now includes the provision of Coordination of Supports and Assist Life for people with MND who are eligible for NDIS funding.

Of the many new providers of services for NDIS participants, the MND Advisor is the only Support Coordinator in the State who has the specialised knowledge and proactive understanding of the best pathways and services for people with MND. It

appears that NDIS allocates support coordinators randomly so it is vital that our members ask their NDIS Planner for the funding to receive coordination of support from our MND Advisor.

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 staff member Hayley Tristram who is the MND Advisor for Tasmania and our NDIS Coordinator of Supports. Board members may also be contacted. The contact details are on the back page. The MND Advisor service is managed on our behalf by MND Victoria and Hayley is based in Launceston. She travels Statewide as required to support our members on a needs-basis.

Vale

We extend our heartfelt condolences to the families and friends of Ian Bryan, Gloria Keil, Amber Phoenix, Leigh Talbot, Adrian Bond and of any other members who have recently passed away.

Donations

Thank you to those members and donors who have been sending a donation after receiving a newsletter.

In addition to the donors mentioned in the Fundraising report, we really appreciate the donations sent in by others including the staff of Crowe Horwath, Launceston.

Vital Statistics

Annual data from the State and Territory MND associations is collected by MND Australia.

The data collected from MND Tasmania during July 1 2017 – June 30 2018 revealed the following information -

- There were 70 members of MND Tasmania at 30 June. (We are a small bunch of people!)
- 45 members of the Association had MND at 30 June. (So there were 25 members who joined to support people with MND).
- 25 new members with MND joined the Association during the year.
- 19 members who had MND died during the year.
- 0.42 FTE (or 0.42 x 38 hours per week) of care and support were provided by the MND Advisor.

- 28 face to face visits were provided to members with MND during the year.
- 377 electronic communication contacts (via, phone, email, skype, etc) were undertaken between the MND Advisor and members with MND.
- About 25 volunteers supported the Association with specific tasks during the year.
- 20 items of equipment were partially or fully funded for 16 members with MND.
- 3 members had home modifications partly funded by the Association.

In addition -

- 100% of funds which are specified for research by the donors are sent to the MND Research Institute of Australia (MNDRIA). The Institute has been funding Australian research (including the Menzies Centre in Tasmania) into MND since 1984.
- 100% of funds not allocated to research are utilised to support people living with MND in Tasmania. As the Association's financial year is January 1 – December 31, the annual audited financial Statement is presented at the AGM in March every year. Copies can be requested from the Board Secretary at email info@mndatas.asn.au or phone 1800 806 632 (message).

Fund-Raising and Awareness-Building

BUNNINGS BBQ

On Sunday the 9th September we had some of our very loyal and organised fundraisers selling sausages and spreading the word on this devastating disease. Eager not to miss an opportunity, merchandise and raffle tickets were on sale also. We will be able share some photos with everyone and let you know the outcome of these efforts in the final newsletter for the year in December.

GLOVES FOR A CAUSE

On the 31st October the students from year 8 at Scotch Oakburn College are hosting an open night where they showcase their special projects they

have been working on through the year. Basically, the students were required to choose a topic or charity to either fundraise or raise awareness for. Tom Gatenby decided he wanted to support MND Tasmania and will be selling kitchen gloves which have had our MND logo applied. Now that is thinking outside the box! We hope to be able to show you a picture of the gloves and let you know how the night went in our next edition.

FRANCESCA JEWELLERY

We are very excited to let you know that Francesca Jewellery will be releasing a limited edition MND awareness bracelet for the month of December. These will be handmade in Tasmania by the Francesca team, creating beautiful pieces whilst raising funds for our cause. I can't wait to get mine and I can't think of a better Xmas present to give.

Note: This is not the actual bracelet, just an indicative picture of styling.

ENTERTAINMENT BOOKS

Please help us to promote the sale of the Entertainment Books. For each book sold we receive 20% of the cost, so far this



year we have raised over \$800. Visit our FB or Website for the link to get yours today:

<https://www.entertainmentbook.com.au/orderbooks/24004m3>

MERCHANDISE

We are building a great range of Tasmanian branded MND merchandise. If you are thinking about holding a fundraiser for MND or know someone that is, please contact us so that we can help make your event as successful as possible.

Once again, a big **THANKYOU** to all our generous fund-raisers and awareness-builders, it is only through your work that we can continue to provide specialised care and support to the Tasmanian community. **#togetherwecan**

If you have any queries regarding fundraising please direct them to fundraising@mndatas.asn.au



See you all at our Walk to D’feet MND.

Michelle Macpherson, Fundraising coordinator

MND Advisor's Report

MND Victoria and Tasmania have signed an agreement to double the time of the MND Advisor position for the three year period 2018-2021. This will bring it up to two staff working the equivalent of 4 days per week.

Hayley has had an increasing workload due to the inclusion of the younger people with MND into NDIS this year. The workload caused by NDIS will increase as it rolls out in full during 2019. Also, the number of MND Tasmania client members with MND at any one time is now consistently over 40. This increase from over 30 has occurred since 2010 and the cause is unknown. However, it is in line with that experienced in the other State MND associations.

Since we commenced the MND Advisor position to support people with MND, the role has been funded by philanthropic grants and donations for 9 years and by the Federal government via Tasmanian Medicare



Local for 2 years. Donations to MND Tasmania have increased during this time and MND Victoria continues to be committed to the people with MND in our state with generous financial and administrative support.

The new position is being advertised and we hope to fill it this year.

Thank you to all those members and supporters who have donated funds to provide the MND Advisor position for the people with MND in Tasmania and their families who need this vital care NOW.

Joyce Schuringa, President

9th National MND Conference

Informing Influencing Innovating



This year's National MND Conference for over 200 people who have MND or have an interest in MND was held in Adelaide on Friday 31 August 2018.

Unfortunately our MND Advisor Hayley Tristram had to cancel her booking due to illness. Five Board members were able to attend the conference and associated meetings to report, learn, network and meet with MND Victoria staff to improve administration processes, advocacy and services for our members with MND, their families and health practitioners. Our reports will be published in the next newsletter.

The President also attended three meetings on Thursday 30 August which comprised of the first two hours of the day's meeting of the support services staff attended by all of the MND Advisors in Australia (except for our Hayley), followed by the meeting of the MND Executive Management Group (= CEO's and executive directors of the other Australian MND associations) and then in the afternoon, the MND Australia Board meeting (as the director for Tasmania).

Further information about the proceedings of the Conference can be found on the MND Australia

Until there's a cure ...there's care

**WALK To
D'FEET
MND**



10am, Sunday 21st October 2018 Athletic Centre, Queens Domain, Hobart

Adults \$35, Children \$15 (5-16yrs), Families \$80 (2 adults + 2 children or 1 adult + 3 children)

5 km walk around the track of the Athletic Centre. Plus: Sausage Sizzle, Raffle, Face painting, Activities for the kids, Disabled Parking for people with MND.

Awards for: Highest individual fundraiser and Highest Team fundraiser

Register on line at: <http://www.mycause.com.au/events/walktodfeetmndtasmania>

If you haven't registered there is still time!! Walk a lap of the track or run the full 5km

Get a team together, bring the family, kidnap some strangers or come by yourself – we would love to have you there to show the world WE are determined to help find a cure and until such time we will never stop caring about those that have been affected by this horrid disease.

If you can't make it on the day you can still support the event by leaving a donation on the MyCause page or purchasing some raffle tickets, all monies raised stay in Tasmania.

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website at www.mndaust.asn.au/national-conference/

Equipment update

People who have MND discover a rapid change in their need for assistive technology which is often complex, unexpected, expensive and previously unheard of. This includes modifications to the home and to their vehicle or a new vehicle. A tangible use of the funds donated for our members with MND is the assistance we can provide with the provision of such equipment.

During the year July 1 2017 – June 30 2018, our Association assisted members as follows -

Home modifications – We contributed \$7,083 to 3 members as partial or full funding for vital changes to their homes.

Equipment – We contributed \$31,865 to 16 members as partial or full funding for 20 items of essential equipment for them to use to enhance their life.

Communication equipment – MND Tasmania owns the Communication Equipment Library which was established with funds donated by Fight MND and is managed on our behalf by the Independent Living Centre (ILC). Currently 7 of our members have 10 items on loan including eye gaze systems, direct or switch access communication systems, voice amplification devices and a rolling floor mount.

All assistive technology prescription and supply is managed by the MND Advisor and the referring health professional.

Thank you to our fundraisers and donors who have provided the money for these services when gaps in government funding would result in otherwise unmet need.

Libby Cohen

Equipment coordinator

Northwest Support Group

The NWSG in Ulverstone invites all MND Tasmania members and supporters to its monthly meetings -

WHEN: The first Tuesday in every month at 10.30 a.m. The next meetings are planned for 2 October, 6 November.

WHERE: Ulverstone Returned Serviceman's Club, 21 King Edward St., Ulverstone.

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

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

MND Tasmania has a volunteer Board and no paid staff. A member of MND Australia and of the Neurological Alliance of Tasmania.

Board

President: Joyce Schuringa

Vice-President: Libby Cohen

Secretary: Kate Todd

Treasurer: Julie Driessen

Public Officer: Shane Chugg

Fundraising: Michelle Macpherson

Logistics: Dr Andrew Moy

Ex-officio support: Chris Symonds

MND Advisor

Hayley Tristram, Phone 0412 599 365

Email: htristram@mnd.asn.au

Support Service

MND Tasmania and MND Victoria work together to provide the MND Advisor service which is based in Launceston and provides State-wide support for members.

Services include:

- needs-based support and assessment, home visits and referrals to appropriate care and support services as required
- information and member support by telephone on 1800 806 632, Monday-Friday, 9am – 5pm
- information, support and training for service providers for people with MND in Tasmania
- free membership and bi-monthly newsletters from MND Tasmania and MND Victoria for people living with MND in Tasmania.

Freecall 1800 806 632

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

MND Tasmania News

Please tell us your stories! Send them to the Editor at our postal or email address. The deadline for the next issue is 31 October 2018.

