



In this edition

Support service update... New publication *I have MND. Now What?*... Australian Motor Neurone Disease Registry... Register now for Walk to d'Feet MND Hunter... Thanks Illawarra... Can you help during MND Week?... and more

A Message from the CEO

The cover photo above features the North Cronulla U23 surfboat crew in their new boat sponsored by David Hammond, putting the MND cause front and centre. The full story can be read on page 2.

In a surfboat the crew try to work together and do their best to make their way through swell after swell. There are moments of calm, moments of turbulence, moments of joy, moments of fear and sometimes, all the crew can do is just hang on. This has much in common with life after a diagnosis of MND and in this edition of e-news we feature a great update on how MND NSW services across NSW, ACT, NT and the Gold Coast can assist you (see page 3).

The growth in our Support Service has largely come about through supporter donations and bequests and is guided by feedback from our members through ongoing feedback and our biennial survey. Thank you for your generosity.

Graham Opie

MND NSW provides information, support, education, services for people living with motor neurone disease, their families, friends and carers, health, community and residential care professionals in NSW, ACT, the Gold Coast and NT.



Winning for MND

David Hammond's 53-year-old sister Jane was diagnosed with MND so he decided to sponsor a new North Cronulla Surf Lifesaving Club surfboat emblazoned with MND awareness details and dedicated it to not only his sister Jane's fight but also to Peter Whitford, a North Cronulla Club stalwart who had died from MND. In February the North Cronulla U23 crew represented NSW (in the interstate series) and Australia (in the Trans-Tasman series against NZ) at Eloura Beach, NSW, winning both in Jane's boat. The North Cronulla Open Women's team also raced in Jane's boat and placed 1st in the Australian Surf Rowing League 2018 Championships. Well done all.



On the Central Coast

Since 2013 Wendy Whitmore has been supporting MND NSW with various fundraising activities on the Central Coast, including a Christmas Wrapping fundraiser in late 2017 raising \$2,300. Thank you Wendy, and the merry band of supporters on the Central Coast, for your continued support.

Introducing new staff...

Ruth Yuthok | MND Advisor - Western Sydney, Blue Mountains, Central West

I have worked for many years across the health sector, from local service provision in community centres, not for profit organisations, hospitals and aged care facilities, to working on specific government health programs.

I have met such a passionate and supportive team at MND NSW and feel inspired to be working alongside them. I look forward to meeting and speaking with our members and their families and/or carer teams.



Support Service Update

Gina Svolos - Manager

MND NSW supports people living with MND in NSW, the ACT, Gold Coast and NT. We provide services to over 540 people living with MND and estimate that over 90% of all people with MND in these areas are linked with us.



MND Advisors

MND Advisors have always been a key component of the services MND NSW offers to members. Our nine MND Advisors provide support, information and advocacy for all members, whether aged 65 years and over, or under 65 years. MND Advisors assist members to link in with services they are eligible for including the NDIS and My Aged Care. They are also able to assist with pre-planning for the NDIS and may be able to attend NDIS planning meetings with members. MND Advisors cover all areas of NSW, Gold Coast and the ACT.

Coordination of Support (COS) and the NDIS

As the NDIS is a new way of delivering services to people under 65 years, we are providing support for people with MND who are NDIS participants through our Coordination of Support (COS) service. We are experienced in negotiating the systems of the NDIS with the aim of getting the best plan possible for people under 65 years. MND NSW has seven COS staff who are currently linked to 90 people. We offer the COS service across greater Sydney, Central Coast, Newcastle and the Illawarra.

FlexEquip

FlexEquip is a service offered through MND NSW. FlexEquip provides assistive technology to all people with motor neurone disease in the ACT and NSW at no direct cost to the individual and to people with rapidly progressive neurological disease who are eligible for the NDIS. In 2017 FlexEquip provided 1694 pieces of equipment usually within seven days of receipt of a referral.

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MND Information Line

The MND Information Line can be contacted ph. 1800 777 175 or 02 8877 0999 Monday to Friday during business hours or email infoline@mndnsw.asn.au. We receive over 3,500 calls and emails to this line each year from people seeking information or advice about MND. The Information Line is often the first point of contact for people who are newly diagnosed with MND.

Education and training

MND education and information sessions are held throughout the year in Sydney and other areas of NSW and ACT. There is usually no charge to attend an MND NSW education or information session if you are a person living with motor neurone disease, a family member, carer or friend. We also provide in-service and other educational events for service providers

Support groups

MND support groups and coffee mornings provide the opportunity for people living with motor neurone disease to meet together regularly to chat and learn from each other. Regular meetings are held in the ACT, Campbelltown, Central Coast, Gold Coast, Illawarra, North West NSW (Tamworth), Northern Beaches and Northern Sydney. Meetings are also held from time-to-time in the Northern Rivers and Wagga Wagga/Albury areas.

Information and publications

MND NSW has a range of resources available to provide information about MND for people living with MND, their family, friends and service providers. This includes the MND NSW

- **website** - an excellent range of fact sheets, publications and services and resources directory available at www.mndnsw.asn.au
- **print publications** aimed at people living with MND, their families including children, health and community care providers
- **MND e-news** – a monthly e-news to help you keep up to date as well as a print edition mailed to members every three months.

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We are constantly reviewing and updating our resources about living with MND and below is information about our new publication *I have MND. Now What?*. The concept was initiated and developed by Paul Watson, one of our members, and Anna Fulford, a NSW physiotherapist. We worked with Paul and Anna on production and are pleased that all people living with MND in NSW, ACT and NT can benefit from this quick reference list. We are grateful to Paul and Anna for the time and thought they each contributed to this project.

In the coming months we will be undertaking our biennial member feedback survey and we encourage you to participate. However, please do not wait for the survey to provide us with any feedback you might have - we really appreciate feedback, at any time, about your experience with us and how well we are able to meet your needs.

Gina Svolos

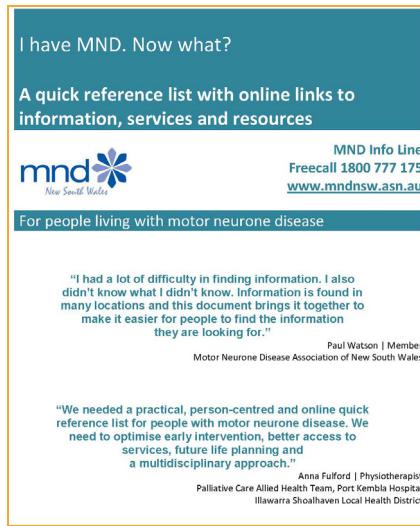
New publication

I have MND. Now What? is a 15 page A4 quick reference list with online links to information, services and resources that may be of interest to people living with MND in NSW, ACT and NT.

“I had a lot of difficulty in finding information. I also didn’t know what I didn’t know.

Information is found in many locations and this document brings it together to make it easier for people to find the information they are looking for.”

Paul Watson | Member, MND NSW



I have MND. Now what?

A quick reference list with online links to information, services and resources

mnd
New South Wales

MND Info Line
Freecall 1800 777 175
www.mndnsw.asn.au

For people living with motor neurone disease

“I had a lot of difficulty in finding information. I also didn’t know what I didn’t know. Information is found in many locations and this document brings it together to make it easier for people to find the information they are looking for.”

Paul Watson | Member
Motor Neurone Disease Association of New South Wales

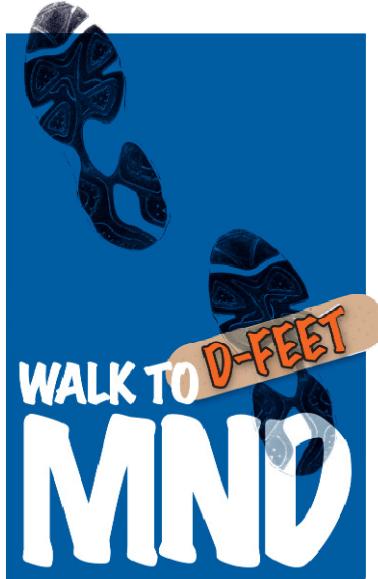
“We needed a practical, person-centred and online quick reference list for people with motor neurone disease. We need to optimise early intervention, better access to services, future life planning and a multidisciplinary approach.”

Anna Fulford | Physiotherapist
Palliative Care Allied Health Team, Port Kembla Hospital, Illawarra Shoalhaven Local Health District

“We needed a practical, person-centred and online quick reference list for people with motor neurone disease. We need to optimise early intervention, better access to services, future life planning and a multidisciplinary approach.”

Anna Fulford | Physiotherapist, Palliative Care Allied Health Team,
Port Kembla Hospital, Illawarra Shoalhaven Local Health District

View the free booklet version on screen with clickable links or find out more information here



Walk to d'Feet MND Illawarra

Bulli Surf Club

Bulli

Illawarra turned on a beautiful day on 18 February for our first Walk to d'Feet MND of the year.

Over \$20,000 was raised with 356 families and friends showing their support for people living with MND and walking in memory of a loved one lost to this dreadful disease.

A big thank you to the Bulli Surf Club who hosted this event again this year. The Surf Club have supported this Walk since the very first one six years ago. Thank you also to our local coordinator Shelly-anne Demirov and the many volunteers who give up their time to assist at this event. Thanks also to the crew from the Woonona Lions Club who always provide a yummy sausage sizzle. Well Hunter it's time to see what you can do.



Supported by



Together, let's take steps to d'Feet MND

Join us at a 2018 Walk to d'Feet MND. The name of this event reflects the hope and inspiration these special days provide for the MND Community. Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with motor neurone disease. Why not join in the fun at a 2018 Walk to d'Feet MND?

25
Mar

Walk to d'Feet MND Hunter
Dixon Park, Merewether

Supported by
Leah Jay
the property management specialists



CAPTURE IMAGING
PHOTOGRAPHY



24
Jun

Walk to d'Feet MND Canberra
Peace Park, Parkes, ACT



15
Jul

Walk to d'Feet MND Penrith
International Regatta Centre, Castlereagh



26
Aug

Walk to d'Feet MND Batemans Bay
Corrigans Beach Reserve, Batehaven



16
Sep

Walk to d'Feet MND Port Macquarie
Westport Park, Port Macquarie



14
Oct

Walk to d'Feet MND Wagga Wagga
Apex Park, Wagga Wagga



4
Nov

Walk to d'Feet MND Sydney
Blaxland Riverside Park, Olympic Park



Past Carers Lunch

26 March at MND NSW Centre Gladesville

This is a lunch and get together for people who have experienced bereavement during the last year. This occasion provides an opportunity for you to reconnect with old friends from MND NSW and to meet others who have cared for someone with MND. After lunch there will be a talk and discussion about some of the experiences of bereavement and possible ways to manage these.



There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.

Can you help?

To make this year the biggest Blue Cornflower Day yet we need your help.



Can you spare a few hours on Friday 11 May to collect donations and sell merchandise at railway stations on the Sydney network or at a local shopping centre?

We need to raise MND awareness and funds to continue the work of the Association because *Until there is a cure, there is care*. If you can help contact Sarah Bouch, Volunteer Coordinator, ph. 02 8877 0928 or sarahb@mndnsw.asn.au.

A gift to MND in your Will can make all the difference to an individual, their family and carers.

Your generosity can give help in many ways. For more information contact Yvonne Hamilton, Supporter Liaison Officer ph. 02 8877 0927 or yvonneh@mndnsw.asn.au.

Australian Motor Neurone Disease Registry

The Australian Motor Neurone Disease Registry (AMNDR) is a de-identified disease based registry that facilitates the collection and storage of MND data. It includes information such as patient demographics, site of onset of disease, diagnosis date, treatment type, changes in disease, complications related to disease progression and the impact of new treatments and interventions for MND.



As at February 2018 NSW/ACT sites participating in AMNDR are:

- Forefront MND Clinic, Camperdown
- Macquarie Neurology, Macquarie University Hospital Clinic, Macquarie University
- St Joseph's Hospital Multidisciplinary MND Clinic, Auburn

For more information see <http://www.mndregistry.org.au/> or speak with your neurologist.

Living Well with MND Information Day

20 March at Bossley Park

25 May at Port Macquarie

15 August at Woden, ACT

25 September at West Ryde

Living Well with MND is an informative day for people living with motor neurone disease, their families and friends.

You will be provided with a range of strategies to live well with MND and to maintain independence. You will also have the opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.

There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.



Upcoming Support Service events

Click to find out more.

20 Mar **Living Well with MND**
Bossley Park

26 Mar **Past carers lunch**
Gladesville

17 Apr **Information Evening for people recently diagnosed with MND**
Gladesville

5 May **Day of Hope and Remembrance**
Homebush

15 May **Care for Carers 15 May, 22 May, 29 May and 5 June**
Gladesville

25 May **Living Well with MND**
Port Macquarie

19 Jun **Information Evening for people recently diagnosed with MND**
Gladesville

14 Aug **Information Evening for people recently diagnosed with MND**
Gladesville

15 Aug **Living Well with MND**
Woden, ACT

17 Sep **Past carers lunch**
Gladesville

25 Sep **Living Well with MND**
West Ryde

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Upcoming Support Service events (cont'd)

16
Oct

Information Evening for people recently diagnosed with MND
Gladesville

16
Oct

Celebrating National Carers week morning tea
Gladesville

5
Nov

Ask the Experts Forum
West Ryde

4
Dec

Information Evening for people recently diagnosed with MND
Gladesville

Pre-order today

2018-19 Entertainment™ Books are a great way to save money and make a great gift for family and friends.

20% of every membership sold on the Entertainment Book Motor Neurone Disease Association of NSW link below is contributed back to MND NSW. Help us achieve our goal by sharing the link below with your family and friends.



Entertainment™ Memberships include over \$20,000 worth of valuable 2-for-1 and up to 50% offers from many of the best restaurants, arts, attractions, hotel accommodation, travel and much more! Pre-purchase your 2018-19 book or electronic membership before 6 April to receive Early Bird Offers you can use straight away.

- Sydney and Sydney North \$70
- Sydney Greater West \$65
- Canberra \$60
- Newcastle, Central Coast and The Hunter \$65
- NSW South Coast \$60
- Gold Coast and Northern NSW \$60
- and many other areas across Australia and New Zealand.

Are you caring for someone with MND? Do you want to increase your knowledge?

15 May, 22 May, 29 May and 5 June at MND NSW Centre Gladesville

Care for Carers is a supportive educational program for those caring for a family member or partner with motor neurone disease. Care for Carers runs once a week for four weeks and participants attend all sessions. Here is what some of the carers who participated last year had to say:

"The new knowledge and confidence I gained during the program was invaluable for me. It's never too early to do this course."

"I now feel stronger and confident of my ability to care for my wife."

"It was wonderful to get to know others with a family member with MND and we all learnt so much from each other. I was hesitant to do this course and I am so happy that I made the time to come along!"

There is no cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd/183-care-for-carers-2018-wk1.html>.



Upcoming community fundraising events

6
May

Run MND 2018

Sutherland to Cronulla



11
May

7th Annual Riddla MND Golf Fundraiser

Twin Creeks Golf and Country Club



13
Oct

Gundaroo Music Festival 2018

Gundaroo Park



Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research?

<http://www.mndnsw.asn.au/get-involved/fundraise.html>

Carers and manual handling

In 2017 the Central Coast Local Health District Carer Support Unit surveyed physiotherapists, occupational therapists, carers and past carers from the local area on safe handling, positioning and transfer techniques (also known as manual handling) for carers and their care recipients. Several carers from the MND NSW Central Coast Support Group were amongst the eleven carers participating in the survey and the findings have now been released.

All 11 carer respondents stated that they assisted their care recipient in transfers, with 73% reporting they do this frequently. "It is very tough on the body when the person you care for does not have the support equipment to assist." The following graph demonstrates what carers consider are the most demanding activities they perform in their caring role.

10 of the 11 carer respondents reported that they had been injured while providing care. 60% had a back injury, 20% a torn rotator cuff injury and 20% muscular strain. One carer stated that "I broke my back when my husband fell - I took full weight whilst I was in an awkward position." Another acknowledged that "over-reaching when using straps" and "being in a bended position trying to reach items" exacerbated her physical condition.

55% of carer respondents reported that they were not taught how to move or lift their care recipient by a health worker. Of those who did receive instruction, less than half reported that those instructions were good to very good. One carer explained "I've been given a few general tips and hints, but never specific instructions." Another carer shared that "OTs have advised doing things differently. Some things work, others don't suit."

70% of carer respondents were taught how to use the aids and/or equipment by a health worker, with many reporting that

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the education received was useful or very useful – "An OT requested the equipment and we were instructed in its use." When asked what information has helped you to safely lift or move the person for whom you care, all 11 respondents replied, with the majority indicating handouts, booklets and manuals. Another favourite form of education was diagrams and pictures.

There are many different techniques for safe transfers. The neck, shoulders, arms, hands, legs and feet of the person being transferred may all need support. There are also many aids and items of equipment that can be used to make transfers safer for a person with MND and the person assisting them.

Your physiotherapist or occupational therapist can make an assessment of your situation and recommend the best techniques for you and instruct you on the safe use of any aids and equipment items used for transfer or lifting.

Additionally the MND NSW publication Living with MND - Day-to-day has general tips for how a person can be assisted to move or transfer from one position to another. Carers may also be interested in attending the MND NSW Care for Carers program commencing 15 May (see p 12 of this edition of e-news).

Living with
motor neurone disease

Day-to-day
for people with MND,
their family and
friends



Member library

Don't forget that members and carers have the opportunity to borrow MND-related books and DVDs for up to a month at a time, at no cost, from our member library. Contact the MND Info Line ph. 02 8877 0999 or email infoline@mndnsw.asn.au for details.



Motor Neurone Disease Association of New South Wales

Building 4 Gladesville Hospital, Gladesville NSW 2111
(Locked Bag 5005, Gladesville NSW 1675)

Ph 02 8877 0999 Freecall 1800 777 175 Fax 02 9816 2077

admin@mndnsw.asn.au <http://www.mndnsw.asn.au>



<http://fb.me/mndnsw>

ABN 12 387 503 221

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**...and many valued
volunteers**