



### **In this edition**

Not too late to attend 2018 Day of Hope and Remembrance 5 May... More MND Week 2018 event locations... Some spots still left for Care for Carers 16 May... Carnarvon Golf Charity Day a great success... Make Aged Care Fair... Physical activity and the odds of developing MND... and more

### **A Message from the CEO**

MND Week is just around the corner, starting 6 May to be exact. During MND Week we will be asking people with MND, their family and friends to help with our advocacy. We are facing a critical moment now, with a dramatic discrepancy in supports and services for those aged under 65 eligible for the NDIS and those aged 65 and over who fall under My Aged Care. Whereas most people are getting the supports and services they require under the NDIS, My Aged Care provides limited and means tested access to supports and services. Read more on page 6.

Saturday 5 May is our Day of Hope and Remembrance, a day that brings together all those whose lives have been touched by MND. This year's guest speaker is Janet Nash. See page 2 for more.

Make sure you keep an eye out for all of the MND merchandise being sold around NSW and the ACT. This is the biggest year yet thanks to the tireless efforts of over 120 volunteers. A list of venues and dates can be found on page 3. I encourage you to get involved this MND Week.

*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.



## Day of Hope and Remembrance

### Saturday 5 May 2018

*This afternoon of hope and remembrance is for all those whose lives have been touched by MND including people living with MND, family, friends, supporters, volunteers and those working with MND.*



We hope you, your family and friends will come along to our annual *Day of Hope and Remembrance* on **Saturday 5 May 2018 from 1.30pm to 3.30pm at Soka Gakkai International Centre, 3 Parkview Drive, Sydney Olympic Park.**

Our guest speaker is Janet Nash, Executive Officer Research with MND Australia, who will speak about the significant developments she's seen in MND research and care during the last two decades. The MND March of Faces banners will be displayed and afternoon tea and light refreshments will be served.

For catering purposes please RSVP by 2 May by phone 02 8877 0999 or 1800 777 175, or email [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au).

### Some spots still left for Care for Carers

Do you have a family member or friend supporting your day to day care? Then you may like to encourage them to attend the MND NSW *Care for Carers* program starting Tuesday 16 May.



*Care for Carers* is a supportive, enjoyable program held in at our centre at Gladesville once a week over four weeks. It aims to increase the practical knowledge and wellbeing of a family member or friend caring for someone with MND.

*Care for Carers* is held just once a year and there is no cost to attend, so do make sure your family member/carer registers their interest as soon as possible. [Register or find out more today.](#)

## MND Week 6-12 May 2018

You can purchase your MND puppy at one of the following sites. But be quick - they sell out fast.

### Cornflower Blue Day

Friday 11 May

### Railway stations

7am-10.30am

- Central
- Chatswood
- Circular Quay foreshore
- Epping
- Hurstville
- Macquarie
- Martin Place
- Parramatta
- Penrith
- Sutherland
- Town Hall
- Wollongong
- Wynyard

### Shopping Centres

- Brookvale Warringah Mall 12 May
- Canberra City 12 May
- Carlingford Court 7-9 May
- Charlestown Charlestown Square 11-12 May
- Chester Hill Chester Square 12 May
- Erina Erina Fair 1 May
- Gungahlin Casey Town Market 11 May
- Kotara Westfield 5 May
- Leura Woolworths 7 June
- Lismore East Lismore Shopping Centre 9-11 May
- Narellan Narellan Town Centre 11 May
- Port Macquarie Settlement City 11-12 May
- Pyrmont Pyrmont Bridge Shopping Centre side 11 May
- Queanbeyan Aldi 5 May
- Tuggerah Westfield 11 May
- Tumut Ice Bucket Challenge 12 May
- Tumut Street Stall 11-12 May
- Wagga Wagga Wagga Market Town 9-11 May
- Woy Woy Deepwater Plaza 7-8 May
- Young Main Street 7 May

### Other Venues

- Coastline NSW branches
- University of Wollongong BioNet Bake Sale 11 May



*The Chatswood team during MND Week 2017*

## Introducing new staff...

Kathleen Doosey | MND Advisor - Central Coast, Lake Macquarie and Mid North Coast

G'day. My background is in social work and throughout my career I've worked with individuals and their families who are experiencing neurological conditions and illnesses, palliative care, and physical and cognitive rehabilitation.

I have an interest in grief and resilience, and my preferred method of support is one that recognises individuals, carer and families living with illness or injury are the experts on their own lives.



I enjoy food (a lot), and love music, and I am in awe of anyone who can sing or play an instrument. I like to have a crack at running, swimming and cycling, although I'm not very good at any of them, and I am very fond of dachshunds. I am really excited to have joined MND NSW, and I hope to connect with many of you in the near future.

## Thai-riffic Night of Food and Fun

Thank you to Joanne Blissenden and everyone who helped organise the recent Thai-riffic Night fundraising evening in Dural. The fundraiser was held in memory of their friend Laurence who passed away after a short battle with MND. Joanne said the evening was a great success with \$5,175 raised through the dinner, raffles and lucky dips.



Joanne and her husband also completed the ice bucket challenge! Thank you to everyone who attended and supported the event.

## For Sale

Ford Falcon Utility 2016, reg. to May 2018, auto, approx. 29000km. White, 2 seater, modified hand controls, hydraulic hoist fitted for wheelchair transportation. \$25,000 ono. Phone Gail on 02 6386 7220

## Get your 2018-19 Entertainment™ Book 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 is contributed back to MND NSW. Let your family and friends know. Help us achieve our goal by sharing the link below with your family and friends.



- 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.

<https://www.online.mndnsw.asn.au/pages/entertainment-book>

## On the Central Coast

MND NSW Volunteer Wendy Whitmore and the Central Coast support group have been very busy over the last few months selling tickets for the Rotary Club Raffle. The cheque for \$970 was presented to Gina Svolos, Manager, Support Service at the Central Coast support group meeting. Gina (pictured on right with Wendy) attended recently.



## Carnarvon Golf Charity Day

This is the second year that Carnarvon Golf Club have supported MND NSW with a charity golf day, this year raising \$6,004. Thank you to everyone who helped organise the day, to the golfers for your support and to everyone who made a donation. Special thanks to Sharon Honeybrook, who once again organised the event, and to the Club for their generous donation of the green fees for the day.



## Make Aged Care Fair

We are pleased to let you know that during MND Week 2018 we are launching the NSW, ACT, NT and Gold Coast **Make Aged Care Fair** campaign – a new campaign that calls on the Government to make sure people diagnosed with motor neurone disease aged 65 or over have access to the right care, in the right place at the right time.

The current system means that people diagnosed with MND when aged 65 and over do not have access to the NDIS and are forced to rely on Aged Care services designed to support people who are frail aged, not people with a rapidly progressing complex conditions like MND.

We know Aged Care services are failing people with MND and many are being pushed into financial hardship or residential aged care earlier than they wish. Many people with MND are waiting for a Community Aged Care Package or have been assigned a lower level package that does not meet their needs and many are also facing stressful and unnecessary reassessments.

MND Australia and the MND State Associations believe this is wrong and unfair and that's why we are calling on our decision makers to Make Aged Care Fair, but we need your help to make sure they listen.

During MND Week we will give you more information on how you can join the campaign to **Make Aged Care Fair** for people with MND diagnosed aged 65 and over. Join the campaign and help make sure that everyone with MND has access to the right care, in the right place, at the right time, irrespective of age.



*Julie and Bob Flack are experiencing multiple problems with Aged Care*



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

Join us at a 2018 Walk to d'Feet MND. 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?

24  
Jun

**Walk to d'Feet MND Canberra** *Supported by*

Peace Park, Parkes, ACT



[Register now](#)

15  
Jul

**Walk to d'Feet MND Penrith** *Supported by*

International Regatta Centre, Castlereagh



[Register now](#)

26  
Aug

**Walk to d'Feet MND Batemans Bay** *Supported by*

Corrigans Beach Reserve, Batehaven



[Find out more](#)

16  
Sep

**Walk to d'Feet MND Port Macquarie** *Supported by*

Westport Park, Port Macquarie



[Find out more](#)

14  
Oct

**Walk to d'Feet MND Wagga Wagga** *Supported by*

Apex Park, Wagga Wagga



**Los Gray Plumbing**

[Find out more](#)

4  
Nov

**Walk to d'Feet MND Sydney** *Supported by*

Blaxland Riverside Park, Olympic Park



[Find out more](#)

## New voice banking initiative announced by Project Revoice

Project Revoice have announced plans to develop a new voice banking service, advising it will take just two to three hours of recordings for the creation of the digital voice clone. Project Revoice was funded through the Ice Bucket Challenge and is a collaboration between Lyrebird in Canada, Finch and Rumble Studios in Sydney and the ALS Association in the USA.



Voice banking uses a digital recording of a person's voice which is provided to a commercial provider who then artificially creates a voice file, that is not the person's actual voice, but a similar, synthesised voice that has a much wider vocabulary than originally recorded. If, later in motor neurone disease progression, the person decides to use a device or app as a speech generating device, they can use these audio files if they are compatible with their selected speech generating device.

The opportunity to 'bank your voice' will not become available through Project Revoice until mid-2018, with voice cloning to commence at the end of 2018. You can find out more information about the project, including registering your interest in future updates, at [www.projectrevoice.org](http://www.projectrevoice.org) and on the website of their technology partner Lyrebird at [www.lyrebird.ai](http://www.lyrebird.ai).

Other commercial voice banking services/apps already available include [CereVoice Me](#), [ModelTalker](#), [VocaliD](#) and [My-own-voice](#) with prices ranging from \$100 to \$4,500. It usually takes from five to seven hours for the user to make the necessary recordings over several sessions, using a headset with microphone connected to a recording device such as a smart phone, tablet or desktop computer.



## FlexEquip equipment

Already in 2018 FlexEquip has purchased 58 new equipment items worth \$55,250 including:

- 8 electric lift recline armchairs
- 11 bathroom aids including shower commodes bedside commodes and toilet aids
- 4 homecare beds with foam mattresses
- 4 specialised Roho mattress overlays
- 7 pressure cushions
- plus other items including portable ramps, walkers, manual wheelchairs, Trackball computer mice, over-bed tables and bed poles.



This equipment was purchased to replenish stock so FlexEquip can provide rapid response as needed.

### Where can I find more information about assistive technology items for people with MND?

People with MND often require equipment to continue living at home. One of the major roles of MND NSW is to help members with MND get access to assistive technology, as soon as the need arises. FlexEquip is a service provided by MND NSW that assists adults diagnosed with MND and other rapidly progressive neurological conditions get equipment to meet short term needs. You can find out more information about getting and looking after your FlexEquip equipment at [flexequip.com.au](http://flexequip.com.au).

### Is there a recommended website where I can look up more information about other assistive technology a health professional has discussed with me?

Assistive Technology Australia is a not for profit organisation that provides impartial advice and information on assistive technology (aids and equipment). Their website at <http://at-aust.org/> has product search information, instructional videos, information brochures and a second-hand register that lists used assistive technology for sale.

*Maree Hibbert, FlexEquip Coordinator*

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## Upcoming Support Service events

Click to find out more.

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

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**10**  
May **Talk-Link Carer Wellbeing Program**  
by telephone

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

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**23**  
May **Living Well with MND**  
Southport, Queensland

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

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

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

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

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**17**  
Sep **Past carers lunch**  
Gladesville

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

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**16**  
Oct **Information Evening for people recently diagnosed with MND**  
Gladesville

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*(Continued on page 11)*

(Continued from page 10)

## Upcoming Support Service events (cont'd)

**17 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

## Living Well with MND Information Day

23 May at Southport Queensland **NEW**

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>.

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



## Upcoming community fundraising events

**5 May** **Quakers Hill Vet MND Day 2018**  
 Quakers Hill Veterinary Hospital



**6-12 May** **MND Week 2018**  
 Various across NSW and ACT



**6 May** **Run MND 2018**  
 Sutherland to Cronulla



**11 May** **7th Annual Riddla MND Golf Fundraiser**  
 Twin Creeks Golf and Country Club



**11 May** **BioNet Bake Sale for MND**  
 University of Wollongong

**2 Jun** **Luskintyre Family Fun Day**  
 Luskintyre Airfield



**27-30 Jun** **Australian Bee Congress**  
 RACV Royal Pines Resort, Benowa, Gold Coast

**7 Oct** **Bunnings Sausage Sizzle**  
 Eastgardens

**13 Oct** **Gundaroo Music Festival 2018**  
 Gundaroo Park



*Do you have an idea for an event to raise funds for MND care, support and research? [Find out more here.](#)*

A gift to MND NSW in your Will can make all the difference.  
 For more information contact Yvonne Hamilton, Supporter Liaison Officer ph. 02 8877 0927 or [yvonneh@mndnsw.asn.au](mailto:yvonneh@mndnsw.asn.au).

## MND support groups and coffee mornings

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. Often, a guest speaker is invited to the meeting. Guest speakers include health workers who know about motor neurone disease or a person with expertise on a topic that may be of interest to the members of the group.

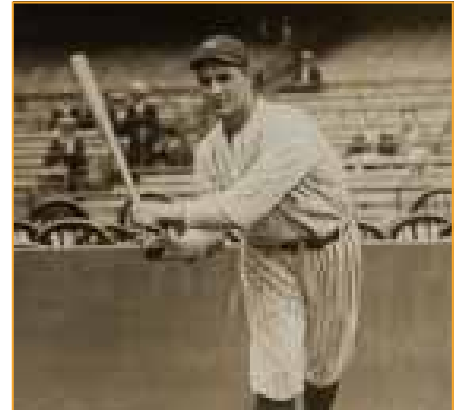
Support groups and coffee mornings are located in city, regional and rural areas of NSW, in the ACT and on the Gold Coast Queensland. Find out more [here](#) or speak with your MND Advisor.

A poster for MND Week 6-12 May 2018. The background is a close-up of a purple cornflower. The text is written in a black, handwritten-style font. At the top, it says 'MND Week'. Below that, '6-12 May 2018'. In the center, the slogan 'Until there is a CURE, there is CARE.' is written in a bold, black, sans-serif font. Below the slogan, it says 'DONATE NOW - GET INVOLVED' in a bold, black, sans-serif font, followed by 'support people with motor neurone disease' in a smaller, black, sans-serif font. At the bottom left, it lists 'Freecall 1800 777 175' and 'Phone 02 8877 0999'. At the bottom right, it lists 'www.mndnsw.asn.au' and 'facebook.com/mndnsw'. The MND New South Wales logo is also present at the bottom right.

## Physical activity and the odds of developing MND

*Extract from [MND Research Blog](#).*

"Physical activity has always been at the forefront of factors associated with MND, but studies investigating its effect have often been conflicting. The reason why we might see contrasting results is often due to different cohorts and numbers of people included in the study, the method by which the data was collected, or the types of questions asked and the way they were presented. Increased number of studies on the same topic might then improve the way these are conducted in the future and provide more reliable conclusions.



*Well-known American baseballer, Lou Gehrig, diagnosed with the amyotrophic lateral sclerosis (ALS) form of MND in 1939.*

The most recent multi-centre study that included over 1,500 people with MND and nearly 3,000 control participants was conducted by the Euro-MOTOR consortium under the leadership of Prof Leonard van den Berg. Today (24 April), [the group published a paper on their findings in the Journal of Neurology, Neurosurgery and Psychiatry](#).

The study collected data using thorough questionnaires, presented to Dutch, Irish and Italian participants either face-to-face or on paper, asking about their exposure to smoking, alcohol, and the type and amount of physical activity throughout their lifetime – both occupational and leisure. A score was then assigned to each person based on the amount of energy expenditure each activity requires – this is called metabolic equivalent of task (MET).

Aside from showing that people with MND smoked more and drank less alcohol compared to control participants, a significant positive relationship between physical activity and likelihood of MND was confirmed, shown by an odds ratio (OR) for all physical activities of 1.06 (1.07 for leisure time activities only). This statistic represents the

*(Continued on page 15)*

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'odds' of a risk effect (here, physical activity) occurring in one group compared to another, where an OR of 1.0 shows no difference between the groups, OR greater than 1.0 shows increased risk and any score below 1.0 shows reduced effect in the test group = protective effect. In effect, this means that there was a 6% increase in risk to people with high activity levels.

While the main focus was on the association of physical activity and the risk of developing MND, other analyses were ran to explore the relationship even further. The researchers looked at whether the relationship is affected by (a) gender, (b) presence of C9orf72 repeat expansions, (c) educational level, (d) hours per week, start and stop time of physical activity, (e) onset of the disease: i.e. bulbar or spinal, and (f) age of disease onset. None of these factors were shown to impact the results and affect the OR of the relationship.

The authors also pointed out that exposure to potential factors during leisure and occupational physical activities (e.g. exposure pesticides) is unlikely to drive the relationship between MND and physical activity and it is rather the direct effect of physical activity that causes the association (and not a side effect of another factor).

While this study adds to the cumulative evidence that physical activity is associated with MND, it is crucial to say that it is not a major factor in the development of the disease. Rather, it is another risk factor that together with others (including genetics) may increase the chances of MND development. It is likely that physical activity is only a risk factor in the presence of certain genetic profile, making some people more susceptible to motor system damage.

It is important to note that the take-home message of this study isn't to stop exercising as the benefits of exercise greatly outweigh the potential negatives, especially when we consider the high odds of developing cardiovascular diseases due to sedentary lifestyle."

*From the [MND Research Blog](#)*



# Motor Neurone Disease Association of New South Wales

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...and many valued  
volunteers