



Royal Commission into Aged Care Quality and Safety

In this edition

Aged Care Royal Commission... ATSA Independent Living Expo... Bring along a drawing to Walk to d'Feet MND 2019... Volunteers needed... Day of Hope and Remembrance 2019... New listings on find.mndhub.org.au and more.

[Have your say - Royal Commission into Aged Care](#)

For many people living with MND, appropriate aged care and support which can and should be delivered within a person's own home, is completely unavailable to them. Many more are struggling to even achieve a fundamental level of support. This is unacceptable.

The current Royal Commission into Aged Care in Australia has primarily focused on the experience of older Australians in residential settings. This only represents part of the substandard care older people are experiencing through our aged care system. Depriving someone of the right to remain living in their own home, simply because of an unavailability of in-home care packages is also substandard care.

Now is the time to add our voices to the discussion and provide a very clear message to the investigators and to the decision makers that people living with MND want, need and expect to access their care, their way in their own homes. You can make a submission or have your voice heard at a hearing. Find out more about making a [submission](#) and [subscribe](#) to Royal Commission updates to receive information about 2019 hearings.



Support Service Update

MND NSW is a very small organisation doing some very big things. While we do provide considerable funds towards finding a cure for MND, the bulk of our work is directed towards supporting members to get the care and equipment that they need.

Sometimes this means advocating at the highest levels in Government to ensure that the decision makers properly understand MND and its unique support requirements. Other times it will mean hunting down the right care providers who not only understand MND and its progression but are flexible in the way in which they are prepared to support people living with MND.

Often it involves sitting with our members and their families to help think through issues as they arise and to facilitate solutions that respond to that person and that family. We do not take a one size fits all approach. We know this just doesn't work for people living with MND.

With so much emphasis in the media of late around advances in research, I thought it important to also highlight the need to continue to support people who are living with the impact of MND here and now. While we all look hopefully to a future cure, the reality is that people living with MND need support and services today.

It has been a busy start to the year and when I sit back and reflect on what we have already achieved I am amazed at how much we do with so few resources. We always need your help to do more. If you are thinking about how you can help, remember our nearly 600 members in NSW and ACT who look to us for support and consider how you can help us meet their needs.

As always, please do not hesitate to contact me if you have any suggestions for how we can continue to improve our services.

Karen Martin | Manager, Support Service

Introducing new staff...

Sandra Woolnough | MND Advisor and Coordinator of Support - Far North Coast

I am pleased to have joined the MND NSW Support Service team as MND Advisor for the Far North Coast and Gold Coast area. Over the last 12 years I worked within a local aged care and disability organisation as a Support Coordinator. I live locally here on the beautiful north coast in the village of Burringbar.



I would like to acknowledge the support that Chris Carroll provided to north coast members over the last nine years as MND Advisor and look forward to meeting and continuing to support and assist our members. I will also be available to provide support and assistance in for members transitioning to an NDIS plan and will work with our members to implement their plan, their way.

North Cronulla Funky Colts take the 2019 title

This time last year we wrote about a new North Cronulla Surf Lifesaving Club surfboat emblazoned with MND awareness details sponsored by David Hammond, putting the MND cause front and centre.



David's sister, Jane, was diagnosed with MND and the boat was dedicated to Jane's fight and to Peter Whitford, a North Cronulla Club stalwart who had died from MND.

In February 2019, the boat featured at the Australian Surf Rowers League Open Carnival at Elouera, an event attended by 328 crews from 86 clubs from six states. Congratulations to the North Cronulla Funky Colts U23 Men who took out the title in the MND surfboat at the Carnival.

Photo: Malcolm Trees and Brendon Grant.

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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. The lunch provides an opportunity for you to reconnect with old friends from MND NSW and to meet others who have cared for someone with MND. Following 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 will need to reserve your place. More information [here](#).



2019 Walk to d'Feet MND

We would like to invite all children attending our Walk to d'Feet MND events this year to bring along a drawing of the person they are walking in honour of. We will have a board available at each Walk to display the drawings. 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 MND.



Lemonade and cookies

A big thank you and congratulations to Jess and friends who held an Australia Day Lemonade and Cookie Stall to raise funds for MND NSW. They raised over \$900, what a great result!



2019 Walk to d'Feet MND

Save the date - registrations opening soon



- | | | |
|-------------------|---|--|
| <p>14
Apr</p> | <p>Walk to d'Feet MND Forbes <i>Supported by</i>
Lions Park
Forbes NSW</p> |     |
| <p>5
May</p> | <p>Walk to d'Feet MND Illawarra <i>Supported by</i>
Bulli Surf Club
Bulli NSW</p> |       |
| <p>26
May</p> | <p>Walk to d'Feet MND Hunter <i>Supported by</i>
Speers Point Park
Speers Point NSW</p> |      |
| <p>16
Jun</p> | <p>Walk to d'Feet MND Canberra <i>Supported by</i>
Peace Park
Parkes ACT</p> |     |
| <p>7
Jul</p> | <p>Walk to d'Feet MND Penrith <i>Supported by</i>
International Regatta Centre
Castlereagh NSW</p> |     |
| <p>2
Aug</p> | <p>Corporate Walk Sydney <i>Would your company like to support this event?</i>
More details soon</p> | |
| <p>8
Sep</p> | <p>Walk to d'Feet MND Taree <i>Supported by</i>
Endeavour Place Reserve, Taree</p> |    |
| <p>20
Oct</p> | <p>Walk to d'Feet MND Young <i>Supported by</i>
Aboretum Park, Young</p> |    |
| <p>3
Nov</p> | <p>Walk to d'Feet MND Sydney <i>Supported by</i>
More details soon</p> |     |

Volunteers needed

To make this year the biggest Cornflower Blue Day yet we need your help. Can you spare a few hours between 7am and 10.30am on Friday 10 May to collect donations and sell merchandise at one of the following railway stations?

- Central Station
- Martin Place Station
- Town Hall Station
- Bondi Junction Station
- Circular Quay Station



We need to raise MND awareness and funds to continue the work of the Association. If you can help contact Sarah Bouch, MND NSW Volunteer Coordinator ph. 02 8877 0928 or sarahb@mndnsw.asn.au.

Neuro Carers Network in Deakin ACT

In conjunction with the MS Society, Carers ACT are starting a new support group, the Neuro Carers Network in Deakin ACT. The group is for family and friends who are carers of people with multiple sclerosis, motor neurone disease or other conditions that affect the nervous system to share some similar experiences. The first meeting is from 6pm-8pm Monday 25 March at Gloria McKerrow House, 117 Denison St, Deakin. For more information and to RSVP contact Carers ACT ph. 6296 9975 or support.groups@carersact.org.au.

Exciting news!

Run MND has two venues this year, Sutherland and Central Coast with both events held on the same day, Sunday 26 May. You can run or walk 10km or 5km at both venues. Sutherland will start at Don Lucas Reserve Cronulla and Central Coast will start at Long Jetty Foreshore Reserve. [Register online](#).



Ice Bucket Challenge in Canberra

A big thank you to the staff from the Department of the Environment and Energy in Canberra for the continued support with their Ice Bucket Challenge event. The event, known as The Scott Lisle Memorial Ice Bucket Challenge, is now in its fourth year and is held in memory of a former colleague. A special thank you to Tara McGowan and Phil Bates who coordinated the event which raised a fantastic \$8,329. Pictured is Finn Pratt, Secretary of the Department of the Environment and Energy. Photo credit Wolf Sverak.



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

10am-3pm 14 May, 21 May, 28 May and 4 June
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. There is no cost to attend the program but you need to reserve your place. [Find out more.](#)



ATSA Independent Living Expo

Sydney Olympic Park 8-9 May
Canberra National Convention Centre 27-28 August

The Assistive Technology Suppliers Australasia (ATSA) Independent Living Expo will have over 100 exhibitors displaying products and services in assistive technology, mobility solutions, pressure care, accessible recreation/holiday ideas, modified motor vehicles and more. A key feature of the Expo is the free conference program. More information [here.](#)



New listings on find.mndhub.org.au

The Living with MND online directory at find.mndhub.org.au provides information about services and resources that may be of interest to people living with MND. Recent new and updated listings include the following.



[Blue Badge Insurance Australia](http://www.bluebadgeinsurance.com.au)

Blue Badge Insurance provide insurance specific for people with modified vehicles and also for power wheelchairs. Find assistance on insurance for Disability Parking Permit Users, Car Insurance – Disability Converted Vehicles, Comprehensive Mobility Scooter Insurance and Comprehensive Wheelchair Insurance. They also have info on how the 'extra' costs of insuring your modified vehicle can be claimed through NDIS. Find out more at www.bluebadgeinsurance.com.au or ph. 1300 304 802.

[National Relay Service \(NRS\) / Accesshub Australia](http://www.communications.gov.au/accesshub)

The National Relay Service (NRS) is a Government initiative that enables people with speech or hearing difficulties to communicate with voice callers. There are a number of relay call options that can be accessed by phone, web or TTY depending on your situation or needs. For more info visit www.communications.gov.au/accesshub or contact ph. 1800 555 660 or TTY 1800 555 630.

[A chandelier in the gum tree](#)

Thank you to the wonderful support provided by the Rotary Club of Narrandera from their Christmas Party which raised \$3,200 for research. Special thanks go to Joy and Robert Norrie, and Beth and Greg McVicker who organised and catered for the event. Robert said of the evening, "We had a great night even though it was very hot, 36 degrees, until late. We had 98 people seated on our lawn beside the Murrumbidgee River. A chandelier hung in the overhead gum tree and as night settled in we were entertained by some of the Riverina Men's Choir."



MND education events in Orange

On 20 February Ruth Yuthok, MND Advisor for the Central West and Kristina Dodds, MND NSW Education and Carer Support Coordinator, conducted the one day Living Well with MND program for people living with MND, their family and friends in Orange. The 25 participants included many who had travelled far to attend - from Broken Hill, Wagga Wagga, Young, Kelso, Bathurst and Rylstone.



The highlight of the day was hearing from Dr Louis Christie, who is based in Orange with the Western NSW Local Health District Palliative Care Service. Louis spoke about both the physical and emotional aspects of an MND diagnosis and as a participant wrote in the evaluation, "Dr Louis pointed out a different way of thinking about MND". Louis asked some of the 'big questions' that covered dignity, being a burden, distress and more. He also outlined four rules around MND for the individual and how they feel about treatment.

- If it seems like a good idea – do it
- If it seems like a bad idea – don't do it
- If you thought it was a good idea, but you change your mind – stop doing it
- If you don't know just wait. Whatever is a 'good idea' will become apparent.

Thank you also to the very experienced allied health practitioners from Orange Health Service who presented at the event. Chloe Yarwood - Senior Speech Pathologist, Niki Weston - Senior Dietitian, Jenna West - Senior Occupational Therapist and Amber Gunn - Senior Physiotherapist all gave their time to share their extensive expertise in working with people living with MND and how each allied health speciality can help people with MND live better for longer. Kristina and Ruth wrapped up the day presenting on 'It takes a team' - not only a team of professionals, but a team of family, friends and community.

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On 21 February, also in Orange, we conducted our MND Aware training for health and community care professionals. This training focusses on learning about MND, MND evidence based interventions, the benefits of working in a multidisciplinary team, networking, and learning from each other. 100% of the participants rated the day as very good to excellent and there was time to work in small groups, discuss short videos, work through case studies and talk about the NDIS and My Aged Care.

In 2019 Living Well with MND for people living with MND, their family and friends will be held in Newcastle, Ryde and Berry. It is not too early to register for these events. The MND Aware program for health and community care professionals will be held in Newcastle in May.

Kristina Dodds | Education and Carer Support Coordinator

Living Well with MND Information Day

11 April at Newcastle

24 September at Berry

22 October 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. [Find out more.](#)



Community Calendar

30 Mar **MND Fundraiser**
The Country Club, Sanctuary Point

30 Mar **Dinner Dance**
Bathurst City Community Club

5-11 May **MND Week 2019**
Various across NSW and ACT

14 May **Warringah Golf Club Ladies Charity Day**
Warringah Golf Club

26 May **Run MND - Sutherland Shire**
Don Lucas Reserve, Cronulla

26 May **Run MND - Central Coast**
Long Jetty Reserve

27 May **Hike for Health - Great Wall of China**
Raise vital funds for MND NSW

18 Jun **Riddla MND Golf Fundraiser 2019**
NSW Golf Club, La Perouse

29 Jun **Lift4MND**
RealFITT

28 Jul **East Hills Charity Car Show**
Kelso Oval, Panania

12 Oct **Gundaroo Music Festival 2019**
Gundaroo

Do you have a great idea for an event or activity that will raise funds for MND support and research? <http://www.mndnsw.asn.au/get-involved/fundraise.html>

Day of Hope and Remembrance

Saturday 11 May 2019

We hope you, your family and friends will come along to our annual *Day of Hope and Remembrance* on Saturday 11 May 2019 from 1.30pm to 3.30pm at Soka Gakkai International Centre, 3 Parkview Drive, Sydney Olympic Park.

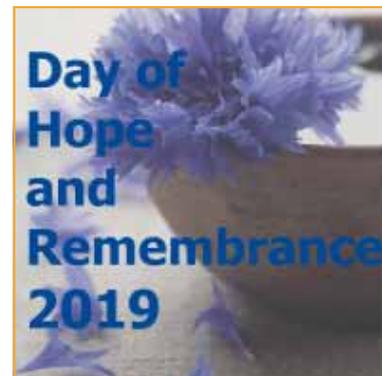
Our afternoon of hope and remembrance is for all those whose lives have been touched by motor neurone disease; including people living with MND, family, friends, supporters, volunteers and those working with MND.

There will be a candle lighting ceremony to represent the hopes and losses of those whose lives have been touched by MND. Let us know if you wish to volunteer to write a dedication or light a candle.

Our guest speaker is Professor Ian Blair, recipient of the inaugural MND Australia Leadership Grant, whose research career has focused on determining the molecular and cellular basis of a variety of neurological disorders, including motor neurone disease.

The MND March of Faces banners will be displayed and afternoon tea and light refreshments will be served.

For catering purposes please RSVP by 8 May by phone 02 8877 0999 or 1800 777 175, or email reg@mndnsw.asn.au.



National Disability Insurance Scheme (NDIS) Workshops

From time-to-time the NDIS conducts workshops for participants, family and carers. Upcoming sessions in NSW are listed for Campbelltown, Campsie, Leichhardt and include Making the most of your NDIS Plan Paid Supports, Self-Managing My Supports and Achieving more choice and control Self managing My Supports. There are no current sessions listed for the ACT. Find out more at <https://www.ndis.gov.au/news/events>.

Upcoming Support Service Events

Click the event for more information.

26
Mar **Past carers lunch**
Gladesville

11
Apr **Living Well with MND**
Newcastle

11
May **Day of Hope and Remembrance**
Homebush

14
May **Care for Carers 14 May, 21 May, 28 May and 4 June**
Gladesville

12
Aug **Ask the Experts Forum**
West Ryde

17
Sep **Past carers lunch**
Gladesville

24
Sep **Living Well with MND**
Berry

10
Oct **Celebrating National Carers Week morning tea**
Pennant Hills

22
Oct **Living Well with MND**
West Ryde

7-8
Nov **Link and Learn**
Hunter

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. However, bookings are essential.



Motor Neurone Disease Association of New South Wales

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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