



Join the campaign to Make Aged  
Care Fair

### In this edition

Thanks Forbes!... Show your support during MND Week 2019... Non-invasive ventilation during a power outage... Get in quickly for Walk to d'Feet MND Illawarra on 5 May... Be a City2Surf 2019 Charity Superstar for MND NSW... and more

### A Message from the CEO

With MND Week and a Federal election just around the corner MND NSW and other state MND associations are calling all candidates and all parties to **Make Aged Care Fair**. Aged Care services are designed to support people who are frail aged and experiencing dementia, not people with progressive, complex and life limiting conditions like MND. Along with improvements to Aged Care we are calling on all candidates and parties to support:

- Timely access to a full range of assistive technology
- Development of MND Guidelines
- No cost access to IVF and pre-implantation genetic diagnosis
- Funding for specialist MND multidisciplinary clinics
- Increased investment in research

To find out more, make sure your voice is heard and stay up to date register your support at [MND Action](#).

MND Week kicks off on Sunday 5 May with our Walk in the Illawarra, events and stalls throughout the week culminating in our Day of Hope and Remembrance on Saturday 11 May.

*Graham Opie*



## MND Week 5 - 11 May 2019

### Cornflower Blue Day - Friday 10 May

Keep an eye out for our amazing volunteers selling merchandise, collecting donations and raising awareness of motor neurone disease across NSW and ACT.

Spread the word, support our volunteers, support MND NSW, so we can support our members.

Motor Neurone Disease Association of NSW is the only organisation in NSW supporting members with MND, their families, friends and colleagues.

We are a not for profit organisation, only 15% of our funds comes from the government. The balance, we must raise ourselves.

If we do not raise these funds, we cannot provide the support for our members as we do now.

TOGETHER WE CAN raise funds and awareness so we, MND NSW, can continue to support people living with motor neurone disease.

[You can find our volunteers at the following locations](#)

#### **3 May**

- Stocklands Glendale

#### **4 May**

- Majura Park Shopping Centre

#### **5, 7, 11 May**

- Deepwater Plaza, Woy Woy

#### **5-11 May**

- Community Health Centre, Grenfell

- Cheltenham Girls High School

#### **6, 7, 8 May**

- Carlingford Court Shopping Centre

#### **8, 9, 10 May**

- Wagga Market Town, Wagga Wagga

#### **9 May**

- Chester Square, Chester Hill

**10 May** - Railways stations from 7am-10.30am

Circular Quay and Foreshore	Central
Martin Place	Town Hall
Wynyard	Milsons Point
Chatswood	Epping
Paramatta	Macquarie
Bondi Junction	Wollongong (6am – 10am)

**10 May**

- Narellan Town Centre
- Port Macquarie, Horton Street (outside the Commonwealth Bank)
- Tuggerah Westfield
- Tumut Street stall
- Nyngan
- Loretto Kirribilli

**10 and 11 May**

- Castle Towers Shopping Centre

**April/May**

- Coastline Credit Union Branches, Kempsey and surrounds
- Colouby Creations, Parkes

**Thank you** to everyone who is volunteering and supporting us during MND Week 2019 raising funds and awareness so we can continue to provide education, support, equipment and resources for our members.

**TOGETHER WE CAN**

**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.



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

## Support Service Update

Once again there have been several stories circulating in the popular press about causes and cures for MND. We know and support the many researchers who are working to find a cure and to unlock the mystery of MND. We do not however, support sensationalism nor profiteering from the experience of others. Please be assured that we will always provide information of break throughs and research progress through our newsletters, our social media accounts and by direct communication with our membership. Additionally, you can contact the MND Infoline ph 1800 777 175 to check any stories.

You will notice that MND NSW has adopted some new language around our services and the way in which we deliver them. We recognised that together with our members and their families, we have been working hard over the years to really break down some of the barriers for people living with MND. With your support we have been able to make some real changes in areas such as the NDIS. While not perfect, we are seeing better plans and better outcomes as the result of our advocacy work. We will continue to smash at the doors of government until we can see similar positive moves within the aged care space, access to equipment and delivery of appropriate services for people living with MND. Below is an overview of our branding refresh.

*Karen Martin | Manager, Support Service*

### MND NSW - Breaking down the barriers for people living with MND

MND NSW is a small organisation, doing big things for people living with MND. We are really proud that not only do we support research into this disease but that we also deliver practical assistance and support for people currently living with MND. We see our role as very much breaking down barriers to receiving the very best care and in advocating for the systemic changes that will ensure service provision meets expectation.

We do this by

- Providing MND Advisors who connect people living with MND to care and services while challenging government and providers to deliver what is needed most – ***we break down the barriers to getting the care and services people living with MND want in the way that they want them.***

- Offering a highly skilled team of professionals who understand how to get the most from an NDIS plan and who will not stop until the right NDIS plan is in place giving the person with MND real choice and control – ***we break down the barriers for people in accessing and implementing an NDIS Plan.***
- Operating an MND specific Information Line which provides information about MND, its progression and offers the support a person and their family will need both practically and emotionally – ***we break down the barriers to getting information about MND as well as linking to services and support.***
- Delivering an exceptional range of education and carer support programs that seek to inform and empower both people living with MND and their professional health network – ***we break down the barriers to understanding MND for people living with the disease while upskilling health and community care professionals to deliver better MND care.***
- Making available a range of assistive technology and equipment to support daily activities and social connection for people living with MND at no direct cost to the person with MND – ***we break down the barriers to living an inclusive and self-directed life.***
- Giving a voice to people living with MND by participating in discussions with government, decision makers, the media and others to ensure that the experience of people living with MND is accurately represented and their needs clearly understood – ***we break down the barriers to ensure social inclusion, services and policy meet the needs of people living with MND.***
- Directing funds towards research and seeking to improve the experience of people living with MND. The ambition of MND NSW is to contribute to the growing body of information on MND, its causes and evidenced based treatments – ***we break down the barriers to unlocking MND and finding a cure.***

### Together We Can

In 2019 we have made it even easier for you to register for a Walk to d' Feet MND and raise funds when you participate. All of our Walks and the local information for each venue can now be accessed through the one site. Register today at <https://walktodfeet.org.au/>.



I look forward to seeing you at a Walk in 2019. Together We Can.

*Kym Nielsen | Fundraising Manager*

### Thank you to our supporters

Walk to d' Feet MND Forbes  
14 April 2019  
Lions Park, Forbes NSW

Congratulations Forbes! Our biggest Walk yet in this town, with 180 participants and \$15,490 raised to date. A huge thank you to our participants, fundraisers and amazing sponsors, Duncan Stockcrates, Grand Ridge Brewery, Anytime Fitness, Bernardi's Farmers Market, Lions Club and the wonderful support from Forbes Shire Council.



*Supported by*



Together We Can  
**2019 Walk to d'Feet MND**

Register today at [walktodfeet.org.au](http://walktodfeet.org.au)



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

## Powering a non-invasive ventilation machine during a power outage

Increasingly, many people with MND are choosing to use non-invasive breathing support, known as non-invasive ventilation or NIV. NIV provides relief from symptoms such as fatigue, breathlessness and disturbed sleep patterns, but does not prevent progressive weakening of the respiratory muscles.

NIV uses room air and is not oxygen therapy. To use NIV the person wears a mask connected to a



small machine. This creates just the right pressure to keep the persons airways open so that room air can easily come in and out of their lungs when they breathe.

People with MND most commonly use variable positive airway pressure (VPAP) or bi-level positive airway pressure (BIPAP) machines. VPAP and BIPAP can provide a lower level of pressure when the person breathes out. In addition, they can be adjusted to provide increased respiratory support if needed. The NIV machine is usually used at night but, as the respiratory muscles continue to weaken, it is commonly used at times during the day as well. If you are worried about powering your NIV machine during a power outage:

- speak to your respiratory specialist. Ask about back up options for NIV and if any spare battery packs are available (or if the NIV has a back-up battery already installed – some models do such as the Trilogy from Phillips).
- notify your power supply/ electricity company to add you to a 'life support register' which means the company is aware of the fact you are using equipment to assist with breathing and so are a priority if there are any power concerns. For AGL Energy phone 131 245 and for Ausgrid see [Ausgrid information online](#)
- in case of power failure and if someone is very anxious and breathless or has accidentally damaged their breathing unit, they can always call an ambulance and be taken to hospital until the power is restored or the machine is replaced.
- have an uninterruptible power supply (UPS) available, an electrical apparatus that provides emergency power to a load when the mains power fails. A UPS differs from an auxiliary or emergency power system or standby generator in that it will provide near-instantaneous protection from input power interruptions, by

supplying energy stored in batteries. These battery-operated systems can often be hired or purchased from NIV suppliers or from retailers including Jaycar and Officeworks, and can provide for up to six hours emergency power. Prices vary depending on how big and powerful the unit is. The UPS needs to be fully charged and ready to go before use.

- use of a small generator/alternative battery source.
- some people using NIV to treat their orthopnoea can often manage to breathe spontaneously sitting upright in a chair and this can be a short-term way to manage a short power failure. Your respiratory specialist can advise.

### City2Surf

We are very excited to announce MND NSW and MND Australia will have a combined team in this year's City2Surf. We have limited spots available for the Charity Superstar entries. As a Charity Superstar you will receive free entry to the City2Surf, a starting position in front of the pack, merchandise and lots more. Commit to raising \$1,000 today and join us for the 2019 City2Surf.



### 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.



### 2019-20 Entertainment Books

Entertainment Books are a great way to save money while enjoying a night out or a day with the family. 20% of every membership sold on the Entertainment Book Motor Neurone Disease Association of NSW link is contributed back to MND NSW.



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## Upcoming Support Service Events

Click the event for more information.

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**1**  
May **MND Chat and Connect**  
Gladesville

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

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

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

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

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**24**  
Sep **Living Well with MND**  
Berry

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

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

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

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### [New listings on find.mndhub.org.au](http://find.mndhub.org.au)

The Living with MND online directory at [find.mndhub.org.au](http://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:

- [Enware](#) provide fittings and solutions for bathroom and home modification including toilets, hand rails, wash basins and adjustable benches and cupboards.

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## Community Calendar

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**2**  
May **Annual Charity Day**  
Saint Margaret's Church Hall, Hackett

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

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

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

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

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

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**15**  
Jun **MND Fundraiser Event**  
Woy Woy Leagues Club

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

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**29**  
Jun **Lift4MND**  
RealFITT

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**28**  
Jul **Bunnings Balgowlah Sausage Sizzle**  
Bunnings, Balgowlah

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

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**26**  
Oct **Gundaroo Music Festival 2019**  
Gundaroo

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# Motor Neurone Disease Association of New South Wales

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<http://fb.me/mndnsw> ABN 12 387 503 221

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Team Sue Donaldson,  
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Sandra Woolnough, Ruth  
Yuthok

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Matouk

Team Cathy Amatya,  
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Lauren Lovegrove,  
Samantha Potter, Marnie  
Roelink, Kristie Stamford,  
Rosemary Tome

### Admin Assistant NDIS

Brenda Smith

...and many valued volunteers