



### In this edition

Make Aged Care Fair, resources for carers, accessible beaches, Walk to d'Feet 2019, honouring carers and more...

### A Message from the CEO

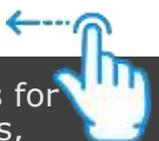
Christmas is nearly here and this will be our last e-news for the year. And what a year it's been. We've supported 563 people with MND as well as their carers and families. Providing education, Info Line, MND Adviser services, equipment, advocacy and funds for research. All of our support services are provided at no cost to families and people with MND. Our equipment went to 347 people across NSW and the ACT when they needed it. The total value of that equipment was \$2,640,782. It's not an exaggeration to say that we'd be unable to provide any of these services without your support.

You should have received our Christmas Appeal by now. Please support us so we can Make Aged Care (a little more fair) and give back the voice of people with MND over the age of 65.

Our last Walk to d'Feet was held in Sydney in early November. In 2019 our 8 Walks saw 3000 people raise nearly \$300,000. Next year there'll be 9 across NSW and the ACT. The dates and venues will be up on our website soon so make sure you earmark one close to you and be part of a fantastic community event.

Please be aware that our holiday closing will be from 12pm Tuesday 24 December 2019 until 9am Thursday 2 January 2020. On behalf of the Board and staff of MND NSW I'd like to wish everyone a happy and safe Christmas and New Year.

Graham Opie





## Support Service Update

As I write this, I am very conscious of the terrible fires that are ravaging and threatening to ravage NSW and the ACT. Inevitably some if not many of our members, their families and our own staff are caught up in the crisis and we send our love, thoughts and prayers to all at this time.

I would especially like to note our MND Community on the far north coast who travelled to be with us a few weeks ago to share in a two-day event honouring carers and remembering those we have lost to MND. I am very appreciative of MND NSW staff Eileen O’Loughlen, Sandra Woolnough and Kate Maguire, who hosted these events in what can only be described as difficult circumstances. They tell me however, the opportunity to get together and to share their stories and remembrances has been incredibly valuable. We plan to run similar events regionally in 2020, hopefully under more settled conditions.

I have written much about the NDIS and My Aged Care systems this year. We have made some advances and with your help have been able to provide strong advocacy on behalf of people living with MND

*(Continued on page 3)*

(Continued from page 2)

and their families. The fight for better support will continue into 2020 as we urge government at all levels to provide access to all people living with MND to the NDIS regardless of age.

We will shortly publish our calendar of events for 2020. If you haven't been to one of our events then I strongly encourage you to do so next year. We are planning to run more events in regional areas and will again offer programs for the carers in our midst. If you missed any of our events this year you can always visit the [MND NSW You Tube channel](#) where you can watch some amazing presenters talk about everything MND.

Christmas is nearly upon us once more and again I wonder where the year has gone. Soon the party hats will be out, and celebrations will be had. As we head into the end of year, I urge us all to take some time to relax, recharge and remind ourselves of just what a wonderful community we all belong to. In the past year I have been struck by the generosity, the good humour, the love and the commitment of the people who make up the MND Community. No matter where we are or how we plan to spend the Christmas break, just know that we are all connected and strong in the fight against MND.

Bye for now,  
*Karen Martin | Manager, Support Services*





### [Donate to our Christmas Appeal and help to Make Aged Care Fair](#)

You may have received our letter in the mail asking for donations just in time for Christmas so we can give back the voice of people with MND aged 65+ with the gift of a specialised iPad.

For people like Andy\* who have progressively lost the ability to speak because of MND, an iPad is their voice. But not everyone has access to this technology.

Research shows 50% of people with MND are diagnosed when aged 65+. As they do not have access to the National Disability Insurance Scheme, they rely on Aged Care services for support, pushing them into financial hardship.

However, because of the generosity of our supporters, we were able to loan Andy an electric wheelchair (valued at \$13,000) and a specialised iPad (valued at \$1320) free of charge, giving him back his voice and more independence.

*(Continued on page 5)*

(Continued from page 4)



*"We really appreciate the help and support given to us, especially the equipment",* said Andy.

Andy was able to share his wishes with his doctors and carers, determining management of his care and life. He was able to tell his family, especially his wife Terri\* how much they meant to him and helped to prevent social isolation.

*"I am so relieved and so happy that this service exists. The whole process was quick and efficient and meant that we didn't have long waiting times and huge costs we couldn't afford,"* said Terri.



By donating this Christmas, you'll be helping to make a real difference in the life of someone living with MND and in the lives of those they love.

You can make your donation online or by calling us on 02 8877 0999.

\*Names have been changed to protect identities

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## Upcoming Support Service Events

Click the event for more information or contact the MND Info Line ph. 8877 0999 or Freecall 1800 777 175 or email [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au).

10  
Dec

**Information Evening**  
Sydney

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## Community Calendar

Click the event for more information .

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**3-24**  
Dec **[MND Christmas Wrapping Stall](#)**  
[Deepwater Plaza](#)

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**27-29**  
Dec **[Market Stall](#)**  
[Kevin Sobels Wine](#)

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**9 May**  
2020 **[Beat the Beast Team Roping Spectacular](#)**  
[Attunga Sport and Rec Grounds](#)

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**9 May**  
2020 **[March for MND - Larapinta Trek 2020](#)**

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Do you have a great idea for an event or activity  
that will raise funds for  
MND support and research during 2020?

MND NSW supporters can organise events and activities  
to raise funds for motor neurone disease and help provide  
much needed care, support and research.

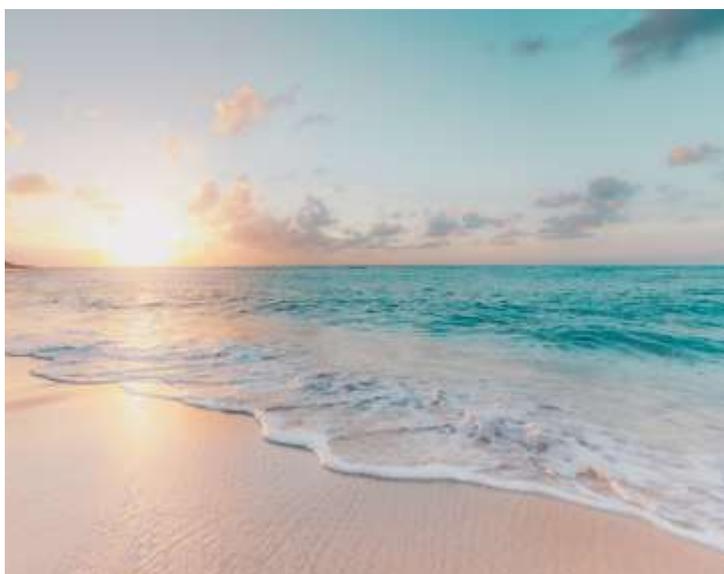
In the past supporters have organised golf days,  
trivia nights, bowls afternoons, auctions,  
afternoon teas, balls, stalls, treks and walkathons.

Your event will help us provide much needed services  
for people living with MND .

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

## [How to find accessible beaches this summer](#)

There are a number of organisations in Australia that provide information on beach accessibility for wheelchair users or people with reduced mobility. For people planning around how to access the beach, accessible parking spots, accessible bathrooms and what equipment may be required is essential.



Directories of Australian accessible beaches include:

- [Accessible Beaches](#)
- [iOceanSwim](#)

If your nearest beach is not listed, contact the local Surf Club or Council to ask for further information on accessibility.

For beach wheelchair hire or purchase check out:

<https://at-aust.org/items/8828#suppliers> or

<https://ilcaustralia.org.au/products/18030>

## **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  
[info@mndnsw.asn.au](mailto:info@mndnsw.asn.au) for  
details.



## [Five resources to help carers of people with MND avoid carer burnout](#)

While caring for a loved one with MND can be very rewarding, it also involves many stressors. It can be difficult for carers to find time for themselves and since caregiving can be an ongoing challenge, the emotional impact can snowball over time. And so, it's important to remember that carers also need to take time out to care for themselves so they can continue to provide the best care for others.

### [But first, what is carer burnout](#)

If the stress of caregiving isn't well managed then it can take a toll on other aspects of your life such as your health, relationships, and state of mind and this can eventually lead to carer burnout. Carer burnout is when you are feeling emotionally, mentally and physically exhausted. When you reach this point of exhaustion, both you and the person you're caring for can suffer. That's why taking care of yourself isn't a luxury, it's a necessity. Cultivating your own emotional and physical well-being is just as important as making sure your loved one is receiving appropriate and loving care.



*(Continued on page 9)*

So here are five of the best resources we've found to help carers of people with MND to avoid carer burnout:

### [#1 CarerHelp](#)

A new website to support people in Australia who are caring for a partner, relative or friend living with a terminal illness.

CarerHelp features:

- Evidence based and practical information about symptoms of carer burnout
- How to get help on financial/legal issues
- Downloadable forms, tools and online learning modules for carers

CarerHelp has been developed as part of the Australian Family Carer Toolkit Project and it aims to ensure that Carers are more informed and better prepared for their role. The idea is that by providing carers with appropriate information and support, they will feel less distressed and more competent, improving their overall well-being. Find out more [here](#).

### [#2 Carer Gateway](#)

If you care for a family member or friend, then Carer Gateway could help you. Carer Gateway provides practical advice and support for carers as well as:

- Helping you to get the services and support you need
- Free counselling services over the phone
- Self-guided free coaching to help you in your carer role

Carer Gateway is an Australian Government initiative and can also provide information on respite and planning for an emergency. Find out more [here](#).

### [#3 Carers NSW / Carers ACT](#)

Carers NSW/ACT is a non-government organisation for carers in NSW and ACT and their focus is on improving the lives of carers. Carers NSW and Carers ACT work with all carers regardless of their age, location, life-stage or circumstances and can support by:

(Continued from page 9)

- Online training and information resources
- Providing counselling and support groups for carers
- Providing specialised information e.g. employee assistance program
- Support for young carers under 25

Find out more here: [NSW / ACT](#)

#### [#4 Carer Gateway Community Forum](#)

This forum is managed by Carer Gateway and provides a safe, anonymous space online for people to connect with other carers and to support each other. Discussion topics include self-care, relationships, money and work, tough times and a social space. Find out more [here](#)

#### [#5 Carer Peer Connect](#)

While face-to-face peer support is shown to be beneficial to carers, it's not always possible for carers to attend a group in person due to the demands of their caring role, their geographic location and/or other commitments like full time jobs and family commitments. Carer Peer Connect provides online chat forums which discuss disability and illness specific issues as well as more general topics, such as managing relationships. Carer Peer Connect is centrally managed by Carers NSW and funded by Family and Community Services (FACS). Find out more [here](#).



We hope [these resources](#) can help carers to find ways of managing their stress and emotional needs as well as providing practical information and peer support.

### [Carer Wellbeing Study](#)

Researchers at the University of Canberra are looking to explore the connection between patient-caregiving relationships, chronic/complex illnesses and caregiver wellbeing. They are seeking adults who provide informal care for another adult with a chronic or complex health condition, including motor neurone disease. This project has received approval from the University of Canberra's Human Research Ethics Committee (HREC 0389). The study involves participants completing [an online survey](#) which should only take 10 minutes of your time.

### [Royal Commission into Aged Care](#)

Recently, the Royal Commission into Aged Care released their interim report. The Commissioners called it a "shocking tale of neglect".

As this report shows, Australians diagnosed with MND aged 65 years+ are not having their complex and rapidly changing needs met. They may even pass away on the waiting list. You can read the response to the report from MND Australia [here](#).

### [Pudding Lane Puddings Back in Stock](#)

No festive feast is complete without a Christmas Pudding and we have the MOST DELICIOUS puddings from Pudding Lane back in stock! Think sweet, fruity flavours and a hint of brandy. The best part is, they were donated to us by the fab people at Pudding Lane so all proceeds can be used to support people with MND and their families. [Get yours before we eat them all ourselves.](#)



### [Honouring Carers and remembering those we've lost to MND](#)

We'd like to thank everyone who travelled to our two-day event on the NSW North Coast in the second week in November to honour carers and remember those we've lost to MND. While the event was held under difficult circumstances due to bush fires in the area, the opportunity to get together and share stories and remembrances was incredibly valuable. We will be holding more of these events in regional areas in 2020. Our thoughts are with all those who have been affected by the bushfire crisis.

## We've been walking all over NSW and the ACT to d'Feet MND

This past year, we've been walking all over NSW and the ACT with our incredible supporters, working together to d'Feet MND. Thank you to everyone who has been involved in these Walk to d'Feet MND events. It's because of you that each has been such an amazing success.



It's been a huge year, with a total of eight Walk to d'Feet MND events held all over NSW and the ACT. It's meant we've been lucky enough to spend time with members and supporters from all over the place—walking in memory of loved ones as well as raising funds and awareness so we can better support people living with MND now, their family and carers. We added two new locations, Taree and Young, while also getting a little trendy with our last walk for the year, holding it in Sydney's Inner West.



We set the bar high this year and aimed to raise a whopping \$300,000! And we've nearly reached our target. All this is thanks to

the amazing support of our participants and the people generous enough to sponsor them. Because of their contribution, we'll be able to continue supporting people with MND and their loved ones, providing much needed equipment and information as well as fostering a community where people can share their experiences of MND and learn from each other. Most importantly, it means we can continue working together with people who are living with MND to ensure they maintain as much independence as possible, so they can

*(Continued on page 13)*

*(Continued from page 12)*

stay at home with their loved ones.

We wouldn't be able to hold our events without the amazing support of our sponsors and we would like to say a huge thank you to Duncan Stock Crates, Kennards Hire, Ego Sunsense, Lions Club Forbes, Anytime Fitness Forbes, Bernardi's Farmers' Market, Bulli Surf Life Saving Club, i98 FM, WIN Television, Woonona Lions Club, Responder1, Waliscags, Rotary International, Penrith Moggas Marquees, Lions Club of Young and Sugarvalley Neighbourhood Centre.

We'd also like to thank the food trucks and coffee vans who came to ensure the walkers at our events were able to refuel with delicious snacks as well as various market stalls who added atmosphere to our Young event. These guys attended free of charge and made generous donations where possible and included; Vege 4 Love, Street Sliders, Retro Birdie Ice-Cream & Dessert Truck, Funky Food Van, Kickin Back Coffee, Wollongong Ice Cream, Xpresso Mobile Café, Cafe2U Penrith South, That Coffee by Jaclyn, Whipit4U Icecream, Salami Bros Pizza, Clicky Cookies, Moava, Bev Maloney and Katie Fisher.

The name of these events, Walk to d'Feet MND, reflects the hope and inspiration these special days provide for the MND Community. We've loved watching teams made up of family, friends, colleagues and individuals walk to raise funds and awareness for research and support for people living with motor neurone disease.



We want to give a big shout out to everyone who walked alongside us this year and we hope each one of you had an amazing time. Your support means the world to us. In the meantime, we're dusting off our boots and getting organised for our Walk to d'Feet MND events in 2020. We can't wait to see you there

## [A huge thank you to our incredible team of volunteers](#)

We're a relatively small charity but we achieve a lot for our size and much of this is thanks to this amazing group of people who volunteer their most precious resource. Time.

Each one of you has made a real difference in the lives of people with MND, their carers and loved ones. We're so grateful for your assistance and generosity. There is no way it would be possible to do what we do without your help.

Together we can break down the barriers for people living with MND, their family and carers. By becoming a volunteer or continuing to volunteer, you'll assist us to raise awareness and funds so we can continue to support people living with MND and everyone they love.

We're always looking for new people to join our Volunteer Program as a volunteer or an ambassador.

If you'd like more information about becoming a registered volunteer of MND NSW so you can begin to raise awareness of MND in your area, please contact Sarah on 02 8877 0999, freecall 1800 777 175 or email [sarahb@mndnsw.asn.au](mailto:sarahb@mndnsw.asn.au).

## Join our Volunteer team today

Volunteers are vital to MND NSW.

Volunteers allow us to continue to:

Support our members with information, resources and equipment

Support our member's family and friends

Educate carers and health professionals

As a Registered Volunteer you can:

Assist at events

Provide office and administration support

Become an Ambassador, speak at events and

meetings and raise awareness of MND and MND NSW



If you would like more information about being involved as a registered volunteer please phone Sarah on 02 8877 0999 or email [Sarahb@mndnsw.asn.au](mailto:Sarahb@mndnsw.asn.au)

### Dubbo Ladies Shopping Trip



A big thank you to Faye Wheeler who again organised a Dubbo Ladies Shopping Trip which raised \$1,200 for MND NSW. Faye said of the event, "Another fabulous weekend with a great group of girls.

Lots of fun, laughter, fundraising and of course shopping." Thank you ladies for your wonderful support!

### Nareen Terrace Tea for MND

We would like to thank the wonderful community at the Nareen Terrace retirement village who recently held a morning tea which raised \$486. Thank you also to MND NSW Ambassador, Don McMurray, who attended the event and spoke about MND and his experiences as a carer. Thank you to everyone who contributed and supported this lovely event.

### High Tea at Ashdon B&B

Our congratulations to Joy London who organised a High Tea at Ashdon B&B event which raised a fantastic \$14,641 for MND research. The High Tea was held in the small community of Arakoon in NSW. It was a great day with 300 people in attendance, and a wonderful community spirit. Thank you to everyone who attended and provided their support.



## Calwell Winter Indoor Fair

Thank you to Liz Stephens along with her family and friends who organised the Calwell Winter Indoor Fair in Canberra in support of MND. The fair was a great success with a variety of stall holders and performers creating a wonderful atmosphere. Another fair is planned for 2020. Thank you to everyone who supported this event.



## Campbelltown Support Group Christmas

Our Campbelltown Support Group got together to celebrate Christmas and took this lovely pic. As Christmas celebrations begin we'd love to wish you and yours the very best of the season and into the New Year!

## A New Use for Corn Flowers

Leigh, the mother of one of our board members, Kirsten Harley, sent in this amazing photo from her home in Bright, Victoria. A resident male satin bower bird has begun decorating his bower with cornflowers, they are the perfect blue for him. What a lovely and hopeful image - we just had to share!



Christmas is nearly here and we have some amazing Christmas cards, hand made puddings and Santa approved stocking stuffers on sale! All proceeds go to helping people living with MND and their families. You can order online or call us on 02 8877 0999



Present Cards

"Best Wishes for a Merry Christmas and a Happy New Year"



Bauble Cards

"Wishing you all the Best for the New Year"



Star Cards

"Warmest Greetings of the Season and every good wish for the Coming Year"



Peace, Joy and Happiness Cards

"To wish you Peace, Joy and Happiness for Christmas and the New Year"



Aussie Animals and Santa Cards

"Season's Greetings and Best Wishes for the new Year"



Christmas Pudding  
1kg Pudding Made by Pudding Lane



Keyring Torch



Shopping Bag



Socks  
Ladies - Purple  
Mens - Navy



Photo Frame

Brushed Aluminium. Engraved with MND NSW logo  
205mmH x 153mmW  
(to suit 4"x 6" photo)



Plush Puppies

Black & White, Tan & White, Cream, Black



Dog Bandana



# 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](mailto:admin@mndnsw.asn.au) <http://www.mndnsw.asn.au>

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

## Together we can break down the barriers for people living with MND

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**AUDITOR** Walker Wayland NSW

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**Administrative Assistant** Freya Herschel

**And many valued volunteers**