



## **In this edition**

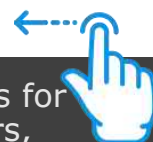
Thank you Taree!... NDIS funding disability-related health supports from 1 October... Carer Gateway update... MND education events in Sydney, Ballina and the Hunter... Christmas Orders - support our fundraising efforts... Don't miss out on Walk to d'Feet MND 2019... March for MND Larapinta Trail Adventure 2020... and more.

## **A Message from the CEO**

It has been incredibly busy this past month (as always) with our first Walk to d'Feet MND in Taree, Living Well With MND education program in Berry, past carers lunch, our first Chat and Connect session and meetings with Federal and State Ministers to further access to an equitable My Aged Care. As we get closer to Christmas, time compresses, and as can be seen in this edition of e-news the next few months are jam packed.

I'd particularly like to thank those of you who have shared your own story of your issues with My Aged Care. Our Make Aged Care Fair advocacy has been a particular focus of MND Associations across Australia during 2019. In October we will be meeting with more MPs and Senators in Canberra to press for a more equitable system. Please keep telling us about any challenges you are experiencing. Personal stories have a greater impact than statistics alone and a person with MND should not just be a statistic on a wait list for services that will be insufficient for their needs.

*Graham Opie*

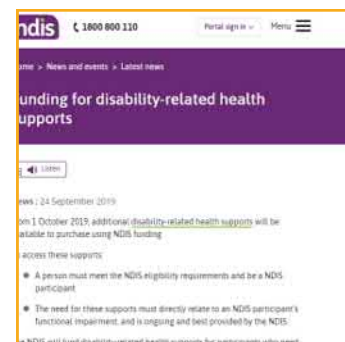


## Support Service update

Great news! The NDIA has finally released details of the health supports now available through a person's NDIS plan. On 24 September the NDIA released the following statement:

*The NDIS will fund disability-related health supports for participants who need help to manage a range of needs including those associated with continence, respiratory care, nutrition, wound and pressure care, dysphagia, diabetes, podiatry and epilepsy.*

*The health system will continue to be responsible for all acute/post-acute care (e.g. hospital and Hospital in the Home) and chronic health conditions not related to a participant's disability, diagnostic, palliative or time limited (non-ongoing) conditions.*



We understand that NDIS participants will be able to access these supports from 1 October 2019 using available Core Support monies. If you are a current NDIS participant, you may also receive a call or letter from the NDIA about how you can begin to access disability health related supports. You should also speak with your Coordinator of Support about having these supports included in your future NDIS plans. As with all things NDIS we know there will be some 'hitches' in the roll out of these changes. If you have any difficulties, please contact us so we can help sort through these with you.

October also marks National Carers Week which will take place between 13-19 October 2019. Throughout the month we will also be celebrating the incredible contribution our carers make within the MND Community. Keep an eye on our Facebook page and your email for events and news about what is happening in your area.

In writing about Carers Week, I looked for some clever words or poem which speaks to the life of a carer. Most of what I found spoke of inspirational works, or using the experience to grow, which of course is all very true, however as a carer myself, I would say caring is also about days that can be long and days that can be hard, days that can be funny, days that can be ordinary and days that can be extraordinary.

*(Continued on page 3)*

(Continued from page 2)

Whether you are a carer, have been a carer or are being cared for do take some time out this month to celebrate and acknowledge your part in our wonderful MND Community.

Thank you to everyone who responded to our call for your experiences with the My Aged Care system. We have received some great information that can now be used to strengthen our advocacy work. It is not too late to add your voice, so if there is something you would like to say then please email me at [karenm@mndnsw.asn.au](mailto:karenm@mndnsw.asn.au).

That is all for now.

*Karen Martin | Manager, Support Service*

### [Walk to d'Feet MND Young, Sunday 20 October](#) [Get in on the early bird special](#)

We're getting excited about our next Walk to d'Feet MND - and the first we've ever held in Young, to take place at 10am on Sunday 20 October at Arboretum Park. It's only one week until the early bird online registration closes at 10am on 13 October. It will be your last chance to purchase a t-shirt with your registration so you and your team can dress all matchy-matchy and raise even more awareness for MND NSW!



We'd love you to get your family, friends and of course, your pooch together and register for the event so we can show support for people battling the challenges of MND. All funds raised will go toward providing essential equipment, services and support for people living with MND and their loved ones. [Find out more.](#)

### [A great Christmas gift idea](#)

Our gorgeous new brushed aluminium photo frames engraved with MND NSW logo will make a great gift for friends and family. Order yours today. They are only \$12. Picture size 10cm x 15cm (4"x6"), frame dimensions 15.5cm x 20.5cm with hanging or tabletop mounting [Visit our online shop to order.](#)





## Walk to d'Feet MND Sydney, 3 November

We're getting all trendy and hosting our Sydney Walk to d'Feet MND at Sydney Park at St Peters on Sunday 3 November.

Being in the centre of Sydney, we're hoping to get more people than ever signing up and taking a walk and showing support for people with MND and the ones they love.

All you need to do is follow the [link](#) and sign yourself and anyone you want to be part of your team (including your puppies) up for the walk so we can work together to raise funds and awareness for research and support for people living with motor neurone disease. [Find out more or register today](#)



## Living Well with MND Information Day 22 October at West Ryde

*Living Well with MND* is an informative day for people living with MND, their family 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.](#)



## MND Connect 2 December - Perth or live stream

Leading international ALS/MND researchers are providing the MND community with the opportunity to ask questions about the latest research advances at the 2019 MND Connect - on 2 December in Perth. If you can't attend, register for the live stream. Speakers include Professor Matthew Kiernan AM - (Australia), Professor Ammar Al Chalabi (UK) and Professor Merit Cudkowicz (USA). The aim of this free session is to connect people living with ALS/MND, their family and friends with leading international researchers. [Find out more.](#)



Join us on the March for MND to provide the best possible support for people living with motor neurone disease, their family and carers

On this incredible adventure, you'll trek through the Australian outback on one of the most spectacular walking tracks—the Larapinta Trail.

As part of this 7 day adventure in September 2020 you will stand on ancient escarpments and gaze out upon the ochre-coloured landscapes of Central Australia. You will follow Aboriginal Dreaming tracks and trek beside one of the world's oldest river systems. Best of all, you'll be raising funds for the Motor Neurone Disease Association of NSW to continue providing support for people living with MND while also advancing research to find a cure. [Register your interest today.](#)



### Study on mental health and ageing

The School of Psychology at the University of Adelaide is looking for volunteers to complete a brief survey about mental health and ageing. The survey will take about 15 minutes and you can enter the draw to win a \$150 EFTPOS gift card. The information from the survey will contribute to understanding how mental health symptoms differ for men and women across the lifespan, leading to better recognition and diagnosis of mental health problems. [Take the survey.](#)

The study has been approved by the University of Adelaide Human Research Ethics Committee (approval number H-2019-109).

### National Public Toilet Map

The [National Public Toilet Map](#) and App show the location of more than 16,000 public and private toilet facilities across Australia. Details of toilet facilities can also be found along major travel routes and for shorter journeys as well. Useful information is provided about each toilet, such as location, opening hours, availability of baby change rooms, accessibility for people with disabilities and the details of other nearby toilets. You can also download the iPhone National Public Toilet Map App.



## Ballina

We are off to Ballina in November. For more information on the events listed below and to RSVP contact [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) or ph. 8877 0999 or Freecall 1800 777 175. Please let us know if you have any special mobility or dietary needs.

There is no charge for you to attend but you will need to reserve your place.

### MND Hope and Remembrance - Ballina

12pm-3pm, 11 November

We welcome you, your family and friends to join us in a gathering to honour and celebrate those who have lost their lives to MND. Following a brief ceremony there will be a light luncheon and opportunity to chat and connect with others. [Find out more.](#)

### Information Evening for people diagnosed with MND - Ballina

6pm-8pm, 11 November

If you or someone close to you has been diagnosed with MND, this evening will provide an opportunity to have some of your questions answered in an informal setting. You will also be able to meet others who also understand the impact of living with MND. [Find out more.](#)



### MND Carers Morning Tea - Ballina

10.30am-12.30pm, 12 November

Are you caring for someone who has MND? Join us for a complimentary morning tea which offers an opportunity for you to meet others caring for someone with MND. [Find out more.](#)



## 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. The study involves participants completing an [online survey](#), which should only take 10 minutes of your time, or for more information contact PhD student, Kath Carleton [u3179444@uni.canberra.edu.au](mailto:u3179444@uni.canberra.edu.au).

This project has received approval from the University of Canberra's Human Research Ethics Committee (HREC 0389).



## Never Give Up Raffle

Get your ticket now for the 'Never Give Up Raffle' with proceeds to MND NSW proudly supported by Big4 Easts Beach Holiday Parks Kiama. Thank you to Angela Holz for your support for the raffle. The Raffle commenced on 17 September 2019, closes on 17 October 2019 and will be drawn on the 21 October 2019 at MND Centre Gladesville at 10am. [See more and purchase tickets here.](#)



## Tathra Beach Women's Bowling Club

A big thank you to the Tathra Beach Women's Bowling Club who continue to support MND NSW with fundraising activities. A charity day in June raised \$800 for MND NSW. Thank you for your generosity and continued support.



Pictured are the women from the Bega-Imlay District Women's Bowling Association who supported the day.

## Thank you Nelson Bay Juniors

A big thank you to the Nelson Bay Junior Rugby League Club who supported our association with their MND NSW Charity Jersey Fundraiser which raised \$3,000. The event was held in honour of Steve Lingard who



has been a significant contributor to the Club and is living with MND. Thank you to everyone who donated and supported this event.

## A fantastic concert in Canberra

Canberra Brass Inc., supported by The Band of the Royal Military College Duntroon, recently held a charity concert to support the work of our Association. We heard that the concert went fabulously well and was an



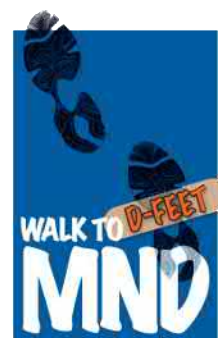
afternoon enjoyed by all who attended. Our thanks to Canberra Brass Inc. and to our volunteers who attended to help on the day. The event raised \$2,086 and will be put towards assisting people living with MND.

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

Register today at [walktodfeet.org.au](http://walktodfeet.org.au) and raise funds when you participate.

Show your support for people living with MND.

It is not too late for you to get involved. Register today at <https://walktodfeet.org.au>. Together We Can.



20  
Oct

**Walk to d'Feet MND Young**  
Arboretum Park  
Young

*Supported by*



3  
Nov

**Walk to d'Feet MND Sydney**  
Sydney Park  
Alexandria

*Supported by*



## Thank you to our supporters

Walk to d'Feet MND Taree

8 September 2019

What a great day it was at our first Walk to d'Feet MND - Taree. A big thank you to the local volunteers, sponsors and to the great team from Taree Lions Club who cooked the yummy sausage sizzle. Over 300 participants walked to show people living with MND that they are not alone with over \$10,000 raised from the day.

*Supported by*





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## Community Calendar

Click the event for more information.

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**Now****Never Give Up Raffle**  
On sale until 17 October**5  
Oct****Market Stall**  
Pokolbin**26  
Oct****Gundaroo Music Festival 2019**  
Gundaroo**27  
Oct****Colour Me for MND**  
Coniston Public School, Coniston**2  
Nov****Harrington Expo**  
Harrington**4  
Nov****High Tea**  
Whites Meadow**29  
Nov****Dave Matthews Seniors Tennis Tournament**  
Nelson Bay Tennis Club

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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 who organise events and activities  
that raise funds for motor neurone disease provide much  
needed funds for MND care, support and research.

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

Help us provide much needed services  
for people living with MND with your event.

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

## Link and Learn

### 7-8 November in the Hunter Valley

Are you a family member, relative or friend caring for someone with MND? If you are keen to gain some extra information and support, this program may be ideal for you. It is suitable for those new to the caring role and also those who have been caring for some time.



The program, called 'Link and Learn', is residential and runs over two days and a night in the beautiful Hunter Valley on Thursday 7 and Friday 8 November 2019.

You will have the opportunity to hear from a range of health professionals and MND NSW staff with expertise in MND, who will answer your questions and facilitate discussion in a relaxed and informal setting. The aim of 'Link and Learn' is to support you to give the best possible care at home for the person with MND by:

- reducing the sense of isolation associated with becoming a carer through meeting other carers and sharing ideas and experiences
- providing you with information so that you can be prepared and able to plan ahead for the changes that may occur. This will help you, and the person you are caring for, to maintain a sense of control over these changes
- letting you know how to find support services and how to care for yourself so that you can carry on caring.

Those who have attended this program previously tell us that they especially valued the opportunity to take time out for themselves and to share their ideas and experiences with others in similar situations. As one person said, "this program is a very valuable insight for anyone in a carers role with plenty of learning, laughter and knowledge gained".

Participation in the program, including meals and accommodation, is free of charge for people caring for someone with MND, but we do ask that you commit to attending the two days. If you have any questions, would like to RSVP or need support in arranging care for your family member while you are attending, contact the MND Info Line ph 1800 777 175, speak to your MND Advisor or email [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) by 31 October 2019.

## Master Locksmiths Access Key

The Master Locksmiths Access Key (MLAK) is an innovative system that enables people with disabilities to gain 24/7 access to a network of public facilities. The MLAK system has been fitted to elevators at railway stations and accessible toilets in Council municipalities and National Parks. People with a disability are able to purchase an MLAK master key which will open all toilets and other facilities which are fitted with this specially designed lock. [Find out more online](#) or phone 1800 810 698.



## 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  
Oct

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

22  
Oct

**Living Well with MND**  
West Ryde

7-8  
Nov

**Link and Learn**  
Hunter

11  
Nov

**Information Evening for people diagnosed with MND**  
Ballina

11  
Nov

**MND Hope and Remembrance**  
Ballina

12  
Nov

**MND Carers Morning Tea**  
Ballina

2  
Dec

**ALS/MND Connect 2019**  
Perth (in person or live stream)



## Beach accessibility

There are a number of organisations in Australia that provide information on beach accessibility for wheelchair users or people with reduced mobility. For these 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

- [www.accessiblebeaches.com](http://www.accessiblebeaches.com)
- [www.ioceanswim.com.au/beach-accessibility](http://www.ioceanswim.com.au/beach-accessibility)

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

Beach wheelchair hire or purchase

- <https://at-aust.org/items/8828#suppliers>
- <https://ilcaustralia.org.au/products/18030>

Beach access mats

- <https://at-aust.org/items/11790#suppliers>
- <https://ilcaustralia.org.au/products/15936>

## Government Integrated Carer Support Service (ICSS) to also offer in person services from April 2020

Online and phone support for carers is currently available via the [Carer Gateway](#) or ph. 1800 422 737. The Australian Government recently announced in person services for carers will commence from April 2020. In person services will include carer support planning, coaching, peer support, counselling, carer directed packages and emergency respite care. These services will be provided by regional delivery partners including [Carers NSW](#).



## Barellan Working Clydesdales

Thank you to Stephanie Dickie who raised \$615 at the Hillston Show. Stephanie and her miniature horses, Beau and Santos, gave carriage rides for a donation to MND NSW. We think they look great in their MND NSW bandanas!



## We appreciate your support

Thank you also to the following supporters

- The Riverina, Urana & Corowa Historical Vehicle Vintage Machinery Clubs Inc. for their donation of \$5,000 for support for people living with MND.
- The Dungog Fundraising Committee who donated \$24,000 to MND NSW from a fundraising dinner.
- The Pambula-Merimbula Golf Club who raised \$1,310 from the David Haig Memorial Golf Day. Thank you for the continued support.
- Quakers Hill Vets raised \$3,052 from a raffle. This is the fourth year they have supported MND NSW with a fundraising event.
- Marnie King and Laruen Morris who organised the Big Freeze At The Booma event which raised \$7,033.
- Roller Disco for MND raising \$507 and a Hot Cross Bun Fundraiser raising \$312, both organised by Chontelle Shore. Thank you Chontelle for your wonderful support.
- Senthuraj and his colleagues from Brand Influence Group who participated in the Sydney Harbour 10k and 5k event supporting MND NSW, with \$1,203 in donations.
- Our thanks to Raylene McKenzie who held the Fight Like Hell for MND & Dave raffle which raised \$1,000. Raylene generously donated ENJO products as the prizes.
- St Francis Xavier's College Hamilton who donated \$614 from their Champagnat House Fund Raiser 2019.
- Koorringal High School for a \$394 donation from Year 12.
- Thank you to the Central Coast MND Support Group and the Rotary Club of The Entrance who raised \$1,500 from their annual raffle.
- Crestwood Public School who raised \$1,204 from their third annual MND Day. Thank you to the students, teachers and the school community for your continued support.
- An amount of \$1,320 donated from the annual Glenn Sargood Fundraiser.
- Our thanks to Linda Howes from the Woolianna Tourist Park in Darwin who raised \$600 from a fundraiser for MND.
- To the residents, staff and visitors of the Eloura Aged Care Facility in Quirindi, NSW thank you for your donation of \$557 for research from a successful morning tea.
- The Ionian Club of Canberra who donated \$2,460.

## When your extended family, friends or neighbours want to help

It is not uncommon for people with MND to get offers of help from extended family, friends and neighbours; or for school communities, sporting clubs or other community groups that know the person with MND to contact them or their family wondering what they can do to 'help'.

It can be hard accepting offers of help. Sometimes people hesitate accepting an offer of help because they feel like they are asking too much, or that what they might need will be an imposition on the person making the offer. Others may feel they want to keep their MND 'private' and not have others in their house, or that they don't want to feel like they might 'owe' a person.

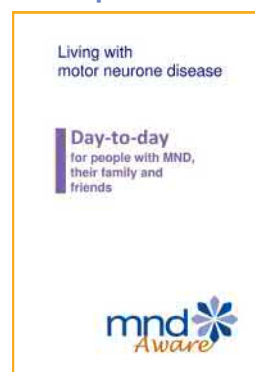
However, when you accept an offer of help from your extended family, friends or neighbours, you are providing them with the opportunity to 'do something' to show their care and concern for you and your family. You are also providing them with a familiar way to stay in touch with you and your family because you are probably not getting out and about as much as you might have previously.

Saying 'yes' to offers of help from extended family, friends or neighbours can free up your close family from tiring daily tasks. This can allow your family to get some time and rest for themselves, and/or spend more time doing enjoyable things with you.

In fact one of the tasks you might be able to delegate to a person offering to help is for that person to help make a specific list with you and to coordinate the offers against what needs to be done. Then, when people offer to help they have a person to speak with and a list to choose from.

By providing the means by which people can 'choose' what they might do, you are enabling the person making the offer to stay within what is comfortable for them to do. For example, some people might prefer a very physical task, like mowing the grass once a fortnight, whereas others might prefer something inside, such as folding the washing, or providing a meal once a week.

Extract from [Living with motor neurone disease: day-to-day for people with MND, their family and friends](#). View the full publication [free online](#).





## Motor Neurone Disease Association of NSW

Christmas Orders 2019 - Support our fundraising efforts - stocks are limited.

**Click the item to view online and place your order**



**Presents**

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



**Australian Baubles**

"Wishing you all the Best for the New Year"



**Decorative Star**

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



**Peace, Joy and Happiness**

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



**Aussie Animals and Santa**

"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



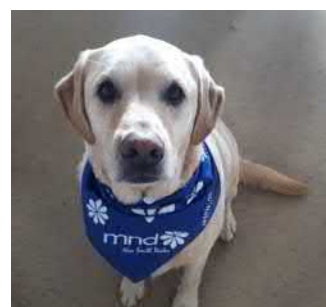
**Photo Frame**

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

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

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

**VICE PATRONS** Melinda Gainsford Taylor, Kevin Langdon OAM, The Hon. Mr. Justice Peter W. Young OA

**AUDITOR** Walker Wayland NSW

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**Receptionist** Arja Aladjadjian

**Administrative Assistant** Freya Herschel

**And  
many  
valued  
volunteers**