



In this edition

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A Message from the CEO

It has been a hectic few months with our national conference held in Adelaide, our Walks to d'Feet MND and our many Support Service events. And to top it off Gina Svolos, MND NSW Support Service Manager for the past 12 years, is retiring. Gina's tenure has occurred during a period of tumultuous change in the disability, health and aged care sectors and she has been instrumental in ensuring MND has been front and centre as policy makers have devised schemes such as the NDIS and My Aged Care. We thank Gina for her contributions and wish her a happy retirement. In October, Karen Martin will commence in the role and we'll have a full introduction in the next edition of *e-news*.

Just a reminder that our Make Aged Fair campaign is ongoing. We are calling on the Government to make sure people diagnosed with MND when aged 65 or over have access to the right care, in the right place at the right time. Find out more and join the campaign [here](#).

Graham Opie



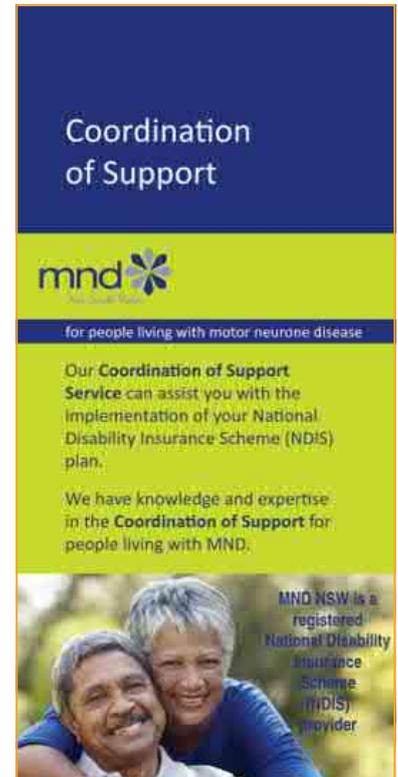
MND NSW Coordination of Support Service now State-wide

We are excited to announce that the MND NSW Coordination of Support Service is expanding to provide services across all areas of NSW. Our Coordination of Support Service can assist you with the implementation of your National Disability Insurance Scheme (NDIS) plan. We have knowledge and expertise in the Coordination of Support for people living with motor neurone disease (MND).

Your MND NSW Coordinator of Support works with you to:

- ensure your plan runs smoothly and efficiently
- identify gaps in service provision
- find other services that can assist you
- address plan issues
- negotiate changes you may want with your plan.

If you have an National Disability Insurance Scheme (NDIS) plan and would like more information about this service contact Alexandra Matouk MND NSW ph. 02 8877 0935 or 1800 777 175 or cos@mndnsw.asn.au, or speak with your MND Advisor.



Celebrating National Carers Week 2018

Northern Rivers - 15 October

Do you live in the Northern Rivers? We are celebrating Carers Week 2018 with a high tea for people with MND and their carer on Monday 15 October at Alstonville, with support from Carers NSW. More information [here](#).

MND NSW Centre Gladesville - 17 October

We warmly welcome former and current carers of people with MND to attend our 2018 Carers Week morning tea on 17 October at the MND NSW Centre at Gladesville. More info [here](#).



Support Services Update

This will be my final contribution to our *e-news* as I shall be retiring from my position of Manager, Support Service, at MND NSW on 25 October after almost 12 years. And what an amazing 12 years it has been. I have met so many wonderful people living with MND and their families and friends.



They have taught me so much about life, caring, love and resilience and I thank each and every one of you whether I have met you in person or perhaps by phone or email. I have also had the privilege of working alongside many of our very committed health and community care professionals, many of whom have gone out of their way to provide support and care to people whose lives have been affected by MND.

There have been so many changes in the sector since I first started at the Association, although our role has continued to be to advocate for the best possible care and support for people with MND. Perhaps the biggest challenges have been in the last few years, as My Aged Care and the National Disability Insurance Scheme (NDIS) have rolled out. We continue to advocate at a Federal level to highlight the needs of people with MND within both these systems. Neither have been designed to meet the needs of people with MND and we have needed to continue to advocate to ensure that the needs of people with MND are represented.

The National Disability Insurance Agency (NDIA) has been responsive and, while there are still many issues, MND is now recognised by the NDIA in their planning and development of the NDIS. We met recently with national NDIA management to continue our discussions and we expect further positive developments from the NDIA.

Looking back over the past 12 years my biggest disappointment is that we could not have the NDIS take on the care of people aged 65 years and over who acquire MND. Aged Care has not been as responsive to

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the needs of people with MND. MND NSW will continue to meet with government agencies to highlight the needs of people with MND aged 65 years and over and will continue to campaign for change. The MND Associations have launched a national campaign specifically for this purpose - Make Aged Care Fair - and you can find out more information at [MND Action](#).

The wonderful staff at MND NSW will continue to work hard to support people with MND. Their dedication to this work and people living with MND is exceptional and I know this will continue at the helm of the new Manager, Support Service, Karen Martin, who will commence with us on 8 October.

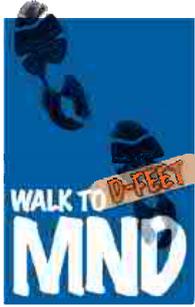
Gina Svolos, Manager

9th National MND Conference

In late August we attended this conference in Adelaide. The conference theme was MND Care: Informing, Influencing, Innovating and attracted over 200 delegates with diverse health, allied health and community support backgrounds from around Australia and New Zealand. There were many interesting speakers who shared their experiences and knowledge about MND which helps keep health and community care professionals up to date with the latest care and supports available to people with MND. The dedication and commitment of those who presented at the conference was very inspiring and is a great opportunity for our staff to learn more about MND from some of the expert researchers and clinicians of various backgrounds from around Australia. You can read more about this conference and view videos of the presentations [here](#).

We also attended the National MND Support Services meeting where MND Association staff from around Australia and New Zealand came together to share the work that each Association is doing. The purpose of this meeting is to learn from each other and to bring ideas back to our own Associations to continue to develop the services we provide.

Wrapping up Walk to d'Feet MND Port Macquarie Sunday 16 September at Westport Park, Port Macquarie



What a great morning in Port Macquarie for our Walk to d'Feet MND. Mother Nature was testing us with strong winds and a very distinct chill in the air but over 200 hardy souls turned up to support people living with motor neurone disease.

Thank you to everyone who supported our Walk, to date over \$21,000 has been raised. What a great effort Port Macquarie!

Supported by



Wrapping up Walk to d'Feet MND Wagga Wagga Saturday 6 October at Apex Park, Wagga Wagga

Thank you Wagga Wagga for the great night. This was our 6th Walk in Wagga Wagga and our first twilight Walk to d'Feet MND. The weather was perfect and so was the company. The Walk began at 5.30pm and participants walked around the very pretty Lake Albert. A big thank you to the amazing Pat O'Hara and her wonderful sidekick Denise Hart who have both worked so hard organising this event every year. Thank you also to Wagga Wagga Rotary for their continued support and yummy sausage sizzle, and special thanks to our local sponsors Les Gray Plumbing and Pirtek Wagga Wagga who have supported the Walk since it's inception. Thank you to the wonderful local volunteers for their tireless and invaluable assistance.



Supported by

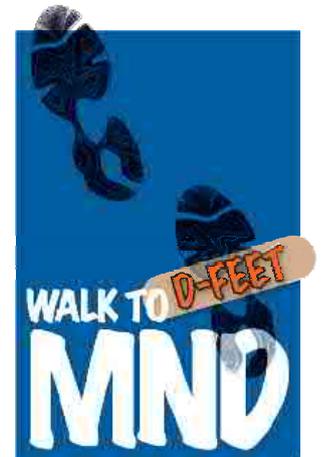


Les Gray Plumbing

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

Don't miss out on a 2018 Walk to d'Feet MND. Join in the fun at Walk to d'Feet MND Sydney!

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.



Sun 4
Nov

Walk to d'Feet MND Sydney
Blaxland Riverside Park, Olympic Park

[Register now](#)

Supported by



Upcoming community fundraising events

Click to find out more.

13
Oct

Trivia Night for MND
O'Donoghues Irish Pub Emu Plains



13
Oct

Gundaroo Music Festival 2018
Gundaroo Park



9
Nov

Newcastle Italian Film Festival
Tower Cinemas Newcastle



16
Nov

Newcastle Royals Korfball Club Trivia Night
Charlestown Bowling Club



29
Nov

Dave Matthews Seniors Tennis Tournament
Nelson Bay

2
Dec

MND Fundraising Garage Sale
Berry

Christmas Puddings by Pudding Lane

Our wonderful Pudding Lane puddings are back. Get yours today!

We have limited stock so don't miss out.

Orders can be placed by contacting the MND NSW Centre at Gladesville ph 02 8877 0999 or online [here](#).



Upcoming Support Service events

Click to find out more.

15
Oct

Carers Week High Tea - Northern Rivers

Alstonville

16
Oct

Information Evening for people recently diagnosed with MND

Gladesville

17
Oct

Celebrating National Carers week morning tea

Gladesville

5
Nov

Ask the Experts Forum

West Ryde

1
Dec

Members' Christmas Party

West Ryde

4
Dec

Information Evening for people recently diagnosed with MND

Gladesville

MND support groups and coffee mornings



MND support groups and coffee mornings are held 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.

Introducing new staff...

Vicki Southgate | MND Advisor
Central Coast and Lake Macquarie (south)

I am delighted to be taking on the role as MND Advisor Central Coast. My background includes case management disability, carers support and community inclusion programs. These previous roles have enabled me to meet people in their own homes or in their community. I have met such a passionate and supportive team of colleagues and now look forward to either meeting or speaking over the phone to you and your family and/or carer team. I have lived on the Central Coast now for three years and it has been a wonderful journey of community engagement.



MND Australia Research Update September 2018

This research update is produced by the MND Research Institute of Australia - the research arm of MND Australia. Read the latest MND research news online [here](#).

Dubbo Ladies Shopping Trip

Thank you to the Dubbo ladies shopping trip who recently raised \$900 for MND NSW. We appreciate how hard you shopped on our behalf, and we hope you all had a great day. A big thank you also to the local businesses who supported this event - Therese from Molly's Place, Kerry from Mason & Walsh, Myer Dubbo and Maryanne and Mikaela Sommerville who supplied cute shopping bags to sell.



MND NSW Christmas Cards now available

Support MND NSW with the purchase of our Christmas Cards. There are three lovely new designs this year. Purchase your cards by contacting the MND NSW Centre at Gladesville ph 02 8877 0999 or online [here](#).



A commitment to compassion

Congratulations to MND NSW Member, Joanne Pugsley, recipient of the Jo Wilton Memorial Award at the 2018 UTS Human Rights Awards for her sustained contribution to the abolition of human trafficking and slavery both in Australia and internationally. One of her students in the Law Faculty says: "She has taught me the importance of perseverance and strength through adversity ... pushing through and continuing to fight for those who need a fighter even when dealing with your own challenges". Read more [here](#).



I have MND. Now what?

"I had a lot of difficulty in finding information. I also didn't know what I didn't know". Paul Watson, MND NSW Member, has been the driving force behind our latest online resource [I have MND. Now what?](#) and it is one of the many resources that your support has helped fund for all people living with MND. Thanks for your support!



Carers Day program at 11th International Conference on Frontotemporal Dementias

About one out of every ten people with MND will receive a diagnosis of 'motor neurone disease with frontotemporal dementia' or MND/FTD. Often the symptoms of dementia precede the motor symptoms, sometimes by a number of years. The 11th International Conference on Frontotemporal Dementias (ICFTD) is on in Sydney during November and running concurrently with the ICFTD 2018 program will be a specialist day on Tuesday 13 November focused on issues and challenges for carers. The day is designed to provide insightful presentations that speak to those faced with caring for those with FTD. Registration is \$150. More information [here](#).

Thank you HMAS Kuttabul FSU

What a great morning we had with the team from the Fleet Support Unit (FSU) at South East Kuttabul, Garden Island. The members of the FSU competed in the 'Amazing Race' to raise funds and awareness for MND.

Twenty teams consisting of six members, guys and girls, took on eight challenges including a Sudoku challenge, wheel chair obstacle course and, in the final challenge, a team member was nominated for an Ice Bucket Challenge.

Over \$850 was raised on the day, what a great result! The FSU will also be assisting MND NSW with their engineering skills to repair equipment from the MND NSW equipment pool. Thank you to everyone involved, we look forward to a great partnership with this Navy Unit.



Dental offer for unpaid carers - 20 October

Maven Dental Group have teamed up with Carers Australia to offer free dental exam, x-rays and clean during Carers Week 2018 on 20 October for unpaid carers. Appointments are for unpaid carers only, on a first come first served basis. Maven Dental have limited appointments available across Australia. More information [here](#) or phone Maven Dental 1800 162 836.

Bankstown Theatre Company

Thank you to the Bankstown Theatre Company for their generous support during their recent production of The Sound of Music. MND NSW was chosen as the charity to benefit from donations given at performances, a raffle and sales of our MND NSW puppies with over \$1,000 raised!





Motor Neurone Disease Association of New South Wales

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Yuthok

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Matouk

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Rosemary Tome

Admin Assistant NDIS

Brenda Smith

...and many valued volunteers