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A Message from the CEO

Our Walks to d'Feet MND over the past year have been an outstanding success. To date we have raised over \$192,400 for care, support, equipment and research.

We have three more Walks before the end of 2019. These are in Taree, Young and Sydney and you can register by following the link on page 7 of this edition of *e-news*. Don't miss out on these great community days because together we can make a difference.

It is never too late to get on board our Make Aged Care Fair campaign. And not just you. Your neighbours, work colleagues, family and friends really need to get behind this important piece of advocacy as well. You can find out more information and join our Make Aged Care Fair campaign [here](#). The only way to change this inequitable and unfair system for people aged 65 years and older is to make your voice heard.

Don't miss out on the MND NSW Ask the Experts Forum to be held on Monday 12 August at West Ryde. Find out more on page 5.

Graham Opie



Support Service update

July started with an amazing workshop for our Special Interest Group which saw nearly 160 health and community care professionals come together to share their skills and knowledge. Their commitment to people living with MND was clearly on show on the day and we thank everyone who took part in this event. You can read more about the Workshop on page 14.



MND NSW has been undergoing our first **NDIS Quality and Safeguarding Audit**. Thank you to everyone who was randomly selected to provide their feedback to the Auditors, we really appreciate it and your comments will always help us continue to improve our services. The Audit itself looked in fine detail at the policies, processes and operations of MND NSW. I can promise you it was an exhaustive examination which can give you some assurance that we are committed to providing the best service to you that we possibly can.

The NDIS Quality and Safeguards Commission is '*an independent agency established to improve the quality and safety of NDIS supports and services*'. They are available to assist with any complaints you may have about the services you receive under an NDIS plan as well as to support providers to understand their responsibilities and improve their services.

More information about the NDIS Quality and Safeguards Commission can be found at www.ndiscommission.gov.au or you can call them during business hours on 1800 035 544.

On 28 June 2019 the Council of Australian Governments (COAG) Disability Reform Council met, endorsed and announced a series of **important changes to disability health related supports**. These changes will take effect from 1 October 2019 and will mean supports such as respiratory, nutritional and swallowing supports can be funded under a participant plan. This includes the supply of BiPap, cough assist and other respiratory equipment.

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This is fabulous news for NDIS participants and comes on the back of past legal challenges to the NDIS as to who should pay for these supports. As at writing we are still waiting for how these supports should be requested and who the NDIS will consider as an appropriate 'expert' to make the recommendation. We will continue to meet with the NDIA to work through these changes as they affect people living with MND and keep you informed as new information comes to hand. If you are interested in reading more about the COAG Disability Reform Council announcements then these can be found by clicking this link: <https://www.ndis.gov.au/news/3033-disability-reform-council-update>

While this is great news for NDIS participants, we note that the **My Aged Care** system still lags well behind in providing people over the age of 65 with what they need. Please continue to help us in our advocacy by sending in your stories and experiences of accessing services through My Aged Care. We are continuing to meet with both State and Federal Ministers and Shadow Ministers to get the changes we need and every one of your stories helps us demonstrate the current impacts and inequities for older Australians living with MND.

Until next time

Karen Martin | Manager, Support Service

Moratorium on genetic testing and life insurance

On 26 June the Financial Services Council (FSC) issued a press release announcing a moratorium on genetic testing and life insurance captured under FSC Standard No 11. The moratorium allows Australians to get up to \$500,000 of life cover without disclosing an adverse genetic test result. The moratorium came into effect on 1



July 2019 and will remain in effect until 30 June 2024 but will be reviewed in 2022. The change will also allow for disclosure of favourable genetic test results. Members of the Financial Services Council are required to abide by the FSC standards. All companies offering insurance in Australia are members of the Financial Services Council and are bound by the industry code of practice. The press release can be found at <https://www.fsc.org.au/news/media-releases>.

Introducing new staff...

Freya Herschel | Administration Assistant – NDIS

I have recently joined the MND NSW team as the Admin Assistant – NDIS. I aim to keep things running smoothly so that staff and members alike can have quick responses to their COS and FlexEquip NDIS related enquiries. My previous workplace experience has been in the food industry and I'm enjoying the contrast here as part of the small team at MND NSW.



Lucy Hobbs | Coordinator of Support

Having recently completed postgraduate studies in public health I am looking forward to assisting members and their families navigate the NDIS. I am grateful to be afforded the opportunity to provide support and guidance and looking forward to providing Coordination of Support for MND NSW participants in my area.



Thank you Quakers Hill Vets

Thank you to the wonderful team at Quakers Hill Veterinary Hospital. This is the fourth year they have held a fundraiser for MND NSW. This year's event included a raffle and the sale of MND NSW merchandise, raising just over \$3,000. Thank you to everyone who supported this wonderful fundraiser and to Quakers Hill Vets for their ongoing support.



Help Can MND

The 'Help Can MND' trivia and auction night fundraiser was recently held in Bathurst in support of MND. A donation from the event of \$10,000 was made to MND NSW to be used for much needed equipment for our members with MND. A big thank you to everyone who organised and supported this event. Pictured are Anthony Campbell (L) and Janine Graham.



Don't miss out - Register now for Ask the Experts 2019

Monday 12 August, West Ryde

Come along to the Ask the Experts Forum at Ryde Eastwood Leagues Club and have your questions answered by the experts. There is no charge to attend but you will need to RSVP by 7 August. Morning tea and lunch will be provided. To RSVP or for more information contact reg@mndnsw.asn.au or ph. 8877 0999 or Freecall 1800 777 175.



If you are unable to attend, you can email your questions to katem@mndnsw.asn.au by 5 August and we will ask the question for you. Sometime after the event, you will be able to view the presentations online.

Officeworks Kotara

We were thrilled to be the recipients of the 'Round Up to Make a Difference' program during the month of June from Officeworks, Kotara. Amanda Dean, the store Business Manager, coordinated the event and was very happy to let us know that the team had raised \$2,891 for MND NSW. A big thank you to Amanda and team, and to everyone who generously donated. Pictured are Eileen O'Loughlen from MND NSW (L) and the Officeworks Kotara team.



Warringah Golf Club Ladies Charity Day

A big thank you to the Warringah Golf Club who held a Ladies Charity Day in May raising \$5,880. The funds raised will go towards providing support for people living with MND. The event was a huge success and all participants thoroughly enjoyed the day. The Warringah Golf Club is a small club and were overwhelmed by the generosity of their members and friends. Thank you to the organisers and to those who participated and supported the day. Pictured are three ladies from the winning team along with volunteer Ian Alexander who has MND. Ladies Captain, Barbara Myers said of Ian "He was an inspiration collecting money at the 12th hole where we had a nearest the pin competition. It was our pleasure to be able to raise funds for MND."



Thank you to our supporters

Walk to d'Feet MND Penrith

14 July 2019

International Regatta Centre, Castlereagh NSW

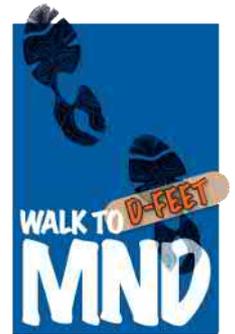
What a great morning we had at the Walk to d'Feet MND in Penrith raising \$26,475 for MND. It was a great atmosphere, the weather was perfect and a great crowd of over 300 people walked to show their support for people living with MND. Thank you to our wonderful volunteers who assisted, Penrith Rotary for their yummy food, Cafe2U Penrith South for the wonderful coffee and the boys in the band for their great music. Thank you also to all our participants who make the Walks so special.

Supported by



Together We Can 2019 Walk to d'Feet MND

Register today at walktodfeet.org.au and raise funds when you participate.



Show your support for people living with MND.

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



- | | | | |
|-----------|---|---------------------|---|
| 8
Sep | Walk to d'Feet MND Taree
Endeavour Place Reserve
Taree | <i>Supported by</i> |     |
| 20
Oct | Walk to d'Feet MND Young
Arboretum Park
Young | <i>Supported by</i> |    |
| 3
Nov | Walk to d'Feet MND Sydney
Sydney Park
Alexandria | <i>Supported by</i> |     |



Together we can

Leaving a gift in your will to MND NSW will help us to provide support as needed for people living with MND. Until there is a cure we need to make provision for the support and care required by our members and their families. For more information about making a gift for the future please contact Kym Nielsen, MND NSW ph. 02 8877 0912 or kymn@mndnsw.asn.au.

Upcoming Support Service Events

Click the event for more information.

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

Past Carers Lunch

17 September at MND NSW Centre Gladesville

This is a lunch and get together for people who have experienced bereavement during the last year.

This occasion provides an opportunity for you to reconnect with old friends from MND NSW and to meet others who have cared for someone with MND. After 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 need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.



Care for Carers Program Wrap-Up

During the recent Care for Carers Program in Gladesville, three former carers came along to speak with the group about their personal experiences of caring for their partner with MND. Many thanks to Dianne, Philip and Colin for coming along to share your experiences.

It was so valuable for the course participants to have the opportunity to hear these personal insights about what contributed most significantly to enhancing their quality of life as a couple, as they adjusted to living with MND.

Each of these former carers spoke about the social and practical benefits gained by being willing to accept offers of support and involvement from their family, friends and personal community. Some other life-enhancing suggestions included:

- Plan a mini-break or holiday if possible and accept any disability assistance that is available to make your journey easier.
- Use all available supports, printed or online resources and education programs provided by MND NSW.
- Learn about the available local health services or clinics that provide multidisciplinary care and/or home care (your MND Advisor can provide information about all your available options).
- Find reasons and personal occasions to celebrate.
- Don't be afraid to engage as early as possible with available local community palliative care services. Community palliative care can provide support for both the carer and the person living with MND.
- Ask for an occupational therapist to suggest how your current home can be adjusted to meet the potential future requirements of the person in your life with MND.
- Empower and support the person in your life with MND to make an advance care directive.
- Remember the MND InfoLine is available five days a week to answer any questions that you may have ph. 02 8877 099 or 1800 777 175 or email infoline@mndnsw.asn.au.

Is there something that you have learned as a carer that you would like to share with others through *e-news*? Send your contribution to katem@mndnsw.asn.au.

Kate Maguire | Education and Carer Support Coordinator

General information on mobile phone and tablet accessibility settings

Many portable devices such as mobile phones and tablets have built-in accessibility settings which have been designed to make these devices easier for individuals to use. These can include voice control, one handed mode, speech to text, increased font size and more.

Each device has different accessibility setting options and below are some links to accessibility settings for common devices.

All devices

- <https://mediaaccess.org.au/digital-technology/mobile>
- <https://mediaaccess.org.au/digital-technology/mobile/android>
- <https://mediaaccess.org.au/digital-technology/mobile/ios-%E2%80%93-93-ipad-iphone>

Android

- <https://www.androidpit.com/android-accessibility-settings>
- <https://www.computerworld.com/article/3346010/android-accessibility-features.html>
- <https://support.google.com/accessibility/android/answer/6006564?hl=en>

Apple

- <https://www.apple.com/accessibility/>
- <https://support.apple.com/en-au/guide/ipad/ipad9a2465f9/ios>
- <https://support.apple.com/en-au/HT204390>

Samsung

- <https://www.samsung.com/au/support/mobile-devices/accessibility-features/>
- <https://www.samsung.com/uk/accessibility/mobile-assistant-menu/>
- https://www.youtube.com/watch?v=67S_BUSIEjE
- <https://www.samsung.com/uk/accessibility/overview/>

The MND NSW FlexEquip service does not endorse or show preference for any device or device information provider. If further specific information or assistance is required please contact your device supplier or manufacturer or your occupational therapist.

Maree Hibbert | Team Leader - FlexEquip

Living Well with MND Information Day

24 September at Berry

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.](#)



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 infoline@mndnsw.asn.au for details.

Community Calendar

Click the event for more information.

8

Aug

Australian Federation of International Forwarders Charity Golf Day

Macquarie Links International Golf Club

10

Aug

Saturday Night Italian Cinema

Event Cinemas, Kotara

17

Aug

Motor On

Radford College, Bruce

26

Oct

Gundaroo Music Festival 2019

Gundaroo

27

Oct

Colour Me for MND

Coniston Public School, Coniston

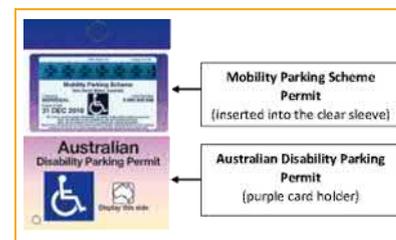
Do you have a great idea for an event or activity that will raise funds for MND support and research?

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

Mobility parking scheme (MPS)

The Mobility Parking Scheme provides special parking conditions and concessions to eligible people with a disability. All Australian states and territories participate in the Australian Disability Parking Scheme, so you can use your permit Australia-wide, as long as it is valid and current.

Parking permits are issued with 5 years validity to people with a clinically recognisable disability, this is a permanent disability that has been certified by a doctor and includes MND as well as other neurodegenerative disorders. The parking concessions apply when the mobility parking permit is displayed in the vehicle that is being used to transport the individual to whom the card is issued.



Parking concessions under the Mobility Parking Scheme are only offered at on-street and council-operated car parks. If you park in metered, coupon or ticket parking areas operated by councils, no charge applies. Car parks that operate behind boom gates are privately operated and no concessions will apply in these areas.

Once approved, you will be issued a licence-style card that includes the cardholder's photograph and additional security features. When you apply for a Mobility Parking Scheme (MPS) permit, you'll also be issued an Australian Disability Parking Permit, there is no additional charge for this Australian permit. You need to insert your NSW/ACT permit card (licence-style card) into the Australian Disability Parking Permit (large purple card) and both must be displayed when parking.

Parking concessions

The MPS card entitles a person with a disability to park in spaces marked with a symbol for people with disabilities. The card also provides parking concessions (as at August 2019) in other on-street and council-operated spaces:

- When parking in metered, coupon or ticket parking areas, no charge is applied.
- Where parking is limited by a sign to over 30 minutes, the vehicle can park for an unlimited time.
- Where parking is limited by a sign to a maximum of 30 minutes, the vehicle can park for 2 hours.

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- Where parking is limited by a sign to anything less than 30 minutes, the vehicle can park for a maximum of 30 minutes.
- At a 'No Parking' sign you may park for up to 5 minutes, the driver must remain within the vehicle or within 3 metres of the vehicle to drop off or pick up passengers or goods.
- MPS cards do not allow vehicles to stand or be parked between 'No Stopping' signs or on taxi stands or bus, loading, construction or truck zones or clearways.

To apply for a permit

Download, print and fill out the Mobility Parking Scheme application form [NSW](#) or [ACT](#) or ask your MND Advisor for a copy. You can also get a copy of this form from any government service centre. If submitting the form at the service centre, you will need to bring with you your proof of identity and payment for the \$44 fee (unless you qualify for a concession or free permit such as eligible pensioners). You will need a photograph for your permit, and you have the option of using an existing valid photo stored in the Roads and Maritime system or a new photograph can be taken.

The medical certificate section of the mobility parking application form needs to be completed by a legally qualified medical practitioner, such as your GP or neurologist, to confirm that you are medically eligible for the scheme. You must complete the first section of the application form in full before seeing your doctor. Your doctor then must complete Section 2 of the application form (Medical Certificate).

In NSW the medical information in this application will be used for the administration of the mobility parking permit and, where appropriate, for the Driver Licensing Scheme. Roads and Maritime has a responsibility to ensure that all NSW licence holders are medically fit to drive. If you hold a current driving licence and have not already notified Roads and Maritime of your MND diagnosis, then you will also need your doctor to complete Section 3 (Medical Report).

The medical information provided will be used to verify your medical fitness to drive and you may also be asked to provide the driver licensing scheme with a medical assessment report.

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If the medical practitioner recommends restrictions to your driver licence or certifies that you are medically unfit to drive, this may result in restrictions being placed on your drivers licence or the suspension of your drivers licence. If you agree to the restrictions, a condition will be added to your drivers licence (R019) where appropriate and you will be asked to provide a General Medical Assessment Report. The General Medical Assessment Report form needs to be completed by your doctor and it must be returned within eight weeks. If you don't return the form within eight weeks, your licence will be suspended.

Any further questions can be directed to:

- Roads and Maritime Services customer enquiries (NSW) ph. 13 22 13 between 7am-7pm Monday to Friday.
- Access Canberra (ACT) ph. 13 22 81 between 7am-8pm Monday to Friday, 8am-5pm Saturday and 9am-5pm Sunday.

MND Special Interest Group Workshop 2019 a great success

Over 150 occupational therapists, speech pathologists, physiotherapists, dietitians, social workers, COS, MND Clinic Coordinators, doctors and others from across NSW and beyond attended the 8th Biennial MND NSW Special Interest Group (SIG) workshop on 2 July 2019 at West Ryde.



This year the MND SIG workshop was at capacity six weeks out from the event. It is a positive sign of the commitment clinicians and community care professionals who work with people living with MND have to improving their knowledge and clinical practice for the benefit of those living with the disease.

Registrants were updated with evidence based clinical and practical information from experts in their allied health field. They also were provided with opportunities to network with their fellow practitioners, exchange ideas and problem solve, particularly in the workshop sessions.

Senior clinical practitioners shared their tips and practical advice on secretion management, respiratory management, environmental

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controls, communication, future care planning, PEGs and tele-practice. Lyn Brown, a past carer, shared her journey of caring for her husband Alex. In one of the workshop sessions, smaller groups brainstormed improving communication and collaboration across the multidisciplinary team. MND NSW had an opportunity to share our experience on transitioning people living with MND onto the NDIS.

The evaluations were very positive for each of the 15 sessions, with over 90% of those attending rating each session as above average or excellent. As you can imagine it was a jam-packed day and as one person commented, "Great workshop-so much in so little time-might have to go to two days". Others commented:

- "Speakers were from different areas around NSW so we can all learn from each other"
- "All sessions develop understanding of the complexities of MND care"
- "I will definitely apply to my clinical practice and share my new knowledge to my colleagues"
- "Thank you for bringing us all together!"
- "Lots of interesting topics and engaging speakers, great day"



MND NSW looks forward to conducting the next MND SIG workshop in 2021 and we thank the health and community care professionals who participated in the SIG Advisory group and ensured the program was relevant to their discipline, gave ideas, shared their expertise and presented. Thanks also to all the MND NSW staff who worked hard on the day as table hosts, facilitators and organisers. It was very much a team effort.

Kristina Dodds | Education and Carer Support Coordinator

Have your say on the top issues for carers

Each year Carers NSW makes a pre-budget submission to the NSW Government. Carers NSW is inviting carers to make suggestions for their next pre-budget submission.

Provide your suggestions about what the NSW Government could be funding to benefit carers to the Carers NSW Policy team at policy@carersnsw.org.au.



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 <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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...and many valued volunteers