

## Walk to d'Feet MND

With eight locations across NSW and the ACT, the Walks were created to raise funds to support people living with MND and to raise funds and awareness for research.

[Join a walk](#)

### In this edition

New Walk to d'Feet MND website... Advance care planning... Carer Gateway... Riluzole now available on PBS in liquid form... MND Chat and Connect... Home care packages... MND Decision Tools... [find.mndhub.org.au](http://find.mndhub.org.au) and more.

### Together We Can

Together We Can... three small words, that mean so much to our fundraising team.

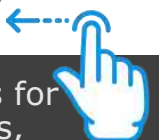
They highlight the important role our community fundraisers play in raising vital funds for us. They emphasise the important work done by our volunteers selflessly giving their valuable time and skills at events, doing administration work, as ambassadors for our Association and so much more.

These three words enable us to reflect on what we can achieve if we all work together towards a shared goal - providing the best possible support and assistance for each and every one of our members and their families.

Our Walks are a great example of what we can achieve together. They bring together family, friends and colleagues to show people with MND that they are not alone in this journey.

Join us in 2019 at a [Walk to d'Feet MND](#). Experience the wonderful camaraderie and atmosphere at a Walk, thousands of participants walking together in a sea of blue with a shared purpose. Funds raised at Walks help us to provide our information line, education for members and their families,

*(Continued on page 2)*



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equipment and advisors who connect people living with MND to care and services, plus vital funds for research.

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*

## 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.

There will be a candle lighting ceremony to represent the hopes and losses of those whose lives have been impacted by MND. Let us know if you wish to volunteer to write a dedication or light a candle.

Our guest speaker is Professor Ian Blair, recipient of the inaugural MND Australia Leadership Grant, whose research career has focused on determining the molecular and cellular basis of a variety of neurological disorders, including motor neurone disease.

The MND March of Faces banners will be displayed and afternoon tea and light refreshments will be served.

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

Advanced care planning is a topic that most of us avoid and yet it is an incredibly important protection which ensures that our wishes, no matter what, can be followed by those around us. There is a belief that it only applies for individuals who are older or who are unwell. This is not true. Every person over the age of 18 needs a valid legal will, an enduring power of attorney, an enduring guardian and an advanced care directive.

The first week of April marked National Advanced Care Planning Week. The theme for the week was 'Your life. Your voice. Your choice.' This is what MND NSW is all about. Making sure our members have a voice and a choice in what happens in their lives.

There are some great free online resources that will make getting organised easy as well as help you to understand what you might need and why. Visit [www.advancecareplanning.org.au/acpweek](http://www.advancecareplanning.org.au/acpweek) to learn more about the week or [planningaheadtools.com.au](http://planningaheadtools.com.au) for more detailed information about how to plan ahead.

## New - MND Chat and Connect

Our members and their families are always welcome to call in and see us at Gladesville. It is often a good opportunity to sit and chat as well as to find out a bit more about what we do here at MND NSW and just what we offer to our members. With that in mind we thought we would set a regular time for people to call in and see us for a coffee and a chat. Nothing formal, but there will be members of our team here who will be able to answer questions if you have them or to just make you a coffee or tea and have a social chat. It is also a great opportunity for people who are just learning about MND to come and connect with us.

- Wednesday 17 April between 10am and 12pm, MND NSW Centre, Gladesville
- Wednesday 1 May between 5 and 7pm, MND NSW Centre, Gladesville

In coming months, we will also be offering an online version to allow regional members to log in to a chat room to share their experience and ask any questions that might need answering.

We know that it is important to make some time to socialise with people who understand. We also know that community connections help to build resilience and manage stress. So, if you find yourself at a loose end or have a question you would like answered why not let us

know you are coming to our next MND Chat and Connect by calling the MND Info line 1800 777 175 or by emailing us at [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au).

Online dates to be announced!

As always, please do not hesitate to contact me if you have any suggestions for how we can continue to improve our services.

*Karen Martin | Manager, Support Service*

### MND Cake Stall

A very big thank you to Stephanie, Aoife, Abbey, Chloe, Maddie and Jemima who recently held a cake stall selling baked goods to raise funds for MND. The girls raised a fantastic \$301. Thank you girls, we hope you enjoyed the day!



### 5th MND Charity Concert

Thank you to Don McMurray who organised his 5th MND Charity Concert in support of MND NSW. It was another enjoyable afternoon of musical items and comedy performances with this year's concert raising \$2,803. We would also like to thank Nick and Helen Moretti who attended the event on behalf of our Association. Thank you also to the Grace Evangelical Church who continue to provide the use of their auditorium at no cost.



Pictured is the Sing Australia Choir who performed three segments at the concert.

### What is a home care package and who is eligible?

The term 'home care package' refers to a fixed amount of money allocated by the federal government to an older person to provide services which will enable them to continue to live independently. You can read more about what a home care package is and who is eligible in the excellent overview provided on The Conversation website [Explainer: what is a home care package and who is eligible?](#)



# Together We Can 2019 Walk to d'Feet MND

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



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|-------------------|---|---|
| <p>14<br/>Apr</p> | <p><b>Walk to d'Feet MND Forbes</b> <i>Supported by</i><br/>Lions Park<br/>Forbes NSW</p>                         |     |
| <p>5<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>26<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>16<br/>Jun</p> | <p><b>Walk to d'Feet MND Canberra</b> <i>Supported by</i><br/>Peace Park<br/>Parkes ACT</p>                       |  |
| <p>14<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>2<br/>Aug</p>  | <p><b>Corporate Walk Sydney</b> <i>Would your company like to support this event?</i><br/>More details soon</p>   |   |
| <p>8<br/>Sep</p>  | <p><b>Walk to d'Feet MND Taree</b> <i>Supported by</i><br/>Endeavour Place Reserve, Taree</p>                     |  |
| <p>20<br/>Oct</p> | <p><b>Walk to d'Feet MND Young</b> <i>Supported by</i><br/>Arboretum Park, Young</p>                              |  |
| <p>3<br/>Nov</p>  | <p><b>Walk to d'Feet MND Sydney</b> <i>Supported by</i><br/>Sydney Park, Alexandria</p>                           |   |

## Tathra Beach Women's Bowling Club

Thank you to the Tathra Beach Women's Bowling Club who have made a donation to MND NSW on behalf of club member Anne Pearson's daughter, Louise Pearson, who has been living with MND for almost 12 years. Anne said of the donation, "As is in most bowling clubs, we have a jar in which members place a coin any time they put down a wrong bias, or use questionable language." Pictured is Louise Pearson, Anne Pearson and club president Judy Malone presenting the donation of \$400 collected from the jar. Thank you ladies for the continued support.



## New cookbooks for people with dietary or swallowing needs

'Don't give me eggs that bounce' and 'It's all about the food not the fork!' are two new cookbooks by Peter Morgan-Jones that provide delightful nutritious meal ideas that cater to an array of dietary or swallowing needs.



The books were written in collaboration with a speech pathologist and palliative care specialist and provide practical and expert advice so food can remain to be a pleasure and a comfort.

A third book in the series, 'Lobster for Josino', provides advice and tips about preparing food for loved ones at the end of life and contains more than 100 innovative and delicious recipes. The MND NSW Library has several copies of the cookbooks for free member loan. For more information contact the [MND Info Line](#) or ph 1800 777 175. Or, if you would like to purchase your own copy (cost \$35-\$40 each less 25% discount using the code enter the code MNDAUST until 31 July 2019), see [Hammond Care](#).

## MND Australia Research Update March 2019

The [March 2019 MND Australia Research Update](#) explores advances in our understanding of the molecular changes that occur very early in the development of MND and in strategies to make the diagnosis in these early stages. This publication is produced by the MND Research Institute of Australia - the research arm of MND Australia.

### Riluzole now available on PBS in liquid form

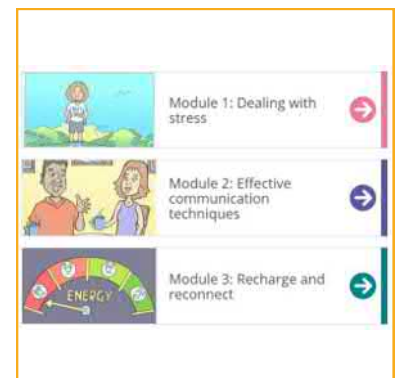
The medication riluzole, which is often prescribed to people with motor neurone disease, is now available in liquid form under the Pharmaceutical Benefits Scheme (PBS). Riluzole is anti-glutamate medication that appears to block the release of glutamate from nerve cells (neurons) and for people with the most common forms of MND it probably prolongs median survival by two to three months.



Teglutik® (riluzole) a liquid formulation (for ease of swallowing or use via PEG tube) of riluzole, distributed by Seqirus (Australia) Pty Ltd, is now listed on the PBS under the same prescribing conditions as Rilutek™ and APO-Riluzole. Your doctor can provide you with more information.

### New resources for carers on Carer Gateway

Carer Gateway provides information about the services and support available for people who care for someone with a disability, chronic illness, dementia, mental illness or who are frail aged. This service is available by phone 1800 422 737 Monday to Friday, from 8am to 6pm or online at [www.carergateway.gov.au](http://www.carergateway.gov.au). Educational resources recently published on Carer Gateway include Dealing with stress, Effective communications techniques and Recharge and reconnect.



### 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.



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## Upcoming Support Service Events

Click the event for more information.

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**11**  
Apr **Living Well with MND**  
Newcastle

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**17**  
Apr **MND Chat and Connect**  
Gladesville

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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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## Community Calendar

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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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*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>*

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## 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 [https://](https://www.online.mndnsw.asn.au/pages/entertainment-book)

[www.online.mndnsw.asn.au/pages/entertainment-book](https://www.online.mndnsw.asn.au/pages/entertainment-book) is contributed back to MND NSW. Help us

achieve our goal by sharing the link with your friends and family. Thanks for your support! Entertainment Memberships include over \$20,000 worth of valuable 2-for-1 and up to 50% discounts from many of the best restaurants, arts, attractions, hotel accommodation, travel and much more! Entertainment Books are available to purchase for:

- Sydney \$70
- Canberra \$60
- Newcastle, Central Coast and The Hunter \$65
- NSW South Coast \$60
- and many other areas from across Australia and New Zealand.



## MND Decision Tools

MND Decision Tools is a new Australian website developed to assist people with MND make decisions for their care and quality of life, particularly when the decision is hard to make, or there is no clear answer. Tools for three topics - gastrostomy/PEG, predictive genetic testing and assisted ventilation (NIV) - have already been developed and are ready to use, with other topic areas to be developed in the future. Each tool explains the advantages and disadvantages related to the decision and guides you to consider your personal feelings about each choice.



The MND Decision Tools project is led by Dr Anne Hogden and the site was developed in consultation with an expert panel of people with MND, their family members, health professionals, MND Association representatives and researchers. [MND Decision Tools](#) is available free online and you do not need to register to use the site.

## Channel 10 The Project speaking with MND Genies

On Sunday 3 March 2019 Channel 10 The Project spoke with sisters Kaitlyn and Jessica Ellis about the impact of having an MND related genetic mutation, which increases the risk of later developing MND. They also talked about MND Genies, the MND NSW Facebook group where people can connect and share their experiences. You can watch [online here](#) (the interview starts at around 15mins into the program) until 3 June 2019. Find out more about [MND Genies here](#).



## Professional football and MND – looking at the evidence

Following the announcement last year that professional football players, Len Johnrose and Stephen Darby, had been diagnosed with MND and previous announcements from other prominent footballers in England and across the world in recent years, the MND Research Blog featured [Professional football and MND - looking at the evidence](#) in March 2019. In the article some of the studies that investigate the incidence (rate of newly diagnosed cases) of MND in professional football players are reviewed and potential related causes, including head injuries, physical activity, substance abuse and pesticides, are discussed. The authors find that the headlines surrounding MND and football should be approached with some clear thinking and that it is vital that the causes of MND and any possible underlying factors are uncovered and understood. More studies are needed that use matched groups of professional sports people from different countries, together with control groups, to draw a definitive conclusion.



## About MND NSW Coordination of Support

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). To access this service MND NSW must be included as your Coordinator of Support Service on your NDIS plan. For more information speak with your MND Advisor or contact the [MND Info Line](#) ph 1800 777 175.

## 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:

- The Obi Feeding Device is a dining robot providing a person with the option to eat independently and at their own pace. It works by automating the motion of a human arm and allows the diner to select the food of their choice and dictate the pace at which the food is fed to them. The cost of the device starts at around \$8000 and it works with many accessibility switches. It is easy to transport and carry.
- Availcare provides 'stylish bathroom safety rails and accessories' that can be used to prevent slips and falls, without the clinical look.
- Flexyfoot walking sticks, crutches and replacement feet for sticks and crutches are designed to maintain full contact with the floor and improve grip and stability on slippery and uneven surfaces. The Flexyfoot rubber tread can also independently rotate through 360°, so full ground contact is still maintained even when twisting or turning around.
- Scribs are adaptive scarfs that double as a practical adult bib and clothing protector. The Scrib scarf range are washing machine friendly and includes various colours, patterns and either button or Velcro fastening options.
- The Big Bandana DryBib resembles a bandana or scarf and helps prevent wet or stained clothes by absorbing and dispersing moisture. The bibs come in a variety of colours and patterns with three stud fastening and are machine washable.
- Timeless by Heather Hill - adaptive clothing provides easy dressing tops, pants, dresses, skirts, sleepwear and clothing protectors for women. Their clothing is designed with features that allow for ease of dressing for a person with limited or no mobility while seated, standing or lying down. These include invisible zips on the left and right hand sides to assist independence, extra space in the lower crutch area to allow room for personal products, stretchy elastic waist at the back for comfort, padded zips that don't dig into the skin, petal back closures with snap studs placed in hidden locations and closures with additional cloth to provide maximum modesty.



- [Special Care Clothing Solutions](#) provide a range of adaptive clothing that have back openings and other adaptive features. The range includes tops, skirts, dresses, trousers, shorts and night shirts. There is also a page on clothing tips you might find helpful.
- [Adaptive Fitz Clothing](#) split back clothing provides easy dressing styles suitable for women and men for both day and night.
- [Confident Care Products](#) is a NSW based online product store for linen, aids, oral care and cleansing. Range includes clothing protectors, bed linen and protectors, slide sheets, chair pads, oral care and nail care products.
- [Voice Banking - MND and Me at home brochure](#) is for individuals living with MND (MND), other individuals living with a condition which leads to a loss of voice, as well as their families. Section 1 provides general information on voice banking, what it is and who it is for. It also provides general steps for voice banking and a summary table of different programs you can use to voice bank. Section 2 has specific step-by-step instructions of each of the voice banking programs mentioned in the summary table to help you voice bank independently at home.
- [Wheelies Van Rental](#) hire wheelchair accessible vans in most major cities in Australia and NZ. Both short term and long term hire is available. Drop off and pick ups can be arranged at selected airports, collection points and railway station.

### NBN and medical alarms

As the NBN gets rolled out, old landline telephone technology is being replaced. This may affect how medical alarms connect and provide services.

If you use a medical alarm and are not already sure about how your medical alarm connects to alert your emergency contact your medical alarm provider.

You can also register your medical alarm with the NBN and the NBN can provide medical alarm users with additional information and support when they move across to the NBN. For more information speak with your occupational therapist or medical alarm supplier or see the [NBN information online](#).





# 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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...and many valued volunteers