

WINTER 2020 SPECIAL EDITION

the cornflower

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND INC NEWSLETTER

**SPECIAL
EDITION**

**Continuing to Care
Through the COVID-19
Pandemic**

Services Update

**MND Equipment
Service Continues
Delivering**

**New National MND
Virtual Fundraising
Event**

REGISTERED
PROVIDER



MND QUEENSLAND AGM & OTHER EVENTS POSTPONED

We regret to inform you that the MND Queensland Annual General Meeting which was scheduled for Saturday 16 May has been postponed due to the current COVID-19 pandemic. We will inform our members of the rescheduled date once it has been confirmed.

This is only one of many of our events that we have had to cancel or postpone because of the Coronavirus pandemic, but associations have been granted special permission from the Government to postpone AGMs to a later date which we will announce in the near future, when we can get a clearer picture on public gatherings.

It is with great disappointment that we have had to cancel or postpone many of our fundraising events such as the Walk to D-Feet MND events scheduled for the Gold Coast, Springfield and Brisbane. We are hoping to reschedule some walk dates later this year, but at present, Councils aren't allowing bookings until there is a clearer picture on how the pandemic is getting under control.

Sadly we've also had to postpone our gala event which was due to be held on Saturday 29 August and this has been pushed back until 2021.

We have a Motor On for Motor Neurone Disease fundraising car rally planned for Sunday 21 June (to coincide with Global MND Awareness Day) and at this point, we are proceeding, but won't be having a community picnic at the end point, but we're hoping that the laws soften a little by June to allow us to host this FUNdraising event again.

In good news, we do have a new national virtual event that will be launching soon 'Australia Moves for MND' and you can read more about this on the back page of this edition.

For the most up-to-date information, we encourage you to follow our Facebook page www.facebook.com/MNDAQ.

CONTACT US

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SOCIAL MEDIA

Facebook: www.facebook.com/MNDAQ

Walk to D-Feet MND: www.facebook.com/Walk2DFeetMNDQLD

Twitter: twitter.com/MNDQueensland

Instagram: @mndQLD

LinkedIn: www.linkedin.com/company/4869077

FEEDBACK AND CONTRIBUTIONS

Please send your feedback or story ideas to fundraising@mndaq.org.au.

DONATIONS

You can make a donation by credit card by calling 07 3372 9004 or at www.givenow.com.au/mndaq. You can also post a cheque or money order (made out to MND Queensland) to the postal address above. Donations \$2 and over are tax deductible.

Cover Image - by Miroslava Chrienova from Pixabay



FROM THE CEO'S DESK

A big hello to all of our MND community. If this Cornflower issue seems a bit out of sync, its because it is. This is the very first issue of Cornflower outside of our regular publications... the very first Special Edition. The reason why we have chosen to do this is because of the extraordinary times we are living in and we believe that the most important thing that any of us can do in times like this is to **COMMUNICATE**.

COVID has become a word that defines the way that we live and work at the moment. It impacts relationships, freedom of movement, daily living tasks and how we relate to our world. This is a new world that has found its way into our lives; we seek to understand it. We adapt our lives around it. We redefine what is most important to us. MND is another word that is impactful to our lives; when we first hear it in a diagnosis we seek to understand it, then we adapt our lives around it and yes, MND redefines what is most important to us. It seems to me that those whose lives are impacted by MND are better prepared for COVID-19 than those who don't know what MND means or stands for.

As an organisation, we have been learning from YOU. For 36 years, this organisation has been funded by donations and philanthropy, through the support of fundraising events and grants. In these times, our funding is struggling. With record unemployment and social and government disruption, these traditional revenue sources have also been disrupted. Some of our long-time financial supporters have generously stepped forward to help but we are still faced with a long hard look at how we can secure another 36 years of providing service and support for those whose lives are impacted by MND. This has and continues to present some huge challenges for us, but we have looked to the challenges faced by our MND Community and learned from them. This is what we have learned:

- The most important people in the life of this organisation are those of you who need our help
- My first challenge is to keep and protect the people in our organisation who are dedicated to providing that help, that includes...
 - ◇ The wonderful staff team who give so much more than we could ever pay them for, and who care deeply about every single one of our clients and carers
 - ◇ The members... those who have put their hand up and said "we want to be involved" and "we want to support the future of this organisation". Many of you have been loyal this organisation for a very long time



- ◇ The volunteers... who give their most valuable possession (their time) to provide assistance and support to our organisation
- My second challenge that you all continue to teach me is to Never Give Up
- The great lesson that you have taught me is that no matter how hard the going is, there are huge rewards and insights from the journey itself... if I remain open to them.

Our relationship with the National Alliance of MND Associations has never been stronger and the support from around the country has been incredible.

With the restrictions that COVID-19 has placed on our fundraising and the flow on impact to our cashflow, I have been busy trying to secure the funding we need, from the Government support packages and our bank (NAB). If successful, this will buy us the time to get through this, but equally critical is the journey beyond that. We need to plan for a time in the months ahead, where the impact of MND is still with us and central to our existence but where COVID-19 is behind us.

As you read through the messages from the Management Team, you will see how we are not stuck in a corner waiting for COVID-19 to pass; we are fighting, and growing and changing as we need to.

We need and want to be still here for you and that is a goal worth fighting for; and so we shall... as you have taught us... Never Give Up!

Kind regards
Ian Landreth

Never Give Up!

MND ADVICE & SUPPORT COORDINATION DURING A PANDEMIC

It's pretty safe to say that the last few weeks have been the most unusual and challenging we have ever experienced at MND Queensland. With the situation changing on a near daily basis, we have been working hard to stay informed and to share all relevant information with you as well as continuing to provide the support and advice that we know is critical to our community.

Keeping our clients and staff safe will always be our priority and as such we have introduced a number of measures aimed at minimising risk whilst maintaining our daily operations. These include utilising phone calls and video calls as an alternative to face-to-face interactions and specific guidelines for when face-to-face meetings do occur, such as the use of personal protective equipment as well as improved infection control practices.

It has always been our desire to continue delivering services in the way that most benefits our clients. We recognise that this comes down to individual choice and as such, as well as implementing the changes already mentioned, we are making sure that we take the time to understand each of our clients' circumstances and work with them to meet their needs.

Despite the additional challenges we are all facing, MND doesn't stop in the face of a health crisis and neither will we. We were fortunate to welcome Sandra Biffin, our new MND Advisor/Support Coordinator to the team just before the Government restrictions were introduced. Whilst the first few weeks have not been what I or Sandra imagined for her onboarding experience, she has worked hard to get up to speed on MND and the role so that she can start supporting our community as soon as possible.

Sandra lives on the Gold Coast and will predominantly support clients in that area. Sandra's role is a dual one so that she can provide general advice and support to all

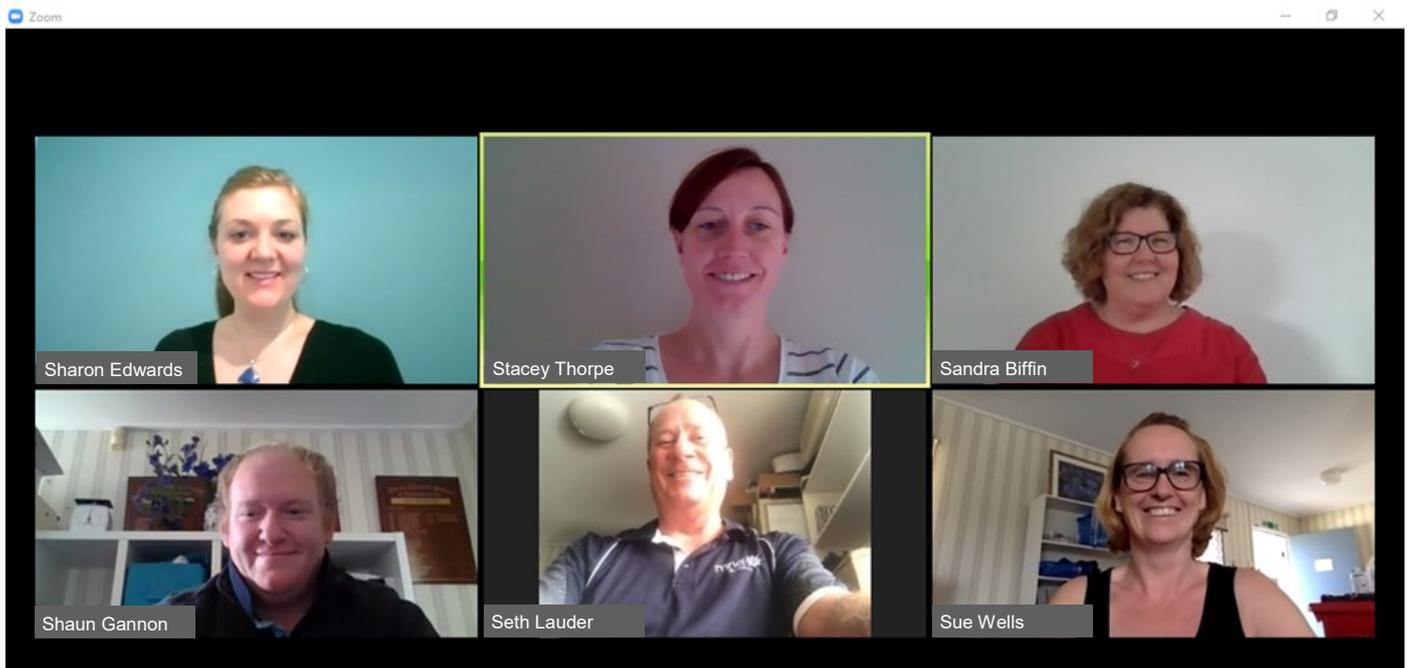
people living with MND and their family members and can also assist with understanding the NDIS, submitting access requests, pre-planning as well as Support Coordination once NDIS plans are in place.

We are also seeking to grow our team further and are currently advertising for an exceptional Occupational Therapist to join us. The role is advertised on Seek and can also be found on our Facebook page. We encourage everyone in our community to share the advert to help us find the best person to fill the role.

Social distancing requirements led us to have to make the very difficult decision to cancel all support groups for the foreseeable future but we do understand that connection is more important now than ever so we have launched online support groups. Invites have been sent to all registered clients but the support groups are open to anyone living with MND, their family members and carers so if you didn't receive one but would like to attend, give us a call on 07 3372 9004 or email supportgroups@mndaq.org.au.

We need the support of our community now more than ever. I'm sure that my colleagues will draw your attention to current fundraising appeals but there are other ways that you could help us too. Following us on social media and sharing our Facebook posts to increase our reach is one way you can contribute without it costing anything but your time. We would also be grateful if anyone who has used our services would leave a review on Google or Facebook. Feedback is important to us as we are genuinely committed to providing the best possible service to anyone that needs it so please tell us what you think of us.

We'll continue to keep you updated on the COVID-19 situation and about any changes that might affect our community. Rest assured that we will continue to be available to provide support, advice and information to anyone affected by MND in Queensland.



With most of our team working from home during the pandemic, this is now what a Services Team meeting looks like via Zoom.

MND QUEENSLAND FUNDRAISING & EVENTS UPDATE

Thanks to many of you, 2019 was our biggest fundraising year ever, we were looking forward to another great year in 2020. But now, this has all changed... Within the space of weeks we're living in a different world and we've had to cancel or postpone most of our fundraising events that we've had planned over the coming months and donations and community fundraising have become more important than ever!

Our supporters really went all out in 2019 and together we raised more money than has ever been raised before in the organisation's 36 year history! Thank you everyone that participated, fundraised, donated, volunteered, sponsored or shared a post on social media for contributing to our success. You have helped us grow our Services team to better cater to the needs of Queenslanders with MND.

When planning for 2020, we were anticipating continued growth and we were excited about how we were going to be making such a positive impact in the lives of people affected by MND. But with all of our cancellations and postponements, we now need to find enough support for the organisation to survive through this devastating time.

Many people have lost their jobs, had their hours cut, or taken a blow to their investments and most of us have had to lock down in isolation. We know things are tough for a lot of people at the moment, but right now, we need your support more than ever!

MND Queensland is set to lose hundreds of thousands of dollars this year due to the cancellation or postponement of our fundraising events such as the Walk to D-Feet and our Roaring 20s Reimagined gala. With such a big hole left in our budget due to this expected income drying up, we need the support of people like you.

If you can, why not host a fundraiser. It's a great time to get creative with virtual event concepts and we can help you make your concept come to fruition and be a success.

If you're having a birthday or celebration and don't want

presents, why not consider asking your family and friends to make a donation to MND Queensland instead? We can set up a page for you on My Cause or you can also set up your own Facebook fundraiser and direct the funds to MND Queensland.

Or if you can't put on a fundraiser or donate, why not follow our social media and share our posts to help spread the word and raise funds?

People with MND are some of the most vulnerable in our community right now and it is great to be a part of a team that is continuing to deliver vital services through the pandemic as I know how important our services are to people affected by MND and how valued our work is. But these services come at a cost, we still need to pay staff, overheads, rent, petrol, insurance etc. and with our Queensland Government grant expiring at the end of June, we need the support of our community.

Please give or do what you can to help. To donate by credit card, call us on 07 3372 9004 or go online to www.givenow.com.au/mndaq. Why not consider becoming a monthly donor and help give some security around our funding and simplify the donation process for you? You can also send a cheque or money order (made out to MND Queensland) to: PO Box 470, INALA QLD 4077. If you'd prefer to donate via direct debit, please call us for a reference number.

On the back page of this edition you'll read about a new national virtual fundraiser 'Australia Moves for MND'. We've been planning this virtual event for months now and it's being launched at a time when we need our community's support more than ever! You'll be able to walk, row, skip, cycle or move in whatever way you choose and get sponsored to support people impacted by MND. With most of our events cancelled or postponed, this is a great way to get involved and keep up your support.

Once things start returning to normal, we hope to see you again at our walks and other events. Together we really do make a difference.



Save Thousands of Dollars While Supporting People with MND!

Get your 2020-2021 Entertainment Membership and you'll be supporting MND Queensland's work to help people with MND. You'll get hundreds of fantastic discounts that can save you thousands of dollars! We receive 20% from every sale so get yours now at www.entertainmentbook.com.au/orderbooks/2221j21

There are memberships available for Brisbane, Sunshine Coast & Surrounds, Gold Coast & Northern NSW, Cairns, Palm Cove & Port Douglas, as well as Townsville. Plus you can access memberships for other parts of Australia, as well as New Zealand & Bali. They make fantastic gifts! Order now & save!



HINTS AND TIPS ON STAYING SAFE AT THIS TIME

The amount of information on COVID-19 is almost overwhelming and at the time of writing, changing daily. We wanted to bring together some of the key information and referrals for you in one place.

GENERAL COVID-19 CARE

Our best advice to our MND clients and their immediate family/carers is to continue to self-isolate until advised by the Government otherwise. Take advantage of home delivery services (groceries, medications) telehealth (doctors and our own MND Coordination of Supports NDIS service) and avoid contact with others as much as possible at this time. People with MND are particularly susceptible to respiratory infections, so please take care.

As well, please wash your hands or sanitise them upon returning home and avoid touching your face with unclean hands.

If you or a household member begins to feel any symptoms, contact your doctor immediately and further self-isolate somewhere in the home and avoid contact with other householders until the condition is confirmed. To halt the spread of COVID-19 the ill person should also wear a face-mask and disposable gloves if they should leave their isolation. They should always try to cough into a tissue and dispose of it immediately or otherwise cough into their inside elbow (if possible).

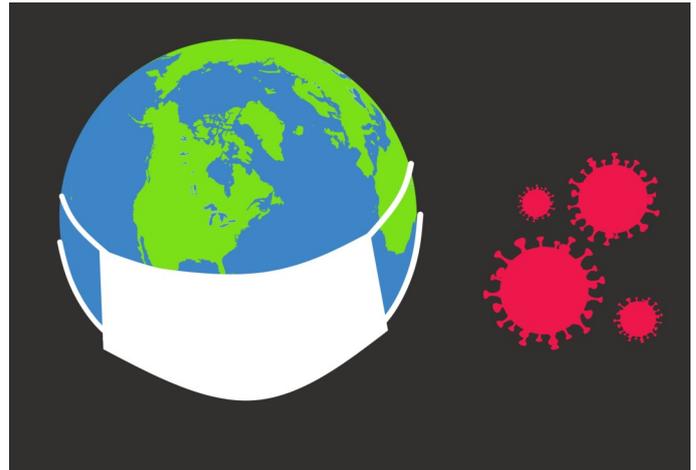
MND QUEENSLAND

For all MND Queensland updates, if you don't already follow our Facebook page, we strongly encourage you to follow us at www.facebook.com/MNDAQ/. This is the fastest way we can get information out to you. Otherwise, we'll always try to email our registered clients with an email address in our system, so please make sure we have your current email address on file. We've also created a private Facebook Group for our clients and their families and carers. Follow this link to join this group www.facebook.com/groups/580017429388102/

GOVERNMENT UPDATES

The Federal Government has developed a phone app with all of the latest information available. For more information on this visit www.health.gov.au/resources/apps-and-tools/coronavirus-australia-app?fbclid=IwAR02Ph_smT4J-Wvtla9R2tePiyqfyapwwPRfTikPufKDds6C

The Queensland Government has a page with up-to-date information which can be viewed at www.qld.gov.au/health/conditions/health-alerts/coronavirus-covid-19. They have also set up the Community Recovery Hotline and those who are vulnerable in our community can call



1800 173 349 for advice, information and support .

GROCERIES

By now, all NDIS participants should have received a Priority Home Delivery access code via SMS or email. This can be used to access home delivery services from a number of retailers and these retailers are also offering services for Seniors. For more information visit www.ndis.gov.au/coronavirus/priority-home-delivery-services. Woolworths are offering 'Priority Assistance' for their home delivery service to those most vulnerable in our community. You need to fill in an online form to access the service www.woolworths.com.au/shop/discover/priorityassistance?icmpid=sm:online-shopping:priority-assistance. Coles also offer a home delivery service and you can find more information by visiting https://shop.coles.com.au/a/national/content/delivery-information?pid=pr_CCInfoPage_DelInfo. IGA Supermarkets have also arranged a delivery service for those most vulnerable in our community. To access the IGA service call 1800 018 384.

MEDICATIONS

Some pharmacies are offering online ordering and delivery services. Check with your local pharmacy to see if they offer this as an option to save you leaving the house. Australia Post has also launched a Pharmacy Home Delivery Service to support vulnerable community members and those in self-isolation. Again, speak with your pharmacy to see what is available to you.

NEWS UPDATES

For the most factual and up-to-date news and information, we encourage you to listen to your local ABC radio station or tune into ABC news on your TV.

We urge you to take extreme care during this worrying time. If you would like any further advice or assistance, please feel free to call us on 07 3372 9004 or email info@mndaq.org.au.

MND EQUIPMENT HIRE SERVICE IN FULL SWING!

Our Equipment Hire Service has been busier than ever over the last few weeks! We've distributed equipment to numerous clients and continue to receive new requests every day.

We have taken a number of steps to minimise any risk to our clients receiving equipment from us. These include new infection control measures such as all equipment being thoroughly disinfected prior to dispatch and our team using appropriate personal protective equipment when handling the equipment.

We are working with each of clients to understand their individual needs. Prior to making any deliveries, we contact our clients to discuss any risks or concerns they might have and work with them to find a solution to enable deliveries to go ahead.



Sue, taking care to clean our equipment during the Coronavirus pandemic.

We are determined to ensure that our clients continue to have access to the vital equipment that they need. Getting access to an Occupational Therapist (OT) to assess equipment needs is not always easy with the new restrictions. We have been monitoring which services are still completing home visits as well as those that are developing innovative ways to identify needs where face to face is not appropriate. If any of our clients need help finding an OT, we're happy to help.

In coming weeks, we hope to have our own OT on staff so we can be even more responsive to helping all of our



Seth getting our equipment delivered through the Coronavirus pandemic.

clients get the supports they need, whether this is through delivering the service ourselves or working peer to peer with local OT services to support them to understand our clients' unique circumstances.

We know that issues have arisen with importing equipment purchased from overseas but rest assured we still have plenty of items available, so anyone needing any mobility equipment or communications aids should get in contact.

Our low cost equipment hire service is a great interim option until purchased equipment arrives. We offer this on a weekly hire basis for those in receipt of NDIS funding and as a one-off fixed fee for everyone else. Where a client is in receipt of a Home Care Package, they can use that funding to pay for the hire as well. We don't just offer our equipment as a short term solution though. Anyone choosing to hire instead of purchase, will also receive the equipment for the same low rates.

We are incredibly grateful to receive generous offers of donated equipment and need these to keep coming so that we can maintain a large pool of high quality products. With increased demands for new deliveries, we are not always able to collect these donations immediately so appreciate patience and understanding around any delays. We can always accept delivery at our office though so where possible, it would really help us out if anyone wanting to donate equipment was able to bring it to us!

WHAT'S ON

- 3 May - Start of MND Awareness Week and Australia Moves for MND virtual fundraiser
- 8 May - Blue Cornflower Day - Brisbane's Story Bridge, Victoria Bridge & Reddcliffe Place lit in blue.
- 21 Jun - Global MND Awareness Day & Motor On for Motor Neurone Disease Car Rally
www.mycause.com.au/events/motoronwinter2020 & Bundaberg Early Holden Club MND Car Run.
- 1-31 Aug - Ice Bucket Challenge Month
- 18 Oct - Walk to D-Feet MND Redcliffe - keep an eye on our social media for more information to come.
- 8 Nov - Motor On for Motor Neurone Disease Car Rally (Christmas theme) - more information to come.

NEW NATIONAL VIRTUAL EVENT - AUSTRALIA MOVES FOR MND



In late April all MND Associations in Australia will be launching a brand new virtual fundraising campaign called *Australia Moves for MND*. It will officially run between MND Week and Global MND Day (or 3 May to 21 June 2020).

The concept is simply to encourage people to get moving in any way, shape or form. There are no restrictions on what you should do. We will encourage as many people as possible to register for free and share you movements with us and all your networks.

We also see this as a great way for people to raise a few dollars to support all those people within Queensland and all across Australia living with MND. Whilst we are all tucked away inside our own homes a little bit of exercise, fun and creativity will go a long way!

Check the website for more information <https://am4mnd.org.au/>.

MND SUPPORT GROUP MEETINGS GO ONLINE

Due to the current COVID-19 pandemic we have had to cancel all face-to-face MND Support Group Meetings. We have introduced two new weekly Online MND Support Group Meetings which are hosted using Zoom. There is a session each Tuesday at 1PM for carers, and every Thursday at 11AM for people with MND and their families.



So far the meetings have been working well and we've been helping to bridge the gap and help people feel connected. If you would like to participate in one of our Online MND Support Group Meetings please email Leigh supportgroups@mndaq.org.au or call 07 3372 9004 and ask for your Zoom invitation to our support group meetings. You don't need a computer, you can dial in by phone to participate.

MND QUEENSLAND DONATION FORM - WINTER 2020 NEWSLETTER

I would like to donate: \$.....(write amount) I'd like to give this amount monthly via my credit card

I am paying by: Visa MasterCard Cash Cheque/Money Order (made out to MND Queensland)

For direct deposit donation details, please call 07 3372 9004 or email info@mndaq.org.au

My Details:

Name:.....
Address:.....
Suburb:.....
State:.....Postcode:.....
Phone:.....
Email:.....

Card Number:

Card Expiry: CSC: (3-digit CSC on back of card)

Cardholder's Name:.....

Cardholder's Signature:.....

Send to: MND Queensland, PO Box 470, INALA QLD 4077 Please send me information about leaving a gift in my Will
Or, if you are using a credit card you can call us on 07 3372 9004 or donate online at www.givenow.com.au/mndaq