

SPRING 2021 ISSUE

# the cornflower

MND QUEENSLAND NEWSLETTER

**Delivering Services Across  
Regional Queensland**

**MND Queensland's new Speech  
Pathology Service**

**Welcome New Board Members**

**New MND Connect Website  
Launched**

**Meet Speech Pathologist Salma**

REGISTERED  
PROVIDER



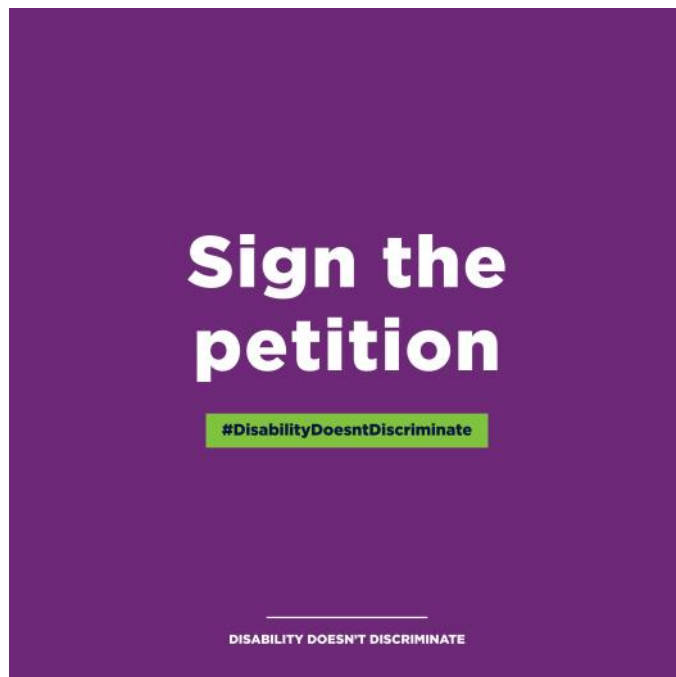
## JOIN THE DISABILITY DOESN'T DISCRIMINATE CAMPAIGN

Did you know that if you're diagnosed with MND after the age of 65 you don't qualify for the NDIS and can't access all its benefits and instead have to rely on the My Aged Care system which never provides enough and takes a lot of time to be approved? This goes for anybody who becomes disabled after the age of 65.

Data shows that a person with MND on the NDIS gets around four-times as much funding over a 12-month period as someone accessing My Aged Care, plus the NDIS isn't means tested unlike My Aged Care! This isn't good enough and people with MND don't have time to wait!

MND Queensland and MND Australia have joined the 'Disability Doesn't Discriminate' campaign initiated by Spinal Life Australia in an attempt to achieve change and equality for people who become disabled after the age of 65.

We need the support of our community. Let's end age-based discrimination. Please lend your voice to



this campaign by signing the petition and help spread the word by getting it out to your networks too

[www.disabilitydoesntdiscriminate.com.au](http://www.disabilitydoesntdiscriminate.com.au)

## CONTACT DETAILS & SOCIAL MEDIA

### MND QUEENSLAND

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Postal Address: PO Box 470, INALA QLD 4077

Web: [www.mndaq.org.au](http://www.mndaq.org.au)

Email: [info@mndaq.org.au](mailto:info@mndaq.org.au)

Phone: 07 3372 9004

Freecall: 1800 777 175

### SOCIAL MEDIA

Facebook: [www.facebook.com/MNDAQ](http://www.facebook.com/MNDAQ)

Walk to D-Feet MND: [www.facebook.com/Walk2DFeetMNDQLD](http://www.facebook.com/Walk2DFeetMNDQLD)

Twitter: [twitter.com/MNDQueensland](https://twitter.com/MNDQueensland)

Instagram: [@mndQLD](https://www.instagram.com/mndQLD)

Linked In: [www.linkedin.com/company/4869077](http://www.linkedin.com/company/4869077)

YouTube: [www.youtube.com/channel/UCf5MA4DA7qGU7BThP9Pg-Cg](http://www.youtube.com/channel/UCf5MA4DA7qGU7BThP9Pg-Cg)

### FEEDBACK AND CONTRIBUTIONS

Please send your feedback or story ideas to [fundraising@mndaq.org.au](mailto: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](http://www.givenow.com.au/mndaq). You can also post a cheque or money order (made out to MND Queensland) to the postal address above.





## FROM THE CEO'S DESK

Growing up I used to know it was spring when the New Zealand countryside had lambs jumping around and daffodils poking through the verdant green grass. Now I find the signs more subtle like... the sun is rising earlier or more obvious signs like... turning the calendar to September! Three of the "...ber" months and then we face Christmas!!!

Talking to people in our MND Community reminds me of the transition of this dreadful disease called MND. Sometimes the signs of progression are subtle and may be noticed by a carer or family member before a person sees it in themselves. Sometimes the signs are obvious like a hand or a foot that just won't cooperate one morning... no mistaking that progression.

However we get our signals of seasons or body changes, we are all faced with how we receive those messages and how we respond to them. For me, I have seen two annual cycles now in this role as CEO of this wonderful organisation. Whilst I reflect on the many changes that have happened, I need to stay focused, as many of you do, on the changes that are around us every day and how they impact us:

- The emotional challenges of the pandemic
- The difficulty of working out which public health advice is current for today!
- Keeping a business operating for our community when faced with so many new obstacles
- Wondering who the heck crawls under a charity's delivery van with disability stickers clearly displayed, and steals critical parts from under it, rendering it unsafe!
- Having to call off another fundraising event!
- Watching the "To Do" list grow faster every day than the "Jobs Done" list.

But then there is that wonderful thank you card to the staff that arrives in the mail from a grateful husband or wife of one of our clients who has passed; a hand grasped in silent thanks and a gaze that says what the words cannot; staff



members who need to be reminded to go home at the end of the day because they have "just one more thing to do" for one of their clients; the examples of courage and love and grumpiness and humanity and resilience and humility and dedication, and fear and amazement and belly aching laughter and free falling tears of shared sadness (and that is just in our office!!) and always... ALWAYS a commitment to help and support those who may be struggling to see the signs or experience all of these things... For all of these signs of change are important and affirm that we are actually alive and involved in this thing called life...

This message to you all has not gone where I had anticipated. Spring is change and change makes me reflective. So after two years in this role with such enormous change, I just want to say thank you; for teaching me about MND and about living life and problem solving and holding on to people and letting people go when you have to.

May spring bring you a time for reflection, increased warmth and freedom and more opportunities to reach out and support someone.

Ian Landreth  
Chief Executive Officer



## WE WELCOME JULIA, JACQUI AND DIANA TO THE BOARD

MND Queensland is pleased to announce that three new Board Members have joined our Management Committee to help lead and govern the organisation. Following are some photos and short biographies so you can get to know our new Management Committee Members a little better.

**Director**  
**Diana Melham**  
MBL, GAICD, GIA



Diana has spent 20+ years as a senior executive in the not-for-profit sector. An experienced CEO, she has led both not-for-profit and commercial organisations involved in agriculture and sport. Diana currently provides professional services to a number of community sector organisations through her consultancy, NFP Assist.

Diana is an experienced director having served on association, private company, and government advisory boards/committees. In addition to serving on the Management Committee of MND Queensland, she is currently sits on the board of a disability charity in the role of secretary.

Combined executive and director experience give Diana a unique insight, enabling analysis from a dual perspective. Her ability to navigate legislative and regulatory requirements is valuable in Board oversight of organisational compliance.

Diana has a Master of Business Law and is currently studying for a Bachelor of Laws. She is also a graduate of the Australian Institute of Company Directors.

**Secretary**  
**Dr Julia Rollston**  
**GP Registrar**  
BSc, BPhy (Hons), Grad  
Cert Pub Health, MBBS



Dr Rollston has worked in the research, health and disability fields for over 25 years, and is currently supporting her community in Brisbane through her work as a GP.

She initially began her medical career as a cancer researcher but soon realised her passion for working directly with people. Julia has been a carer for adults with disability as well as a physiotherapist in Australia and abroad, predominantly in community settings.

Julia studied Medicine as a mature aged student with three school-aged children and all of them have lived to tell the tale. She chose to specialise in general practice as she loves working in the community and helping people overcome their challenges to reach their life goals.

Julia brings a wealth of lived and professional experience in navigating the health system, care provision and funding, including NDIS.

**Director**  
**Jacqui Williams**  
BNursing (post-reg), Dip.  
Frontline Mgt, Certificate IV  
Bereavement Support,  
End of Life Doula



As an End of Life Doula, Funeral Celebrant and one of Australia's most active Death Café Facilitators, Jacqui's career commenced with nursing.

Her passion is to focus on building compassionate communities which support people and their loved ones, at the end of life.

Actively engaged on a number of community advisory committees and having worked in a variety of palliative care roles (clinician, middle/senior management, educator, public speaker and researcher), Jacqui commenced her business, End of Life Transitions in 2018.



We thank Julia, Jacqui and Diana for their dedicated service to Queensland's MND community. If you would like to contact the Board, please email [secretary@mndaq.org.au](mailto:secretary@mndaq.org.au).

## MASTERMIND FOR MND

6PM, Friday 17 September 2021, Metro Community Hub, Woolloongabba

Join us for an evening of trivia and put your mind to the test to see if you or your team can be a Mastermind for MND and raise funds to support Queenslanders living with MND. Get your team together and book a table, but hurry, our last trivia night sold out and there are limited tickets left, so be quick! There will be a bar, grazing platters and a raffle, plus a great prize pack for the winning team.

Book now using the link below or call 3372 9004

<https://www.stickytickets.com.au/q38g4>

sponsored by

MY Plan Manager





## AUSTRALIA'S FIRST MND-SPECIFIC SPEECH PATHOLOGY SERVICE

**MND Queensland is excited to announce that we have launched Australia's first MND-specific Speech Pathology Service!**

This new service will help meet the demand in Queensland's MND community for Speech Pathology services and address delays in access, which in some cases, can be several months.

We know that around 80% of people with MND experience difficulties with communication and that being able to communicate is a vital part of continuing a happy and functional family and community life, and it's also important to be able to communicate with health and medical teams.

A Speech Pathologist can:

- Assist with strategies to help people speak in a way that they can be more clearly understood
- Prescribe communication aids and devices
- Reduce the impact of potential loss of speech e.g. voice banking/message banking

Around two-thirds of people with MND experience changes in their swallowing which can impact on nutrition and hydration (leading to weight loss), cause choking, and can cause people to breathe food or drink into their airways which can lead to chest infections and increase risk for people with reduced breathing capacity.

A Speech Pathologist can:

- Assist with strategies and advise on different swallowing techniques
- Advise on food/consistency/need for thickeners
- Work with a dietician on nutrition management

MND Queensland introduced an Occupational Therapy Service in 2020 and our Speech Pathologist will be able to work with our OT to support effective communication solutions for people with MND.

Multidisciplinary care is vital for people with MND. Having a Speech Pathologist, Occupational Therapist and Support Coordinators - who are all experts in MND - working together will create a seamless, collaborative approach to care and support.

MND Queensland's Director of Services, Stacey Thorpe commented 'We know how important effective communication is to people with MND and their families and want to do everything we can to support access to expert MND services. Every day we get to see the benefits of our OT and Support Coordinators working together to provide seamless supports to their clients and adding Speech Pathology services will inevitably improve outcomes even further.'

We're pleased to announce that MND Queensland's Speech Pathology Service is now open for bookings. Feedback from clients has already been very positive with one client describing our new Speech Pathologist, Salma Charania as 'gorgeous and caring.'

You can read an interview with Salma further on in this edition to get to know her a little better.

If you have any queries or would like to book an appointment with our Speech Pathologist please contact us by calling 07 3372 9004 or email [info@mndaq.org.au](mailto:info@mndaq.org.au).



**WALK TO D-FEET MND REDCLIFFE**  
**9AM, Sunday 17 October, Suttons Beach, Redcliffe**

**REGISTER NOW & GET SPONSORED TO HELP QUEENSLAND FAMILIES IMPACTED BY MND**

[www.mycause.com.au/events/walktodfeetmndredcliffe](http://www.mycause.com.au/events/walktodfeetmndredcliffe)

## DELIVERING SERVICES ACROSS QUEENSLAND - LIZ'S STORY

**While we might have our base in Oxley (Brisbane) MND Queensland's services reach right across the State. We recently spoke with Liz from North Queensland who has NDIS Support Coordination through MND Queensland.**

Liz lives 15 minutes north of Ingham in North Queensland. She was diagnosed with MND in August 2020. 'In November 2019 I developed a drop-foot and I just kept falling over. That's what the doctors were treating me for. Then we bought up here and when I went to the doctors in Ingham they sent me straight down to Townsville to get an MRI.' Liz told us.

Liz's husband, Colin works in the mines as a plant operator and is often away from home, but Liz has help that was organised by MND Queensland's MND Advisor and Support Coordinator, Jason Russell through Liz's NDIS package. 'I have carers here all the time' Liz told us. 'The girls that come out here, they're all fantastic!' Liz said of her carers that come from Optimise Health and Wellness based in Ingham.

Unfortunately Liz isn't as mobile as she once was, but when we spoke she was looking forward to taking delivery of a new motorized wheelchair which was purchased through her NDIS package, another task that Jason has assisted with.

MND Queensland's educational information has also been useful for Liz 'I've gotten to understand what I'm going through. All of the different stages.' she said.

When we asked Liz about how well the local support teams understand MND she said "A lot of them haven't had anything to do with MND, but the one I'm with now researched it and is learning about it.' Providing information about MND is an important function of MND Queensland and it's been helpful for Liz as she told us 'The ones that I've spoken to, they know what it is, but there has been a couple that I've spoken to, like my carers up here, I gave them an information package so that all their care workers will know what's going on, what I need and what changes I'm going through.'

She went on to say that 'A lot of people don't really now about it (MND). They talk about Parkinsons and cancer and that, but nobody knows about MND.'

Our online support groups are also really valued by Liz and a perfect example of how we can support people from across the State wherever they live as long as they have an internet connection. 'What I do really like is getting online and talking to the other people when we have the group sessions because we get to talk and I've



Pictured: Liz who lives in North Queensland

made friends with them.' Liz said about our online support group meetings.

Jigsaw and magazine puzzles are some of the ways that Liz likes to spend her time along with catching up with friends on the phone, but she's really looking forward to getting her new electric wheelchair. She said "When I get my chair I'll be outside doing my orchids and things like that. I want to make a little fernery out where my birds are. I can't wait to go outside because I've got six acres of gardens and I want to get out there and do what I can."

When we asked Liz what she'd say to our fundraising supporters who make so much of our work possible she responded "I reckon they're good!"

Even with her MND diagnosis, Liz tries not to take things too seriously all the time. "I try to keep a positive attitude" she told us. 'I laugh about my little mishaps and Colin is the same, he makes jokes about things. I said to him yesterday "when I get my chair I'll go in Sunday afternoon, to the supermarket when it's quiet so I can test it out and not hit anyone.'" to which Colin responded 'No, we'll go in on the busiest day!'



## DELIVERING SERVICES ACROSS QUEENSLAND - VINCENT'S STORY

**We recently spoke with Vincent who has MND and his wife Marjorie. They live in Mt Isa and are also supported by our MND Advisor and Support Coordinator Jason Russell.**

Vincent was diagnosed with MND on 21 June 2020 at the age of 37. When asked why he was checked for MND he replied 'My breathing... I couldn't lay down properly on the bed. So I sat up on a couch sleeping for two to three months. I went to the hospital and they thought it was my heart, so I had CAT scan after CAT scan and a couple of MRIs and then down the track they did another scan on me, so they decided to do a sleep study to see what was going on and they found out that my nerves were twitching a lot. So I went and done another test where they put needles in to check my nerves and they put electricity through me with these needles in my body and that's when they diagnosed me.'

Talking about his diagnosis, Vincent said 'I didn't know what it was, but my partner checked up on Google. Checked my symptoms and she was hoping it wasn't what she thought it was, but it was Motor Neurone.'

'As soon as I found out and and they told me there was nothing that could be done, I said "I'm going back home" because they put me on a Category Three.' Vincent said about his decision to move back to Mt Isa.

When we asked how this has impacted Vincent he said 'Oh, a lot! I just feel sad most of the time while I've been back here and angry. But now, I've started to accept it. You can't do nothing, so just dealing with what I've got to go through now.'

His partner Marjorie is providing increased care for Vincent and said 'Yeah, it's increased, I do a fair bit. I do a lot of stuff for Vincent. It's heartbreaking.' she told us, her voice breaking up.

MND Queensland's Jason Russell really enjoys helping out and Marjorie said 'He's very persistent with any needs for Vincent. Look, I don't think we could have met a better person! He's so wonderful with what he does and lets us know anything we need, to let him know and he'll try his best and hardest to accommodate Vincent's needs.'

She went on to say 'Being in a remote area, the north-west region, it's not common, you know, no one's got that here in Mt Isa, and he's been so wonderful.'

Jason has organised a great support team around Vincent and Marjorie and she said 'The support network that we've got, they are so wonderful! Words just can't explain how much they're appreciated. From, you know... just

even yarning, just the little things. We're overwhelmed by the support we receive from Jason and the team up here as well.'

Like most people diagnosed with MND, they often have to explain the disease to a lot of people 'At first, when we came back home, we had to explain what it was and make the family have a bit of understanding, but they did a bit of research as well. It's a bit hard going to multiple doctors and retelling our story. It was annoying to have to relay the same story over. Sometimes it gets a bit emotional.' Marjorie said.



Pictured: Vincent and Marjorie in Mt Isa

Jason has even helped to get Vincent and Marjorie into their own unit. 'We put in an application for our own place and we were between family, you know, moving from house to house and not being properly settled. That took a toll on both Vincent and myself. I ended up going to Housing up here in Mt Isa and got Jason on the phone to advocate on our behalf and he just worked his magic!' Marjorie told us. 'Within two weeks we got a phone call saying "we've got a place for you." We moved in straight away. So Jason did his magic! We couldn't ask for a better advocate to speak on our behalf and work in the background.'

We asked them what they'd say to the donors who make our work possible and Vincent said 'Keep up the good work! It's really good what they're doing 'cause I'd be stuck in the house, but now I've got a motorised wheelchair so I can get out and see family and I'm independent a bit now.'

Marjorie added 'Many thanks to all of you guys behind the scenes. All the hard work that you do, including up here in the north-west region, pretty much isolated from where you guys are, but it's such wonderful assistance that we receive. It's beyond words. You know, just very thankful to everyone that does their part. A very big thanks from us.'

**MND Queensland can provide Support Coordination wherever you are located. Call us on 07 3372 9004.**

## THANKS TO OUR FANTASTIC FUNDRAISERS - YOU'RE HEROES

**MND Queensland receives no ongoing government funding and we are reliant on donations and community fundraising efforts to provide our services and support. We've recently had some great fundraising efforts that we wanted to share and give our thanks to.**

The team at Spiecapag put together a team for the Brisbane Marathon and raised funds for MND Queensland. Together they raised over \$10,000 which pushed MND Queensland to the third-highest ranking charity for the event!

Well done and thank you to the Spiecapag team and everyone else that raised funds for MND Queensland through the Brisbane Marathon.



Pictured: The Spiecapag team presenting a cheque to MND QLD's Caitlin

The staff from Kohn Crippen Berger (KCB) also supported MND Queensland recently by holding a family fun day at Orleigh Park, West End.

One of their fundraising ideas was to pie the boss! KCB also set up an online fundraising page to

collect donations which resulted in around \$2,500 being collected. Then KCB dollar-matched this donation so our overall donations were around \$5,000 from the event!

We'd like to thank the team from KCB for your fantastic support.



Pictured: A boss pied at the KCB Family Fun day and MND cupcakes

Our own Events and Fundraising Coordinator, Caitlin Mulcahy and her friend Eloise completed a 5,000 step climb at the Gabba for the Stadium Stomp Challenge 2021. Together they raised over \$2,000.

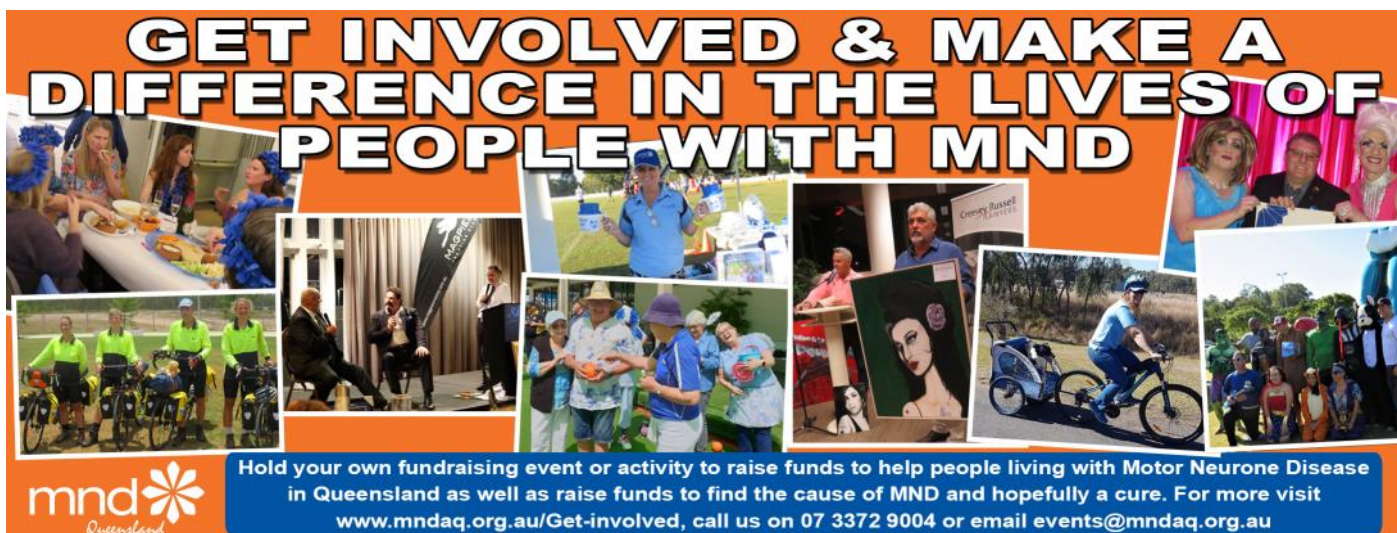



Pictured: Caitlin & Eloise at Stadium Stomp

Get in touch to discuss your fundraising idea and how we can provide support to make it a success. Call us on

07 3372 9004 or email [events@mndaq.org.au](mailto:events@mndaq.org.au).

# GET INVOLVED & MAKE A DIFFERENCE IN THE LIVES OF PEOPLE WITH MND



**mnd**  **Queensland**

Hold your own fundraising event or activity to raise funds to help people living with Motor Neurone Disease in Queensland as well as raise funds to find the cause of MND and hopefully a cure. For more visit [www.mndaq.org.au/Get-involved](http://www.mndaq.org.au/Get-involved), call us on 07 3372 9004 or email [events@mndaq.org.au](mailto:events@mndaq.org.au)



## MND CONNECT WEBSITE LAUNCHED

**MND Australia is pleased to announce that the new MND CONNECT website is live.**

The new website provides a wide range of MND related information for people living with MND, their carers, family, health professionals and service providers.

If you have a few minutes spare jump onto [www.mndconnect.org.au](http://www.mndconnect.org.au) and browse through the friendly, easy to read collection of MND web content, information resources and audio-visuals.

MND Australia worked closely with people living

with MND and their carers, and staff from the State-based MND Associations (including MND Queensland) to help develop the website – you might even see someone you know on one of its pages!

MND Australia received funding from the Australian Government Department of Social Services through an information, Linkage and Capacity Building (ILC) Grant to develop these resources.

We would love to know what you think so please feel free to email us at [info@mndaustralia.org.au](mailto:info@mndaustralia.org.au).

# MND Connect

MND Info Line

## 1800 777 175

9am to 4.30pm Monday to Friday

## Information & Support

MND Connect provides resources, information and service linkage for people living with MND, their carers and family, as well as the health professionals and services providers who support them to live well.



What is MND? →

Overview of motor neurone disease, types of MND & newly diagnosed



Find services & support →

State MND Associations, MND clinics, NDIS & My Aged Care



Living with MND →

Living well day-to-day, accessing assistive technology & managing symptoms



Support for carers, family & friends →



For health professionals & service providers →



Resources →

An A-Z of all MND resources

## NEW END OF LIFE GUIDE

Conversations about dying can be difficult and without planning, there is often a burden left on the loved ones we leave behind. It's something we'll all go through and unfortunately for people with MND, it's much sooner than one would hope. But there is some help available... MND Australia has produced the 'End of Life Care' guide to gather together relevant information to help plan and help make sensitive, and important conversations about dying a little bit easier.

Under our MND Australia national alliance, MND Queensland helped to develop this useful resource for people living with MND. Being part of a national alliance means that we can work together with other States to share information and expertise and create useful resources for the MND community.

The guide explores topics such as:

- Planning ahead
- Managing emotions
- Having difficult conversations
- Talking with family and children
- MND progression
- Care and support available
- Organising financial, legal and other personal affairs
- Inherited MND and genetic counselling
- Organ and tissue donation
- Advance care planning
- And much more...

We know that these conversations will never be easy, but if you have MND, we strongly recommend that you read the guide to help you plan ahead. You can contact our office to request a copy to be sent to you, otherwise you can also access it online on the new MND Connect website [www.mndconnect.org.au](http://www.mndconnect.org.au) or at <https://bit.ly/3sUYMsX>.



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## MND QUEENSLAND'S EDUCATIONAL RESOURCES

One of MND Queensland's key services is education, not only for people diagnosed with MND and their families/carers, but also for Allied Health Professionals who help people with MND in the community to improve their knowledge about this disease and help them provide better care for people impacted by MND.

We host fortnightly special presentations with guest speakers presenting on a range of interesting and educational topics. We also make these presentations available online on our website and YouTube channel. Since we started our YouTube channel in February this year we've had 965 video views! We're so grateful to all of the health professionals who have volunteered their time to present these webinars to help the MND community. You can subscribe to our YouTube channel at <https://bit.ly/38gGWY2>.

MND Queensland also offers education to service providers and residential aged care facilities to help them better understand MND so that they can provide quality support to people diagnosed with MND under their care.

If you'd like to learn more about MND Queensland's educational resources, or book an education session for your service or facility, please contact our office by calling 07 3372 9004 or email [info@mndaq.org.au](mailto:info@mndaq.org.au).

# WALK TO D-FEET MND TOOWOOMBA

9AM, Sunday 12 September, Botanic Gardens, Queens Park



**REGISTER NOW AND HELP RAISE VITAL FUNDS TO HELP FAMILIES IMPACTED BY MOTOR NEURONE DISEASE**

[www.mycase.com.au/events/walk2dfeetmndTWB21](http://www.mycase.com.au/events/walk2dfeetmndTWB21)



## MEET SALMA - MND QUEENSLAND'S NEW SPEECH PATHOLOGIST

**MND Queensland is delighted to announce that we have launched Australia's first MND-specific Speech Pathology Service and we'd like to introduce you to our new Speech Pathologist (SP) Salma Charania.**

### **Can you please tell our readers a little about your professional background?**

Before joining MND Queensland at the beginning of August I was working as a Speech Pathologist within aged care and home settings. I worked with adults presenting with communication and/or swallowing difficulties caused by conditions including but not limited to stroke, dementia, Parkinson's disease, Multiple Sclerosis, Multisystem Atrophy, and Motor Neurone Disease over a 4-year period. Furthermore, I began my PhD in July 2016, focusing on the impacts of dysarthria in people with MND over a 12-month period.

### **Can you please tell us a little about your previous work with people with MND?**

Throughout my PhD which aimed at mapping dysarthria and the impacts on activities of daily living (ADLs) and psychosocial wellbeing on people with MND (PwMND) I developed an in-depth understanding of dysarthria presentation associated with MND and of the ongoing impacts on not only the person with MND but their families as well. Spending time with my participants at regular intervals over the course of a year provided me with insight into the variability of speech deterioration and impact on quality of life. Furthermore, my research highlighted the need for a holistic, patient-centred and multidisciplinary approach to speech pathology management of PwMND.

### **What are the benefits that people with MND can get from working with a Speech Pathologist?**

A Speech Pathologist is responsible for monitoring changes in speech and swallowing throughout disease progression to ensure provision of timely and relevant management strategies. Compensatory strategies such as pacing speech to conserve energy and communication partner training to help repair communication breakdowns may be introduced by the SP. Furthermore, as speech deteriorates, the SP will introduce alternative and augmentative communication (AAC) devices to support communication within the ADL's meaningful to the person with MND. An SP will provide appropriate swallowing management strategies to reduce the risk of aspiration (i.e., food or fluid going into the lungs), which can lead to aspiration pneumonia or a severe chest infection.

### **When do you advise that people diagnosed with MND engage with a Speech Pathologist?**

Due to the rapid and variable nature of MND, it is advised that PwMND meet with a SP whether or not they are presenting with speech and/or swallowing symptoms. This enables the SP to determine baseline speech and swallowing functioning, and to monitor any deterioration. In turn the SP can provide timely and relevant management education and strategies (e.g., AAC devices, change in food/fluid consistencies) to ensure PwMND are able to maintain quality of life.



### **What makes you passionate about working with people with MND?**

I've always had a passion for helping others and strive to make a positive impact where I can. While my PhD allowed me to develop a fundamental understanding of MND, it was my participants that made a significant impact on my life. Their courage and resilience is unmatched. Each one touched my heart in a different way, sparking my desire to apply my research within clinical settings to ensure PwMND remain connected to their lives using communication, as well as continuance of mealtime enjoyment.

### **MND is a complex condition to manage. What do you see as the benefits of being a part of a multidisciplinary team at MND Queensland?**

Due to the rapidly progressive and heterogeneous nature of MND working in a multidisciplinary team (MDT) is vital to managing PwMND. MDT care allows for organisation and integration of health care services to meet the need of PwMND in a timely manner. For example, having support coordinators, equipment coordinators, and allied health professionals under one roof at MND Queensland allows for provision of care to be quick and seamless.

### **What do you get up to in your spare time? Do you have any interests or hobbies?**

In my spare time, I enjoy going to the gym, yoga, running/walking along the Brisbane River, and reading. As I am a foodie, trying the newest restaurants in Brisbane and going to the local markets for a chai and fresh produce are must dos for me! I also love making a mean charcuterie board and matching it with a nice bottle of wine when I have guests over.

## WHAT'S ON

- 12 Sep - Walk to D-Feet MND Toowoomba**, 9AM, Queens Park Botanic Gardens. Register now and get sponsored at [www.mycause.com.au/events/walk2dfeetmndtwb](http://www.mycause.com.au/events/walk2dfeetmndtwb)
- 17 Sep - Mastermind for MND**, 6PM, fundraising trivia night at Metro Community Centre, Woolloongabba. Tickets at [www.stickytickets.com.au/Q38G4](http://www.stickytickets.com.au/Q38G4) or call 07 3372 9004.
- 17 Oct - Walk to D-Feet MND Redcliffe**, 9AM, Suttons Beach, Redcliffe. Register, get sponsored and support people with MND at [www.mycause.com.au/events/walktodfeetmndredcliffe](http://www.mycause.com.au/events/walktodfeetmndredcliffe)
- 27 Nov - Rotary Club of Mt Gravatt Christmas Fair**, MND Queensland is the charity of choice for this event on at the Mt Gravatt Showgrounds. Starts late afternoon.

## MND SUPPORT GROUP MEETINGS & SPECIAL PRESENTATIONS

If you've been impacted by MND you are welcome to join in on our free MND Support Group Meetings. The meetings sometimes have special guest speakers and you will get to meet other people who are experiencing, or have experienced MND so that you can share and learn from one another.

Due to COVID-19, we've introduced regular online support group meetings via Zoom. All clients are sent invitations to participate via email. Please make sure we have your current email address on file to make sure you're getting your invitations. If you would like an invite or support to use Zoom then email [supportgroups@mndaq.org.au](mailto:supportgroups@mndaq.org.au) or call 07 3372 9004. You can participate in Zoom meetings using a computer, laptop, tablet or phone.

**Gold Coast MND Support Group** - Meets every second month at 1PM at Level 2, Kay House, 35-39 Scarborough St, Southport. Upcoming dates: 9 October. RSVP to Leigh on 07 3372 9004.

**Monthly Carers' Support Group Meetings** - Via Zoom, 1PM every fourth Tuesday. The next meeting is at 1PM on 14 Sep then the following meeting will be at 1PM on the 12 Oct (and then every fourth Tuesday).

**Online MND Support Group Meetings** - For people with MND. 11AM every 2nd Thursday via Zoom.

**MND Queensland Special Presentations** - Educational and informative webinars with guest speakers are held every 2nd Thursday via Zoom at 11AM. The sessions are recorded and can be viewed on our website at [www.mndaq.org.au/Get-informed/MND-QLD-Webinars](http://www.mndaq.org.au/Get-informed/MND-QLD-Webinars) and you can also find us on YouTube by searching for MND Queensland.

## MND QUEENSLAND DONATION FORM - SPRING 2021 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](mailto: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](http://www.givenow.com.au/mndaq)**