

AUTUMN 2021 ISSUE

the cornflower

MND QUEENSLAND NEWSLETTER

Whitsundays Kayak Challenge for MND

Sam's Story - Somebody Does Care

2021 is Your Year to Make a Difference

Meet Hannah - Occupational Therapist

REGISTERED
PROVIDER



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Do you love getting a great deal? The Entertainment app has hundreds of fantastic discount offers on dining, shopping, entertainment and experiences which can save you thousands of dollars! Every membership that MND Queensland sells helps to fund our work to provide support and services to Queenslanders impacted by MND.

A new version of the app was launched in February. Instead of the old, heavy books, you carry the app with you wherever you go with your phone. This makes taking advantage of the discounts very convenient. The savings pay for membership within just a few uses, plus there are new offers being forwarded to your app all the time. It's a great way to discover new places and support local businesses.

You can buy a Single City/one-year membership, Multi City (21 cities inc. NZ and Bali) or a Multi Plus (21 cities for two years).

Order now to get a bonus \$10 eGift Card!
www.entertainment.com.au/orderbooks/2221j21.

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BONUS \$10 eGift Card	BONUS \$20 eGift Card	BONUS \$20 eGift Card
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1 YEAR MEMBERSHIP	1 YEAR MEMBERSHIP	2 YEAR MEMBERSHIP
Discover all the best savings in your city	Enjoy savings across Australia, New Zealand and Bali	2 years of savings across Australia, New Zealand and Bali
\$14 goes to our fundraiser!	\$24 goes to our fundraiser!	\$46 goes to our fundraiser!

Support us & buy now

All kinds of ways to enjoy everyday



REMINDER - 2021 MEMBERSHIP RENEWALS DUE

Annual membership fell due on 1 January 2021. All previous members should have received a renewal notice recently. For more information contact our Membership & Community Liaison Officer, Leigh Gilbert by calling 07 3372 9004 or email info@mndaq.org.au.

CONTACT US

MND QUEENSLAND

ABN: 75 990 922 939

Street Address: Unit 1, 89 Factory Rd, OXLEY QLD 4075

Postal Address: PO Box 470, INALA QLD 4077

Web: www.mndaq.org.au

Email: info@mndaq.org.au

Phone: 07 3372 9004

Freecall: 1800 777 175

SOCIAL MEDIA

Facebook: www.facebook.com/MNDAQ

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

Twitter: twitter.com/MNDQueensland

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

Linked In: www.linkedin.com/company/4869077

YouTube: www.youtube.com/channel/UCf5MA4DA7qGU7BThP9Pg-Cg

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.



FROM THE CEO'S DESK

Autumn is the breath we take between the summer heat-flood-disasters and the cooling chill of winter. On another measure, we have come through 12 months of COVID impact. For some of you, the seasons will be less important than the milestones of fighting this insidious disease.

For MND Queensland, we have the joy of gathering again as a community as our events schedule starts up again. We recently shared some special moments in a movie preview of "Blackbird" which is based around a woman with MND and her family coming to understand her wishes around voluntary assisted dying. Some of our clients have suggested to me that we should not be advocating for this so let me be clear on MND Queensland's position on this; We have clients who believe it is absolutely wrong and others who desperately want to know that option is there for them. We advocate for clients... all of them... no matter what their beliefs or preferences. We advocate for each one of you to make choices for you. Every single day our people are fiercely advocating for your rights to make choices for you.

Our Queensland Government is seeking to advance legislation in this area in the current year. We will fight for you to have choices where you don't currently have them. We do not have to agree or disagree with your decisions in order to fight for you and support you and those around you impacted by this disease. MND Australia has been leading a body of work with our National Alliance of MND Associations that will result soon in a comprehensive resource of information around all aspects of End-Of-Life-Care. We will bring this to your attention when it is launched. Thank you so much to those of you who joined us at the movie night and then stayed and shared your thoughts afterwards. I am always touched by the strength of this MND community supporting each other.

After a year of restrictions to gatherings there is a wonderful opportunity to come together at our Gold Coast Walk to D-Feet MND. Our walks are a great opportunity to bring family, friends and furry friends together safely in one place and draw attention to this cause whilst at the same time experiencing the sense of connection with others going through this or supporting someone going through it. Some people walk (or wheel) for themselves, others in memory of someone they have lost and others walk to support someone else impacted by this disease. Check out our website or Facebook page and look at the event notices in this publication and you will see details of the different regions in which we are holding a walk. If you can't make any of those... and some people attend more than one of them... you can organise a walk in your area for your people and can seek support from our Events team to pull that together.



Also we should celebrate being able to come out of pandemic restrictions and gather in our MND community and enjoy this wonderful country and all it offers. Don't forget to look into and encourage anyone who might want to attend our first adventure fundraising event... the Whitsundays Kayak Challenge for MND. For those of you who have MND, a little whisper... I have heard that one of our awesome MND people is not letting their disability determine whether or not they participate and is talking with our team about how that might happen... go or not, the planning is an adventure in itself... watch this space and anyone out there with a disability who would like to join us on this adventure... we will support you but we need to speak with you soon so we have enough time to plan.

It really feels like we are creating a new "COVID-Normal" as we head into autumn. The weather is settled, the vaccines have arrived, we know a lot more about COVID than we did a year ago and a lot more about ourselves. We have renewed perspective on how important our health and our family and friends are to us, so come and join us in a celebration of all those aspects of life that are important to us. See you at the Walks.



2021 IS YOUR YEAR TO MAKE A DIFFERENCE

One of the best ways to get involved and make a difference that directly benefits the lives of Queenslanders with MND is through hosting your own fundraiser. The best part about holding your own event or activity is that you can do it at a time that suits you and a place that you choose. This can be a great way to actively get involved by increasing awareness of MND by creating a conversation while taking action and having fun!

Some fundraising ideas include:

Host a morning tea or high tea

Put on a fashion parade

Organise a bingo or trivia night

Have a wine and cheese night

Organise an art class (clay or paint)

Host a girls night in & ask for donations

Hold a long lunch & ask for donations

Put on a comedy night

A golf tournament with your business contacts

Gather some friends for a ball, exhibition or gala

Hold a raffle at your club

Have a bake sale or sausage sizzle

Put on a car wash

Dress up or down day at work or school for a gold coin

Set your own physical challenge & get sponsored

Mute Me for MND (sponsored silence for a day)

Organise a concert, performance or play

Do the Ice Bucket Challenge

Or why not do you own Walk to D-Feet MND event?



Pictured: In 2019 Mackay local Mick Scholar organised the 'Moranbah to Mackay Ride for MND' and raised over \$30,000 for people with MND.

If you're hosting a tea, lunch, dinner etc. you might want to ask people to make a donation instead of bringing a plate or bottle of wine. Approaching your company boss/ employer is also an idea as they might dollar-match your effort with a donation too, doubling your fundraising!

MND Queensland can support your fundraising effort in several ways including:

- Providing a Letter of Authority to Fundraise (officially endorsing your effort so you can seek sponsorship or donations)
- Social media promotion to attract people to your event or activity
- Help set up a fundraising page to collect online donations
- Provide fundraising merchandise to sell at your event and donation buckets to collect donations
- Help with artwork or signage for the event

Getting started is as easy as picking up the phone. If you would like to start your own fundraiser please get in touch with MND Queensland's Event and Fundraising Coordinator, Caitlin Mulcahy by emailing events@mndaq.org.au or call 07 3372 9004. We can support you to make sure your effort is a success!

Make 2021 the year you make a difference for Queenslanders with Motor Neurone Disease.

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



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, call us on 07 3372 9004 or email events@mndaq.org.au

CHOICE & CONTROL IN SERVICE PROVISION

I have had a number of conversations with clients and their family members recently that made me think that it was time for a discussion about choice and control. Given this is an article, it will be a pretty one-sided discussion initially but hopefully it prompts some more interactive ones in the future!

The unavoidable reality of living with MND means having to engage with a variety of supports and whilst that is often overwhelming, it is made a little easier by having a team that puts you at the centre of everything. It is vital that each and every person supporting you takes the time to understand who you are and listens to your views at every interaction. This is your RIGHT!

At MND Queensland, we often talk about the 'Specialist' services we offer. Whilst we take pride in the knowledge and experience we have in our team and our ability to support our community, we never lose sight of the fact that YOU are the expert on your life and every service around you needs to be tailored to how YOU wish to be supported. This goes for your medical team, us, your Allied Health team, any personal care service providers used or any other services you access.

Before engaging any supports, it is worth taking the time to think about what you are looking for in a provider, how you expect the service to operate and the tasks you want them to complete as well as what you want them to know about you. If you have the time and inclination, I would recommend interviewing any provider before you commit to using them. This is obviously more important to do with an Allied Health Professional or Personal Care provider than with someone doing cleaning once a week but making sure that you are on the same page with what is expected is key to a satisfactory service.

We regularly see service arrangements failing because the provider overpromised and under-delivered or didn't fully understand a client's expectations and were never realistically likely to meet them. For example, at MND Queensland, our Support Coordination service operates during business hours. If we have a client come to us looking for a Support Coordinator but it is their expectation that they'll have access to that person 24 hours a day, we will only ever disappoint them so instead we'd prefer to be upfront and then the client has a **choice** to make, look for



Picture: MND Queensland's Director of Services Stacey Thorpe (left) meeting with Tony who has MND (right) and his wife Beris to discuss the most suitable aged care providers for their needs.

a different service that can meet their expectations or adjust them because accessing a specialist service might be deemed more valuable than 24-hour access.

If you do find yourself disappointed in any of the services you are receiving, it is really important to let them know. That way, they can either improve the service being provided or explain why this can't be achieved and again the choice is yours. You can accept that they might not be perfect but the good things outweigh the bad OR you can take **control** and change to another service provider. Whatever you do, don't put up with it. You have enough to deal with, frustration with service providers shouldn't be something you have to worry about.

I do recognise it's easy for me to sit behind my desk and tell you that if you're not happy, do something about it. But you're not on your own. We recognise the importance of organisations like ours taking an active role in advocating for individual client's needs as well as on behalf of our community as a whole. So, if you need our help to advocate for better supports, we're only a phone call away!

Stacey Thorpe
Director of Services

WALK TO D-FEET MND BRISBANE 2021
9AM, Sunday 18 April, New Farm Park

Register now, get sponsored & help make a positive difference in the lives of people with MND
www.mycause.com.au/events/walktodfeetmndbrisbane2021

mnd Queensland
WALK TO D-FEET MND

WHITSUNDAYS KAYAK CHALLENGE FOR MND

Imagine paddling through the beautiful, tropical waters of the Whitsundays... camping on pure sandy beaches at night... seeing the sites from a local's perspective... making life-long friends... and at the same time, making a positive difference in the lives of people with MND! We're seeking participants in our very first adventure fundraiser, the 'Whitsundays Kayak Challenge for MND'. Join MND Queensland as we pledge to increase awareness and raise vital funds for MND by kayaking around the beautiful Whitsunday Islands in August 2021.

From 16 - 21 August ten participants will take on the challenge of kayaking around the spectacular Whitsundays and pledge to raise \$1,500 each in support of Queenslanders with MND and help to increase awareness about this terrible disease.

Over four consecutive days and nights you will be kayaking the pristine blue waters of the Whitsunday Islands interspersed with snorkeling the reefs, hiking up to picturesque outlooks, spending time making lifelong friends around the campfire on the white sandy beaches and much more. You'll also get to spend time at the amazing Whitehaven Beach, voted one of the best beaches in the world!

August is also the perfect time to see whales make their way through the islands, so who knows... you might even have a special encounter with these glorious creatures! Plus, it's out of stinger season and being a very mild winter in the tropics, it's a great escape from the cold.

Along with our tour partner, we've organised everything so participants will have all catering, accommodation, transfers, kayak equipment and activities provided while on the tour. You just need to bring your hat, sunscreen and clothes, and make your own way to Airlie Beach and back where we're providing a night's accommodation on either side of the tour for you too.

Limited places are available for this once-in-a-lifetime opportunity! Why not take on this challenge on behalf of a loved one or as a personal challenge to fundraise for a worthy cause? Then get everyone you know on board to support your fundraising efforts! Your participation will directly benefit people with MND and you'll have the support of MND Queensland to help you reach your goal.

Hurry... don't hesitate! Contact us now to secure your place on this adventure fundraiser. For more information and to apply please get in contact with our Fundraising and Event Coordinator, Caitlin Mulcahy, events@mndaq.org.au or 07 3372 9004.



MND QUEENSLAND EVENTS WRAP UP

MND Queensland had to cancel almost every event we had planned for 2020 due to COVID-19. This caused a massive decrease in our fundraising income last year. We're coming back though with two events already held so far in 2021!

On Wednesday 17 February MND Queensland hosted a fundraising preview of the film 'Blackbird' starring Susan Sarandon and Sam Neil. The film is about a woman who has MND/ALS and is spending her last weekend with her family before ending her life on her terms. It was a very touching film and many of us left the cinema with a few tears shed. We raised over \$1,500 from this event and we are very grateful to Dendy Coorparoo for donating the cinema and film to MND Queensland.

Next up was our second Motor On for Motor Neurone Disease car scavenger hunt on Sunday 21 February which saw 15 cars filled with excited participants following cryptic clues and finding their way around south-east Brisbane. It was a fun day out followed by a picnic, award ceremony and raffle draw on the Wynnum foreshore. This event raised around \$6,500 and we are grateful to all of the participants and donors for making this such a successful event. Here are a few photos from the day.



Pictured: (above) Motor On rally winners Higgs's Hobbits. (above right) Jojo Legends - Best Dressed Team. (following below) Highest Fundraising Team - Team McMahon. (following, below left) event volunteers Louise & Wayne (right) major raffle prize winner (bottom) a crowd shot.

Blue Cornflower Day Tribute Event

5:00PM, Friday 7 May, Wilson Outlook Reserve, New Farm

Please join us for this free event to watch the Story Bridge light up in blue for Blue Cornflower Day during MND Awareness Week 2021 as we pay tribute to those currently battling MND & remember those who we have lost.

Never Give Up!

mnd
Queensland

SOMEBODY DOES CARE - MND QUEENSLAND IS HERE TO HELP

Sam was diagnosed with Motor Neurone Disease in December 2019. Initially he thought that perhaps his diabetes was playing up as he was heavily fatigued after working all week as a driver. At first his doctor thought the same thing too, but tests found all his levels were fine, so he was referred to the Toowoomba Hospital where their first thought was that he may have MND. After going through nerve tests, the doctor's suspicion was proven correct so he was referred to a specialist, Dr Siu who did more tests to confirm the diagnosis. At that time, Dr Siu gave Sam a life expectancy of making it until Christmas 2020. Sam has outlived the doctor's expectations and with the help of MND Queensland he's still as mobile and independent as he can be. We recently spoke with Sam and his friend Lesley who is Sam's live-in carer.

Lesley had been living at Sam's place in Nanango as a caretaker of his property during the week while Sam worked in Brisbane. When they learned of Sam's diagnosis Lesley said "As you can understand we were both dumbfounded because before that, I had never heard of MND. It was a bit of a shock to the system."

Sam told us about the impact his diagnosis had on him "I had the idea when I bought this place, that I could pay cash for it and I bought a caravan... all of these plans I had didn't include my diagnosis... it about-faced something chronically."

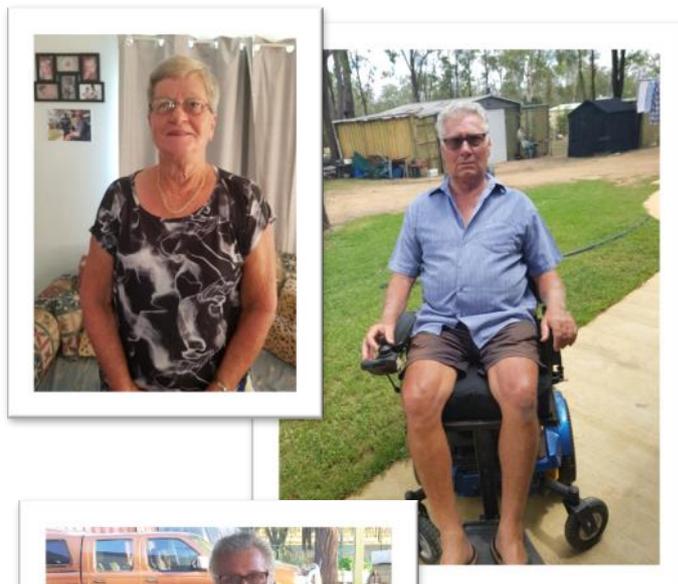
Because Sam was diagnosed with MND after the age of 65 he isn't eligible for the NDIS and he's only just qualified for a Level One My Aged Care Package. Lesley told us that he's currently on the waiting list for a higher level "But he doesn't have time to wait!" she said. Sam added "My gut feeling, the way they're talking, I'm going to pass away long before I get that because I should have passed away last year and because I pushed myself, at least the doctor's told me, I'm doing everything right and I'm still alive, but I've noticed a massive difference towards the end of last year and this year."

Sam is getting some help showering, but they could both use more assistance as Lesley is the same age as Sam and has neck problems herself and she said getting help "is like pulling teeth." She then talked further about her frustrations with the process of accessing help "Oh!... It has absolutely taken us down more than it's picked us up... trying to fight for a bit of help."

But they have had help from MND Queensland. Lesley said "Could I just mention Stacey (*Ed: MND Queensland's Director of Services*) I love that woman! Right from the start she's cared. I'm going to nominate her for Australian of the Year. You know, if you get no other phone calls from anybody else, you always get phone calls from Stacey and that means a lot, because she's got a lot on her plate." Sam added "I'd be lost without her. She's been a terrific help to me."

Sam and Lesley are very grateful that MND Queensland were there when they needed us with information and advice. Lesley said "When the doctor told us at the hospital... he's running through all of this stuff like palliative care, this care, that care, get your Will done, do this... He's bamboozling us with all this information and we'd just heard of Sam's diagnosis!"

When asked about what help MND Queensland has provided, Sam said "A lot really. Wheelchairs... the



Pictured: (top left) Lesley, Sam's friend and carer and (top right and below left) Sam in his electric wheelchair provided by MND Queensland.

scooter... any advice that I want. The telehealth, we like that" (*Ed: our online support group webinars*).

We asked Sam and Lesley what they would say to our supporters who make our work with over 65s possible through donations and Lesley said "The money is being well spent... Their money is being spent fantastically because Sam and myself, as a carer, have had nothing but support from MND Queensland." She went on to add "MND Queensland have been absolutely fantastic. Stacey has been onto other people as well to push them and push them and we appreciate that." Sam added "I'd be lost without Stacey. The other people there that I've spoken with have been a terrific help as well... I can't praise them enough!"

Choking back tears, Lesley told us "When Sam was diagnosed, that was a smack in the face and MND Queensland have come to the front and made him feel special, made him feel like he's somebody... that somebody does care."

MND Queensland deliver a range of specialist services for people impacted by MND including information, advice and referrals, equipment rental, NDIS Support Coordination, support group meetings and an Occupational Therapy service. To find out more call us on 07 3372 9004 or visit www.mndaq.org.au/Find-help.

LACE UP YOUR RUNNING SHOES TO SUPPORT MND QUEENSLAND

MND Queensland recently registered with the Grassrootz fundraising platform which means you can now fundraise for Queenslanders with Motor Neurone Disease. You can run, jog or walk in support of people with MND through a variety of events listed on Grassrootz.

Below are some of the upcoming events you can participate in:

- 7 Cairns Marathon Festival 2021: 28 April 2021
<https://bit.ly/2ZfqK10>
- 7 Rocky River Run 2021: 23 May 2021
<https://bit.ly/3ppBQyt>
- Brisbane Marathon Festival: 5-6 June
<https://bit.ly/3jPb8yc>
- Village Roadshow Theme Parks Gold Coast Marathon 2021: 3- 4 July 2021
<https://bit.ly/37ctg04>
- 7 Sunshine Coast Marathon 2021: 14-15 August
<https://bit.ly/3d88Bho>
- Noosa Triathlon: 27-31 October
<https://bit.ly/3b53w6X>

We're also registered with Go Fundraise and you can find events to get involved with on this page

www.gofundraise.com.au/beneficiary/MotorNeuroneDiseaseAssociationofQueenslandInc

MND Queensland relies on community support and donations to perform much of our work... so why not challenge yourself this year to increase MND awareness, get fit and raise vital funds?!

You might also be interested in joining our first adventure fundraiser 'Whitsundays Kayak Challenge for MND' featured on page six of this edition.

Get in touch with our Events & Fundraising Coordinator Caitlin Mulcahy for more information by calling 07 3372 9004 or email events@mndaq.org.au. Register today and start fundraising to make a positive difference!



Pictured: The 'Move a Muscle for Motor Neurone Disease' team ran in tribute to their Mum in the 2014 Gold Coast Marathon and raised around \$10,000 for MND Queensland.



WALK TO D-FEET MND GOLD COAST 2021

9AM, Sunday 21 March, Hollindale Park, Main Beach
www.mycause.com.au/events/walktod-feetmndgoldcoast

register now & start fundraising

funds raised support people with MND

WALK TO D-FEET MOTOR NEURONE DISEASE

mnd Queensland

OUR NEW CORPORATE PARTNER

"None of us, including me, ever do great things. But we can all do small things, with great love, and together we can do something wonderful." – Mother Teresa

MND Queensland is a charity but charities are also businesses, or at least they are if they wish to survive and deliver on their charitable goals. Small - businesses have many of the same costs as big businesses. Charities every day aim to have their income bigger than their expenses and then they can distribute the "surplus" back into services. Every dollar of revenue we make is invested into services to those with MND... no payouts or dividends, nothing wasted... but it is tough and that's where a Corporate Partner comes in.

We have had and continue to enjoy the support of many wonderful sponsors who help us defray the costs of an event or make donations towards an event and for these we are always grateful. A Corporate Partner is something different; they are an organisation who supports us by understanding our business and providing us with services that we need... they GIFT us their services, which means they gift YOU the benefit of that. It is called pro-bono work... pro-bono in Latin means 'for the public good'.

We are very fortunate and delighted to share with you that we have a new Corporate Partner; it is Thomson Geer. They are a large and reputable law firm that employs more than 560 people and has 126 partners in offices throughout Australia. They provide legal advice to us where we would otherwise have to purchase that. This means that our budget for legal services is now able to move straight to services; benefitting people impacted by MND... so in the end it has the same financial outcome as a donation except that we also get the benefit of professional advice from some of the best legal minds in Australia and some of the kindest people you could wish to meet.

They work at getting to know our business so they can offer the best advice. They have even worked after normal hours or started early to turn around some critical

legal advice for us that we might need the next day. They have supported us through all of our negotiations to sell the Inala property and return the largest proportion of capital possible into our bank account where it will be used for services to our MND Community.

Why would a big important national law firm form such a partnership with a small Queensland charity supporting people impacted by a rare and dreadful disease? Well, it speaks to who they are that they would work for us for no fees and with a wonderful open generosity of spirit. A number of the partners have been touched in their personal lives by the impact of MND on those they care about and they see the relationship with MND Queensland as a way to give back.

"Thomson Geer is proud to support MND Queensland through the provision of pro-bono legal advice. At Thomson Geer, we recognise our responsibility to make a meaningful commitment to corporate social responsibility and we understand the importance of giving back to our community and the NFPs within it for worthwhile causes."

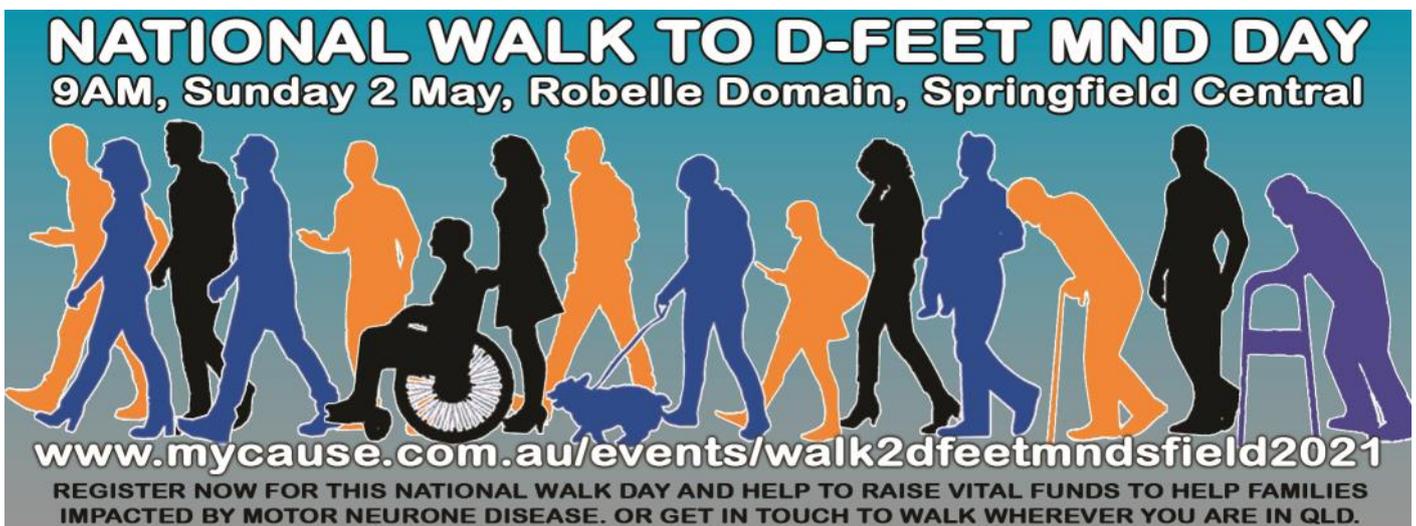
"Providing pro-bono support to MND Queensland gives our lawyers great satisfaction to be able to help MND Queensland to focus their efforts and much needed funds on supporting those people living with MND, their families and carers." Thomson Geer Partner and Brisbane Office Leader, Chris O'Shea said.

We are so grateful for this new partnership that looks to be enduring and rich in opportunity for us to learn and improve our business so we can in turn, do more for all of you in our MND community.

I thoroughly endorse this group of excellent lawyers and wonderful people to all of you. They truly are a valuable partner to us and the whole MND community in Queensland.

Thank you so very much to the team at Thomson Geer.

From Ian Landreth and the MND Queensland Management Committee and Team.



NATIONAL WALK TO D-FEET MND DAY
9AM, Sunday 2 May, Robelle Domain, Springfield Central

www.mycause.com.au/events/walk2dfeetmndsfield2021

REGISTER NOW FOR THIS NATIONAL WALK DAY AND HELP TO RAISE VITAL FUNDS TO HELP FAMILIES IMPACTED BY MOTOR NEURONE DISEASE. OR GET IN TOUCH TO WALK WHEREVER YOU ARE IN QLD.

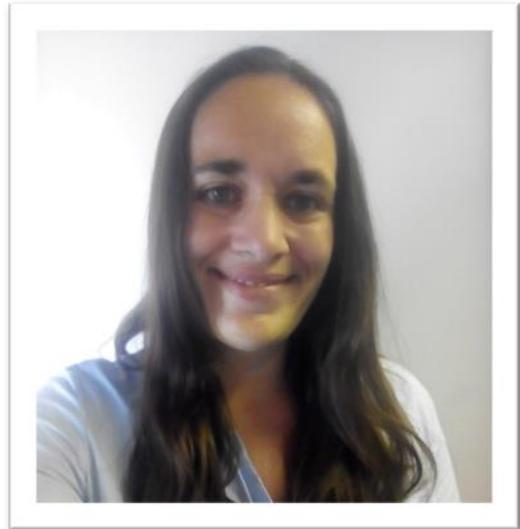
The poster features a row of colorful silhouettes representing diverse people: a person in a wheelchair, a person with a dog, a person with a cane, and a person with a walker. The silhouettes are in shades of orange, blue, and purple.

MEET HANNAH - OCCUPATIONAL THERAPIST

Hannah Woods recently started working at MND Queensland in the role of Occupational Therapist and we thought we'd ask her a few questions so that you can get to know her a little more.

Can you please tell our readers when you started at MND Queensland and a brief background on your professional life and any relevant skills that you bring to the role?

I started working full-time at MND Queensland in January. Prior to moving to Brisbane I was a rural OT servicing the Snowy Mountains region from Merimbula to Jindabyne. Being a rural practitioner you become a jack of all trades however my skill set and training is vastly in complex equipment prescription and home modifications. With so many suppliers here in the city it's been great to get more hands on with new technologies.



"I have found getting to know my clients, their families and having an understanding of their holistic needs as a whole is quintessential to my role"

Can you please tell us a little about your work with people with MND as an Occupational Therapist?

I find working with people with MND requires creative problem solving and great product knowledge to ensure we can help maintain as much independence and function as possible in the day to day. Did you know you can operate some recliners without using a standard recliner remote? Sure can!

What do you find rewarding about working for MND Queensland?

It is a community of its own and having only been here a month I can say I am inspired daily to help achieve bigger things personally and with my clients!

Are there any tips you can give our readers about Occupational Therapy services for people with MND?

Occupational Therapists are all about making sure you are doing the meaningful, life fulfilling things that you enjoy in the day-to-day. So think beyond your mobility and self-care goals and we will try and help you achieve what you thought might not be possible! Fancy going to the beach? Did you know you can get a variety of affordable beach access equipment from councils or lifeguards? We can help make sure it's right for you so you can spend a day at the beach with friends or family.

Have you found any commonalities between clients when working with people with MND? E.g. are there always pieces of equipment or home modifications that you immediately recommend for almost everyone?

Mostly people access Occupational Therapists for self-care equipment e.g. a variety of seated options for the shower from shower stools to complete hygiene commodes, mobility aids (from walking sticks to complete power wheelchairs) adjustable bedding and falls pendants. A lot of people also seek temporary ramping or modifications solutions as they are quick and less disruptive to the home routine e.g. when you get a

bathroom permanently renovated you also need another bathroom for the 2-3 weeks it takes to complete! So some people prefer alternate options such as shower recess inserts or rubber ramping.

While this is common in the scope of Occupational Therapy I feel it's much larger than what it currently attends to. I feel home automation will be increasingly popular in future as the technology becomes more affordable (only parts of it are currently funded under the NDIS). You can complete tasks like open/shut blinds, doors or windows, turn on/off air conditioning, lock your front door all with a touch of a button, your voice or in some cases an eye gaze machine.

MND is such a complex condition to manage. What is one of the biggest learnings you've had since working at MND Queensland?

While it is one condition the impact MND has physically, on the person generally and on their family is so varied. I have found getting to know my clients, their families and having an understanding of their holistic needs as a whole is quintessential to my role in identifying what assistance is wanted /needed and when.

What do you get up to in your spare time? Any interests or hobbies?

My son is 10 months old so I am commonly found rocking out to The Wiggles and playing in the park! We like taking our staffy Lemmy to the dog beaches and go bushwalking.

Is there anything else that you'd like to share with our readers about your role at MND Queensland?

There are no silly questions so if there is something you are finding more difficult, want to do, or miss doing have a chat with your OT.

Occupational Therapy is one of the specialist services that we deliver directly to clients. Call 07 3372 9004 or email info@mndaq.org.au for more.

WHAT'S ON

- 21 Mar - Walk to D-Feet MND Gold Coast 2021**, 9AM, Hollindale Park, Main Beach. Register & get sponsored at www.mycause.com.au/events/walktod-feetmndgoldcoast
- April - Launch of Australia Moves 4 MND** virtual fundraising event. Move however you want and get sponsored. www.am4mnd.org.au. AM4MND officially runs from 1 - 21 June 2021
- 18 Apr - Walk to D-Feet MND Brisbane 2021**, 9AM, New Farm Park. Register and start raising funds at www.mycause.com.au/events/walktodfeetmndbrisbane2021
- 2 May - National Walk to D-Feet MND**, 9AM, Robelle Domain, Springfield Central. Register now and raise funds at www.mycause.com.au/events/walk2dfeetmndsfield2021 Or walk wherever you're located. Call us!
- 2 May - 8 May - National MND Awareness Week 2021** - why not hold your own fundraiser?
- 7 May - Blue Cornflower Day Tribute Event**, 5PM, Wilson Outlook Reserve, New Farm
- 18 Jul - Motor On for Motor Neurone Disease**, our 2nd car scavenger hunt for 2021. Details coming soon online.
- 16 Aug - 21 Aug - Whitsundays Kayak Challenge for MND**, for more info visit www.mndaq.org.au/Get-involved/Event-Calendar/Whitsundays-Kayak-Challenge-for-MND
- 3 Sep - 10th National MND Australia Conference**. More info at www.mndaust.asn.au/conference
- 12 Sep - Walk to D-Feet MND Toowoomba**, 9AM, Queens Park Botanic Gardens. Register and get sponsored at www.mycause.com.au/events/walk2dfeetmndtwb
- 17 Oct - Walk to D-Feet MND Redcliffe**, 9AM, Suttons Beach, Redcliffe. Register and get sponsored at www.mycause.com.au/events/walktodfeetmndredcliffe

MND SUPPORT GROUP MEETINGS

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 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: 10 April, 12 June & 14 August. 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 30 March then the following meeting will be at 1PM on the 27 April (and then every fourth Tuesday).

Online MND Support Group Meetings - 11AM every Thursday via Zoom with special presentations fortnightly as below.

- **18 Mar - NDIS Funding for Holidays** - Presented by Marnie, MND NSW Coordinator of Supports & Knowledge and Development Coordinator
- **1 Apr - Exercise Physiology** - Presented by Jake O'Brien, Exercise Physiologist and Team Leader, Better Rehab

MND QUEENSLAND DONATION FORM - AUTUMN 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

My Details:

Name:.....

Address:.....

Suburb:.....

State:.....Postcode:.....

Phone:.....

Email:.....

Card Number:

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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