

# MNDnews

The newsletter of the Motor Neurone Disease Association of South Australia



While South Australians with cancer have access to dedicated Cancer Care Coordinators, defined clinical pathways and trained cancer nurses, likewise those with cardiac disease and diabetes, South Australians with MND have no such services.



I've got ALS, which is the most aggressive one. I'm very keen to stay positive. I get well looked after because I was 62, nearly 63, when I was diagnosed. But a person who's 65 and one day old get nothing.



People diagnosed with MND over the age of 65 are not eligible for NDIS support and instead must rely on charities like the Motor Neurone Disease Association of South Australia (MNDSA).



Evidence clearly shows that a multidisciplinary approach to the care of people with MND, and early access to that care, is vital.

## MNDSA LAUNCH 2022 SA ELECTION PRIORITIES

**Will the next government give South Australians with MND a fair go?  
Will they meet us half way?**



Until there's a cure, there's care

# MESSAGE FROM THE CHAIRMAN



This is my last Chairman's message given that I am stepping down at the AGM. I will remain on the Board and concentrate largely on issues facing MND Associations nationally.

So, it is time to reflect on my past four years.

It has been a period of enormous challenges and growth, probably the most exciting period in our 35-year history.

We have changed the way we operate and greatly expanded our services to now include greater coordination of the many facets of managing MND and increased occupational therapy and assistance with speech. We now have 13 staff. This, together with an enormous growth in our equipment pool and delivery vehicles, means that we can respond more promptly and efficiently in meeting the ever-changing needs of those living with MND.

We have new premises which co-locate our staff and equipment, provide a pleasant workspace, areas for confidential discussions with our patients, as well as simply meeting people, and training.

We have built our relationship with the Clinic at Flinders and now provide a coordinated approach to care, thus reducing the burden on our patients and carers.

As a Registered NDIS provider, we help those eligible to access the scheme and who choose us as their provider, whilst still meeting the needs of those not eligible aged 65 and over. Despite this group receiving only limited government support, our goal is to meet the needs of all of our MND community, regardless of age or location.

All in, this has been achieved during times of enormous stress. COVID-19 has meant that we have had to work differently and adopt new technologies. Most of our staff have joined us in the past 12 months and have been training on the job. Yet still, we have been equal to the task.

The fact that we have achieved all of this on very constrained budgets is amazing and a testament to all of those who have contributed in many ways. Yet adequate and stable finances still remain our biggest challenge which has seen us recently launch our advocacy campaign for the 2022 SA Election.

I thank my fellow Board members, our CEO, Karen Percival, our staff, our volunteers, and you, our MND community, for your support.

**We have truly met the challenge – Until there's a cure – we care.**

**Geoff Thomas OAM  
Chairman of MNDSA**



# MND SOUTH AUSTRALIA SAYS THANK YOU

If you are interested in volunteering for MNDSA, please get in touch at [volunteer@mndsa.org.au](mailto:volunteer@mndsa.org.au) or call 08 8234 8448 – we have a variety of opportunities available to suit everyone. We simply couldn't do what we do without the support of our volunteers.



## FightMND Care Grant

MNDSA were fortunate to be successful in a grant of \$350,523 from FightMND this quarter to assist in improving the Equipment Pool we have available to people in South Australia impacted by MND.

The MNDSA team had identified items, such as our powered wheelchairs, that can be modified and upgraded, along with some gaps in our current equipment pool. We are really excited to make the best use of these items, as well as adding some new technologies that we have on order to be delivered in the coming months.

**A huge thank you to FightMND – until there's a cure, there's care.**



## Special thanks to our MNDSA Volunteers

MNDSA Volunteer Officers Cliff Beale and Andrew Davies approached us to volunteer 18 months ago after a very close friend of theirs was diagnosed with MND.

Cliff and Andrew have worked tirelessly on our Volunteer Program and other ongoing special projects and have become integral members of our team, even taking on shifts at our weekend Sausage Sizzles. Thanks, Cliff and Andrew, for your friendship, support and passion to assist our Association.

Helen Vaile brings a wealth of career experience as an OT and NDIA planner into her role as a volunteer one day a week at MNDSA. Now retired, Helen works closely with the Client Services team and provides advice about the NDIS and other supports for our community. Helen packs in a great deal of love, care and attention into her volunteer roles in the community, and MNDSA is lucky to have her on board.

## NEW MNDSA Staff and Board Members:

### Jane Barnett, Support Coordinator



We welcome Jane Barnett to MNDSA as a Support Coordinator with broad experience in many areas.

Jane worked at Royal Adelaide Hospital Health Promotion Unit supporting visitors, inpatients and outpatients with health information. She went on to work at COTA SA as a Project Officer for *beyond maturityblues*, a peer education project raising awareness of anxiety and depression in older people, supported by *beyondblue*. Further roles have included intensive support and advocacy for families with young children in the Mid Murray and South-East regions and Social Work support for My Aged Care clients of ECH.

Jane is passionate about supporting people to plan and reach their goals and to ensure they receive the best care in a timely manner.

### Scott Penhall, Board Member



Scott was elected to the Board in August 2021. Scott cared for his wife Anna, who was diagnosed with Motor Neurone Disease in 2018 and sadly passed away late in 2020.

Over the past 5 years, Scott has managed his own consultancy advisory business, assisting the commercial construction industry.

Prior to this time, Scott has worked for large commercial builders, acting in the role of Managing Director for a \$500m+ locally based business, with extensive experience being part of a board and holding executive leadership roles over the past 25 years around Australia and overseas.

# MND SOUTH AUSTRALIA SAYS **THANK YOU**

## Team Not D'Feated

Team NOT "D" FEATED's theme is "Moments Matter". They fundraise in memory of their beautiful mum Brenda, who they lost to MND. Unfortunately, the MND Gene, in this case, is familial and family members may need MNDSA again in the future.

Brenda's daughter, Kirsty Woods, says "MNDSA allowed our mum to spend her end of life at home, making memories with their support. We believe other families deserve the same support. This can only happen with efforts to raise funds. We have had the privilege of meeting Graham and Barb Johnson (Graham is currently living with MND), and teamed up to hold an extra special fundraiser recently."

Their target was \$5,000, and they raised over \$8,000.

This combined group of Kirsty Woods and family, and Graham and Barb Johnson and family can clearly move mountains and



we thank them, all who supported them behind the scenes, and all who attended and donated.

**Thank you - It's because of people like you, that we can do what we do.**

If you would like to hold a fundraiser to support the work of MNDSA, please contact us at [fundraising@mnDSA.org.au](mailto:fundraising@mnDSA.org.au) or call 08 8234 8448.

## MNDSA Research Fellow: Dr Kate Johnson

**Dr Julie Lawrence, a surgeon who worked at Flinders Medical Centre, sadly passed away in 2019 from Motor Neurone Disease.**

In a wonderful act of kindness and generosity, an incredible legacy to help other patients with MND and an MND fellowship was established in Julie's name through the MND Clinic. Dr Kate Johnson was the appointed inaugural Julie Lawrence Fellow, and this is her update:

"2021 has been a fantastic learning year for me and I am grateful that the Flinders Foundation/MNDSA has sponsored me to complete the MND fellowship at Flinders Medical Centre.

I have met and been able to support several patients with Motor Neurone Disease and I have gained a better understanding of the variety of patients and the variety of issues that arise.



Photo Caption: Julie's husband Steve Meldrum, Dr Kate Johnson, and Julie's brother Graham Ragless

Unfortunately, this year has been disrupted by COVID-19, such that the commencement of the Lighthouse II trial, expected in August, was delayed to 2022. We are now busily preparing to launch the CY5031/cytokinetic trial in the next month.

I have also attended meetings with Dr Mary-Louise Rogers, where she is planning to launch a Network in SA to spur on more collaboration and attract research trials in MND to SA. I have also been conducting my data analysis on the side, looking at the association of CK with the urine biomarker, p75, as studied by Dr Rogers' lab at Flinders University."

# LIVING BETTER

## Physical Activity and MND

Finding ways to enjoy physical activity with MND can help, even as it gets harder to keep your body moving.

### Why does physical activity help with MND?

Generally, activities like walking, gardening, yoga, stretches and others that involve physical movement can help support your physical abilities by strengthening healthy muscles whose nerves have not yet been affected by MND. Physical activity can also help maintain joint range of movement, reduce stiffness and pain, and support overall wellbeing and enjoyment of daily life.

Many people living with MND feel that it's important to enjoy physical activity. Recent research finds that personal enjoyment of general physical activity is more motivating for some people living with MND than a more formal exercise program. So you may want to think about the activities you enjoy doing, and how your healthcare team can best support you to do them.

## What you need to do first

It's best to talk to your neurologist, GP, physiotherapist and others in your healthcare team about physical activity and how to manage:

- \* fatigue
- \* getting plenty of rest
- \* pain and stiffness
- \* aerobic, strength and endurance exercises, if they're suitable
- \* assistive technology for maintaining independence, mobility and comfort, if suitable.



## Fatigue is an issue

It's important not to push yourself to exhaustion while exercising and to get plenty of rest after physical activity to reduce fatigue. Even daily tasks like washing and dressing can drain energy, and you may need to rest and take time to recover. Physiotherapist and occupational therapist assessments and regular reviews can help to guide you.

### What can I try?

- \* Walking outside the home, housework, gardening
- \* Yoga, stretching limbs with a physiotherapist, hydrotherapy (activities in a pool of water)
- \* Exploring best ways with a physiotherapist to do physical activities while sitting in a bed or chair
- \* Talking with your health professionals regarding medications that may help with discomfort
- \* Stable and supportive shoes, walkers, braces, orthotics
- \* If active movement is no longer possible, active-assisted physical activity may help, such as active-assisted arm or leg cycling, or various team sports with your local electric wheelchair/powerchair sports association.

## Being active for wellbeing

Physical activity may help you to focus on things that you enjoy. You can have a break from other worries, build your confidence and sense of control, and spend time with others and feel supported by them.

This article has been adapted from the MND Australia factsheet 'Physical Activity and MND'. For more information, visit <https://www.mndaustralia.org.au/mnd-connect/information-resources/physical-activity-and-mnd> (or scan the QR code on the right), contact your local MND State Association or call the MND Info Line on 1800 777 175.

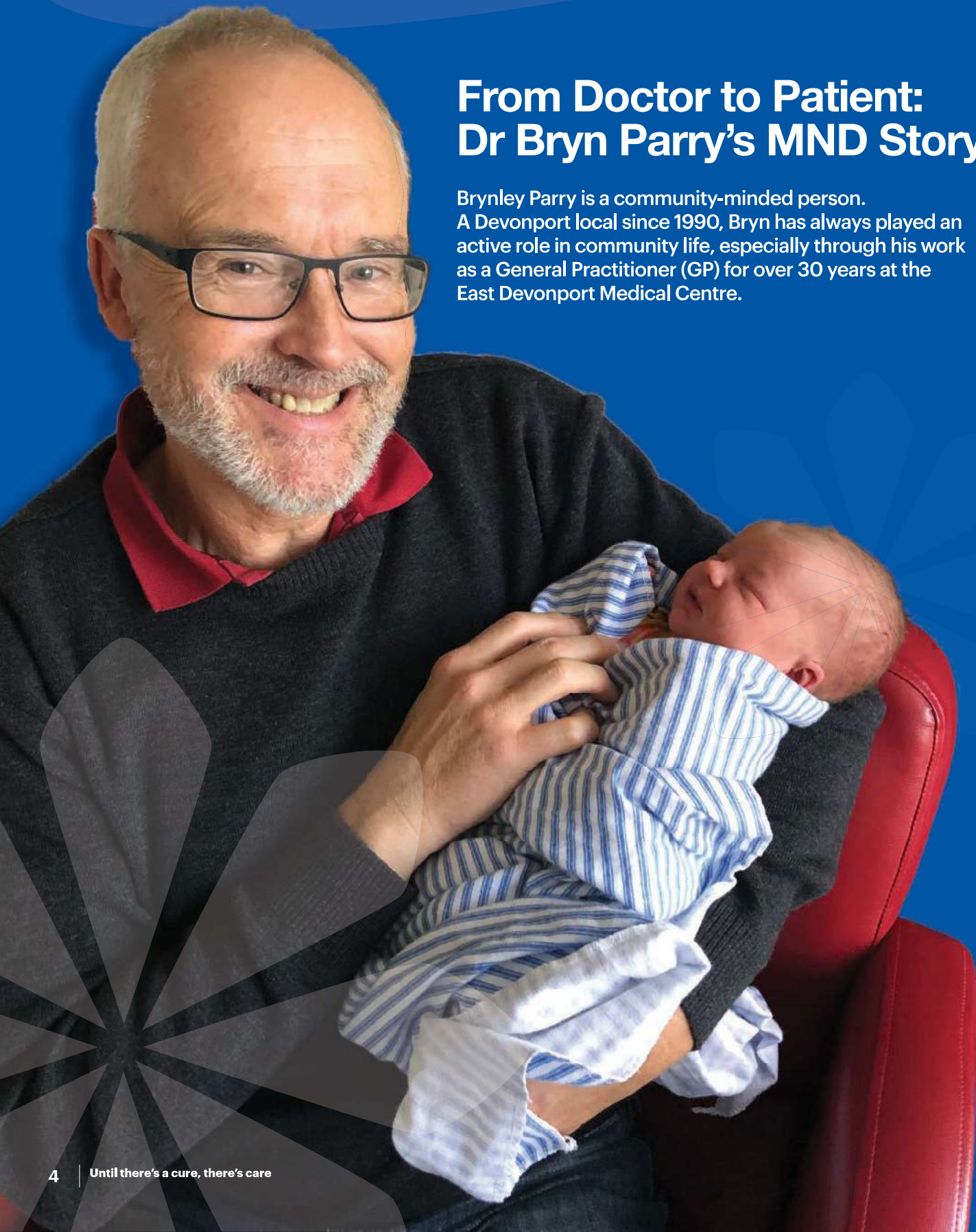


# PERSONAL STORY

---

## From Doctor to Patient: Dr Bryn Parry's MND Story

Brynley Parry is a community-minded person. A Devonport local since 1990, Bryn has always played an active role in community life, especially through his work as a General Practitioner (GP) for over 30 years at the East Devonport Medical Centre.



Like all other Australians living with MND, Bryn receives services from his local MND Association. Please contact your local State Association for more details on the services they provide.



Bryn and his wife, Clare, had not planned to settle in Devonport, but the longer they stayed, the more they felt it was a great place to bring up children and raise a family. Dedicated to his community as well, Bryn signed on as a Partner at the East Devonport Medical Centre in 1992. This was the same day their first son, Lucas, was born. Their next son, David, soon followed and then sixteen years later, their daughter, Myf, was born, completing their family.

During his career, Bryn had only encountered one patient with motor neurone disease (MND). In early 2020, he first started to notice his right foot was dragging when he jogged, but MND was not something that had really crossed his mind. By April, this slight drag was enough to get caught on uneven surfaces, and Bryn fell over a traffic hump when running down to the pool with Myf. It was then that he realised this developing foot drop was not going away and decided to investigate what was going on.

It can often take a long time to get a confirmed diagnosis of MND. For Bryn, it was no different and the impacts of COVID-19 only prolonged the process. His doctor referred him for a nerve conduction study, which was where the delay started. "There is a lack of availability of nerve conduction studies as Tassie, at least in the North, has been reliant on fly-in neurologists to perform nerve conduction studies."

By June, diagnostic progress was still at a halt and his right leg was continually weakening. Being a proactive GP, Bryn referred himself to see a Sports Medicine Physician who specialises in feet and a Neurosurgeon in Hobart. They then referred him for a number of tests to investigate the cause of his symptoms. Although Bryn was not in pain, the results indicated that it was nerve related. He was encouraged to start advocating for himself and push to get the nerve conduction study done.

"It's funny because I was used to advocating for my patients, but it hadn't occurred to me that I should jump up and down on my own behalf. It was interesting as a doctor, having the experience from the opposite side."

Bryn eventually had his nerve conduction study done through the Launceston General Hospital in July, which was then followed by a lumbar puncture. "By the time I had the lumbar puncture and all the results, it was another seven weeks before the formal diagnosis. The diagnosis didn't happen until late September."

He does not see the date he was officially told he had MND as anything in particular. "It was almost just like another day. I think I had virtually accepted that that was going to be the

diagnosis by then. We'd eliminated everything else. Perhaps that was one of the advantages of such a drawn-out process."

One of the hardest things for Bryn was learning of the prognosis of the disease. Typically, the average person lives with MND for 27 months, and that news left him dismayed.

"My son Lucas is actually a GP, so he's well aware of what MND is. When I told my second son [David], I watered it down a bit. I didn't want to shock him. He and his wife were living in Melbourne at the time and within 24 hours he'd phoned to say they were moving back to Tassie. It was a real shock and surprise, but I realised that Lucas has been in his ear telling him about the prognosis of MND."

Myf was only 12 years old when Bryn was diagnosed, so he and Clare gave her the "PG version" of his diagnosis. "We didn't really want to confront Myf with that information, but it was inevitable that she must now have had some idea about it. Our main emphasis has been to try and keep things as smooth, even and normal for her for as long as we can."

Bryn is very thankful for the care and support he has received from MND Tasmania. His MND Advisor and Support Coordinator, Emma Forsyth, has been very helpful every step of the way, personalising everything for Bryn to ensure that all of his needs are being met.

"When you're battling with this illness and coming to terms with a life-limiting prognosis, you don't want to be spending the time you have left in some sort of bureaucratic maze. The service that MND Tasmania offer really converts what could be a terribly difficult, stressful, miserable time into something that is more like it should be – a positive, helpful step. I can't imagine how much more difficult it would have been without them."

Bryn is not letting his diagnosis get in the way of giving back to his community - he is currently a Board Member of the Mersey Colts Cricket Club and part of the Pastoral Leadership Group at the Lifeway Baptist Church. This is his way of supporting the "good people doing good things in the community."

"While it can be difficult on a day-to-day basis to stay positive, one of the big things to remember is that the mind is still able to function. I'm just working on maintaining the right attitude and approach to dealing with the ongoing challenge of MND."

# MND RESEARCH



To learn more, visit [www.mndaustralia.org.au/research](http://www.mndaustralia.org.au/research) or scan the QR code above.

MND Research Australia (MNDRA) supports high-quality MND research to discover the causes, improve care, and find treatments and ultimately a cure for MND. They have recently revamped their website to make it even easier to keep up to date with the latest research information in MND.

## How to get involved with research

There are a number of **clinical trials** and **non-clinical research** currently happening all across Australia, and people living with MND may be eligible to take part in them.

A **clinical trial** tests new treatments and interventions in people to find out if they are safe and/or effective – you will need to speak to your neurologist first to assess your eligibility. **Non-clinical research** looks at other, non-medicinal factors – these are sometimes open to family members of those who have been affected by MND.

A full list of current clinical trials and non-clinical research opportunities can be found on MNDRA's website (see details above).

## Research news and updates

MNDRA are frequently uploading publications, updates and webinars on the latest advances in MND research in Australia and internationally to their website. These updates include:

- \* Advance – a biannual research newsletter, detailing the latest on MND research in Australia.
- \* State of Play Webinars. Developed in 2020 and set to return in 2022, these webinars are open to the whole MND community and are designed to provide an introduction to the advancements of the research community in Australia.
- \* International Research Update – produced quarterly.
- \* Updates from the International Alliance Scientific Advisory Council (SAC) - a centralised resource to review and provide a global perspective on scientific and biomedical announcements, information and opportunities relating to ALS/MND.

## MNDRA's research

Since 1987, MND Research Australia has funded over \$46 million in research grants. A number of these grants are funded by the State MND Associations through the generosity of their supporters and donors. A full list of the current recipients of Research Fellowships, Innovator Grants, MNDRA PhD Scholarship Top-up Grants and currently funded multiyear grants from previous years can be found on MNDRA's website (see details above).

## GLOBAL MND NEWS! A truly monumental day for MND research

The UK Government have announced that they will commit £50 million (AUD\$92.5 million) over five years into targeted motor neurone disease research.

The **United to End MND** campaign started two years ago, with a group of five people living with MND who were determined to accelerate research in the cause, treatments and ultimately a cure for MND. They joined forces with MND Scotland, MND Association, and My Name's Dottie Foundation, as well as leading researchers, neurologists and others living with MND, to call on the Government to fund a virtual centre of excellence for MND research, providing the infrastructure needed for accelerating treatments for MND.

Research into the cause, treatments and ultimately a cure for MND is a joint effort from the brightest minds right across the globe. This investment will accelerate the fantastic work already underway.





# MNDSA is calling on the SA Government to meet it halfway

The Motor Neurone Disease Association of South Australia (MNDSA) is calling on the next South Australian Government to 'meet us halfway' by funding at least 50% of our services. To this end, we have distributed our SA Election 2022 Priorities paper to all politicians across South Australia and we encourage you to support us by writing to your local Member.

Most South Australians diagnosed with MND are shocked to learn that they will be almost entirely reliant on a private charity to meet their ever-increasing needs as the disease takes its toll. As the disease progresses, people living with MND require an increasing and evolving range of services and equipment, and most are dependent on MNDSA's support for this.

We know that when it comes to health there are lobby groups that are louder and diseases which get more publicity, but there is no group more in need of support than South Australians suffering from MND.

As a State, we cannot allow a situation to continue whereby the quality of support for people with MND is contingent on the outcome of raffles and other fundraising endeavours.

If the government met us halfway, it would drastically reduce the MND community's very risky reliance on philanthropy. Caring for people with MND should be a public/private partnership, as it is in other states across Australia.

MNDSA's fundraising efforts have been significantly affected by COVID, and the organisation is calling on the next South Australian Government to provide funding to cover half of its expenses in delivering the services that South Australians with MND rely on every day.

Older people diagnosed with MND are particularly vulnerable.

Almost two-thirds of our clients are over 65 when diagnosed, which means they cannot access NDIS funding. The provision of equipment and assistive technology through MNDSA makes it possible for them to remain at home with their loved ones and retain some semblance of independence.

MNDSA is also appealing to all parties to commit to the provision of adequate committed funding to ensure the future of South Australia's only state-wide MND clinic at Flinders Medical Centre.

Relying on the generosity of South Australians to fund our work through fundraising efforts, MNDSA will continue to advocate for all South Australians suffering from this insidious disease because until there's a cure, there's care.

**Please write to your local MP to show your support.**



# UPCOMING EVENTS



## Flinders Ranges Trek Challenge Event

Join the MNDSA Flinders Ranges Trek 2022 and share the adventure with a group of people who share a common bond. Through your fundraising and physical efforts, every dollar donated will help provide and promote the best possible care and support for people living with MND in SA.

As part of this incredible adventure, over five days, you'll experience the history and majesty of one of the world's oldest, unchanged landscapes. You'll explore some of the most visually stunning scenery in Australia, immersed in the dramatic beauty of high ochre ridges, deep gorges and watercourses lined with river red gums.

Arriving back in Adelaide, you'll feel tired, yet inspired by your team's effort to support MND South Australia's life-changing services and fund research into the cause, cure and treatment of MND. From conquering fundraising to conquering the Flinders Ranges,

you'll be supported every step of the way by MNDSA, fundraising coaches and travel experts. Are you up to the challenge?

Just call MNDSA 08 8234 8448 or register your interest at: <https://events.inspiredadventures.com.au/events/mndsa-flindersranges-2022/> or scan the QR code above.



**EARLYBIRD TICKETS NOW AVAILABLE! The MNDSA 2022 Walk to D'Feet MND will be held on Sunday 1st May 2022, at Pinky Flat, War Memorial Drive, North Adelaide.**

This is the most loved event on the MNDSA Calendar and is suitable for all ages - everyone's welcome. We have people walking and people wheeling, many accompanied by their four-legged companions along the picturesque Torrens River pathway, alive with birdlife and adorned with native flora.

The day starts at 9 am with food and drinks available, and a chance to catch up with other members of the MNDSA Community, MNDSA Board, management and staff. At 10 am, the live entertainment starts, and special guests address the crowd. At 11 am, the walkers and wheelers head off along the beautiful Torrens River walkway.

As the crowd return, the sausages will be sizzling and the live band playing. A great time to sit and relax, enjoy refreshments and entertainment, and be part of our amazing MNDSA Community.

Register now at <https://my.mndsa.org.au/events/21/the-2022-mndsa-walk-to-dfeet-mnd> or scan the QR code on the right.



# GIVING



## MNDSA Christmas Appeal 2021 - Graham Johnson's Story

### Can you give someone the gift of time this Christmas?

Graham is a devoted family man – the loving husband of Barb, father of Kellie and Rebecca, and adored Poppa to his precious grandson Hunter with whom he spends a great deal of time.

Graham was diagnosed with MND on 30th August 2019, when Hunter was just 6 months old, and he is infinitely aware of the heartbreaking reality of the situation.

"I am unlikely to see Hunter on his first day of school or watch him grow up, and this is what hurts me the most".

MND is a terminal illness. There is no remission and the average time from diagnosis to death is only 2.5 years.

Graham's biggest goal following diagnosis is to spend quality time with his loved ones.

At MNDSA, we know that, ultimately, we provide our clients with the gift of quality time. We provide them with practical, physical and psychological support – a means for them, their carers and family to navigate their way through each day as easily and simply as possible so that they can spend as much time as possible with their loved ones.

"MNDSA is a tremendous help to me and keep me positive. I would be struggling without their help, and I would not be where I am at the moment without them," Graham reflects.

Your gift of a donation will help us to give our clients the care and support that anyone with this awful disease so rightfully deserves. Help us give them the gift of time - a quality of life, in the setting of their own choice.

Visit <https://www.facebook.com/barbara.johnson.7796/videos/152870976956441> to watch Graham's story.

To donate to MND South Australia, visit <https://my.mnlsa.org.au/campaign/4/mnlsa-christmas-tax-appeal-2021> or scan the QR code below.



# MNDSA CLIENT SERVICES



People living with MND, and their carers and families, may access a range of services and supports from MND SA including:

- \* Support and care coordination for clients and families, including referral to other services
- \* Information and advice about MND
- \* Occupational therapy assessment and support
- \* Provision of equipment and assistive technology

## Support and Care Co-ordination

MNDSA Support Coordinators are qualified health and community practitioners, working exclusively with people affected by MND. They are a key point of contact and provide information, support and coordination for clients and families.

MNDSA is a registered NDIS provider and recently passed our midway audit with flying colours!

Our Support Coordinators will assist eligible clients to access the NDIS. During this period before the client is funded by the NDIS, MNDSA devotes significant resources to help clients firstly gain access to the NDIS, and then get their best possible first support plan. Once the client has a funded NDIS support plan, these normally include support coordination and other specialist supports such as Occupational Therapy, and each person can choose MNDSA to provide these services longer term and help them implement the plan.

For older people with MND living in the Riverland, Yorke and Barossa regions, MNDSA is funded to provide specialist support coordination, allied health and therapy services under the Commonwealth Home Support Programme (CHSP). For other people who may be accessing or waiting for a Home Care Package, MNDSA staff can provide a limited amount of support coordination, along with access to our specialist services such as OT and equipment.

MNDSA is a not-for-profit organisation, and we rely on donations, bequests, grants and fundraising to continue our vital support services for people waiting to access the NDIS or Aged Care systems.



If you need any assistance please call us on 8234 8448 or email [supportservices@mndsa.org.au](mailto:supportservices@mndsa.org.au).



### MND SOUTH AUSTRALIA

66 Hughes Street,  
Mile End, SA 5031 Australia

Phone: (08) 8234 8448  
Freecall: 1800 777 175

-  [admin@mndsa.org.au](mailto:admin@mndsa.org.au)
-  [www.mndsa.org.au](http://www.mndsa.org.au)
-  [www.facebook.com/mndsa](https://www.facebook.com/mndsa)
-  [www.twitter.com/sa\\_mnd](https://www.twitter.com/sa_mnd)
-  [www.instagram.com/mnd\\_sa](https://www.instagram.com/mnd_sa)
-  [www.linkedin.com/company/mnd-south-australia](https://www.linkedin.com/company/mnd-south-australia)