

MNDnews

The newsletter of the Motor Neurone Disease Association of South Australia



**IT'S NO SECRET,
WE HAVE GREAT
SUPPORTERS**

mnd 
South Australia

Until there's a cure, there's care

MESSAGE FROM THE CEO



Right: Karen Percival, CEO

We remain infinitely aware of the limitations that COVID-19 have brought to our lives. We complain about not being able to go on holiday, throw big parties, or attend sporting events, but for those affected by MND, the implications are genuinely tragic.

It's one thing not being able to tick items off a bucket list, but for many of our clients who are living with a cruel, terminal disease, the past 18 months have meant that they can't even have a coffee catch up with family and friends. It certainly puts things into perspective.

The impact of an MND diagnosis is felt by so many, but it should help all of us to remember the importance of taking time to focus on the things we can do, and be grateful for every day, a sentiment so beautifully shared by radio personality Mel Dzelde who shares her story in this issue. Despite being diagnosed with terminal cancer and now also MND, Mel is living each day to the full with the support of MNDSA.

At MNDSA we have spent the last 18 months adapting our services to meet changing rules and regulations and to working out how we can continue to provide the supports our community so desperately need.

We could not have achieved what we have without the tremendous support from Masonic Charities SA & NT whom we were finally able to host at our premises last month as detailed on Page 2.

Following this event we have also launched our new Partnerships Program which is outlined on Page 9.

Fundraising during COVID has been extremely challenging. We have seen a rise in demand for our services due to COVID restrictions, and this has placed pressure on our resources at a time when our ability to fundraise has also been significantly affected.

We had to reschedule our Gala Dinner twice and delay our "Walk to D'Feet MND" in 2020. We simply cannot ignore the \$200,000 that we hope to raise through holding these events, as it funds our client service staff for the over 65's.

You will see in this edition that we are launching new events and we hope that our community will support our new fundraising efforts. Please help us to continue supporting people living with MND.

I would like to acknowledge the generous support of Dawn Owen's family who featured in our Tax Appeal in the last edition. Dawn sadly lost her battle with MND whilst the Appeal was underway. The family not only supported us in continuing with the Appeal but were also generous donors, helping us achieve our target of \$25,000. We cannot thank them enough and are thinking of all the family over this difficult time.

We are still committed to growing our service offering and are working furiously to raise the funds we need to do that. Know that any contribution you give us goes a long way towards helping us achieve our mission.

Until there's a cure, people with MND need care right now. Help us to deliver it.

**Karen Percival ,
CEO**



Until there's a cure, there's care

MND SOUTH AUSTRALIA SAYS THANK YOU

New Staff Member

Meet the new addition to our team!

Peter Smith – Warehouse Officer

Peter has a passion for 'making a difference' in people's lives, having previously worked in operations and logistics roles over many years with St Vincent de Paul Society, Oxfam Australia Trading, and Domiciliary Equipment Services. Peter has enjoyed his first few months with MNDSA and is looking forward to supporting the team, utilising his skills and experience servicing the equipment needs of our clients.



Community Fundraising From Mel Laycock

On Sunday 22nd August, I ran 21kms ... crazy – yes – especially with a running injury and being WELL out of fitness!! Earlier this year, I determined I would commit to running at the Adelaide Marathon to raise funds for the vital work of MND South Australia. My dear friend's mum, Dawn, had been fighting this terrible disease for 2 years, and I had seen the progressive challenges for her and her loved ones. Sadly, Dawn passed away on 21st June 2021. I was more determined than ever to make this run count. I feel so blessed that I was able to raise \$1,265, and am thankful to those who supported the journey. MND has no cure. These funds will go to much-needed research and support to affected individuals and their families. I felt incredibly proud to #RunforDawn.



Nic's Facebook Birthday Fundraiser

Allow me to introduce myself, my name is Nic and I have been approached by MNDSA to share my experience with running a fundraiser on Facebook.

Every year, generally a week out from one's birthday, Facebook will send out a prompt to consider creating a fundraiser for your birthday. It is an opportunity to raise funds and awareness for your chosen charity. This year, with my friend being recently diagnosed with MND, I felt compelled to create a fundraiser for MNDSA.

After doing some research I discovered that:

- * Facebook takes care of all processing and administration costs; this helps the chosen charity to free up their time, to focus on what they do best.
- * All donations of \$2.00 and more are tax-deductible. Facebook automatically issues a receipt via email.
- * All donations are traceable, allowing the donor to see when their funds will be received by the charity.

My experience with fundraising on social media has been largely positive.

- * I have been able to promote the fundraiser across all of my social media profiles: LinkedIn, Facebook, and Instagram.
- * Any post I create on Instagram can instantly be shared to Facebook. This enables me to be more productive with the little spare time I have.
- * One of the challenges I have faced is the lack of ease to donate without having a Facebook profile, or the ability to donate anonymously. To help overcome this, I created a second page. This time on the MNDSA website, and promoted that page on my fundraiser.

MNDSA has asked me if I would encourage others to create their own fundraiser via Facebook. My answer: a resounding yes!

You never know who may need your help. One share can lead to someone you may not know gaining the assistance and help from the resource they didn't know existed.



MND SOUTH AUSTRALIA SAYS THANK YOU

Masonic Charities SA & NT

We finally managed to have our official handover event on 30th August 2021.

Masonic Charities, the major philanthropic arm of Freemasonry in South Australia and the Northern Territory, provided a grant of more than \$228,000 to MNDSA, funding our expansion to a purpose-fitted facility at Mile End.

The funding helped MNDSA expand from our cramped two-roomed office suite, with low IT functionality, to a new self-sufficient centre of excellence. The new premises provide ample office space for MND clients, carers, and families to meet for support from health professionals, and each other, comfortably, privately, and with dignity.

An on-site warehouse has allowed for all equipment to be consolidated from three off-site storage facilities to one location. A custom vehicle has been secured to deliver critical equipment and devices directly from the warehouse to people living with MND, and the upgrading of IT has been funded for online patient records, asset management, telehealth, e-learning, online fundraising, and e-commerce.

David Booker, the Grand Master of the Freemasons of South Australia and the Northern Territory, said he was extremely pleased the Freemasons were able to support the work being carried out by MNDSA.

"MNDSA rely on donations to remain viable and work to their mantra of, 'until there is a cure, there is care'. Our organisation is pleased to show our respect to MNDSA in this tangible way, to assist in the caring of those who are victims of this cruel disease, for which there is no effective treatment or cure," Mr Booker said.

"Freemasonry is many centuries old and its members join together in an association focused on brotherly love, relief, and truth. These are the principal tenets of Freemasonry and have much in common with MNDSA's mission to support a community that has nowhere else to turn to."

MNDSA simply could not support our community without business partners. Thank you Freemasons SA & NT.



Ryan Petrusevics

Ryan Petrusevics, Year 12 student of Nazareth Catholic College, chose MND for his "Health Task" assignment, a very important project that is graded by SACE. Having lost a family member to the disease, he wanted to explore more about research and support for people affected by MND in Australia, and he also wanted to raise funds for MNDSA to show his support for all that we do. Ryan visited us following his Ice Bucket Challenge, and we were thrilled to give him a tour of our warehouse and equipment to indicate what donations such as his would be used for.

A BIG THANKS Ryan - it was our pleasure to meet you, and you raised \$387.90 with your Ice Bucket Challenge and MNDSA online fundraising page. Your thoughtfulness and passion really touched our hearts.



Sunrise Christian School

Sunrise Christian School (Paradise) held a fundraising event for MNDSA recently and, with the help of an Icy "Dunk Day" challenge for the teachers, raised \$1,900. Their special guest speaker, Greg Downton, shared his MND journey openly and honestly with the students, staff, and wider school community, and told how his faith has played a bigger part than ever before in this chapter of his life. A big thanks to all concerned for their contribution to this very special day which everyone will remember for a very long time to come.



TelethonSA 2021

MNDSA were thrilled to be chosen as 1 of 12 charities of choice for TelethonSA 2021. A mighty \$12,634 was raised via electronic and hard copy ticket sales; a big thank you to all who participated in purchasing and/or selling them. A big shout out to our community in Kadina, (especially Neil David), who always get behind this lottery. Finally, a special thank you to Robbie at TelethonSA for her assistance throughout the campaign.



PERSONAL STORY

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



Mel Dee Dzelde

My MND diagnosis came in January 2021 after already being in a fight for my life for four years. In 2017, I was diagnosed with stage IV rectal cancer, with secondaries in my liver.

Since my cancer diagnosis, I've had multiple operations, weeks of radiotherapy, and multiple rounds of chemotherapy. 2020 meant a year of doing round after round of chemo and, with each round, I became weaker and less tolerant of the treatment. As I'd done chemo before in previous years, my oncologist wasn't sure why it seemed to hit me harder than before. I had to give up my beloved radio career, and my dropped foot that started in November 2019 was also becoming more noticeable and more of a problem. This sinister symptom, initially thought to be a side-effect of the chemo, was my first sign that MND was about to be added to my list of health challenges.

Like many, it seemed to take ages and multiple visits to doctors and specialists before two neurologists confirmed what felt for me the most unfathomable diagnosis. Even when confirming the news to me, my neurologist said, "I can't believe I have to tell you that you have MND and cancer!" It all felt so unreal.

I remember feeling completely numb at first. I knew that I needed all of my strength to stay strong and fight this new disease, but I was already weakened beyond comprehension.

Fortunately, I have a very strong mind and I'm surrounded by love and support. I quickly snapped back into a way of being that had helped me through four gruelling years of cancer treatments, and got back to the business of healing.

My belief in the power of positivity and keeping my vibration high is how I stay happy and grateful. I honestly wake up every day feeling so blessed for all that I have and for all that I am. Having two terminal illnesses keeps me focused on the now. I don't project and I don't allow others to talk about what my future may hold. I honestly believe that there's not

a soul on this planet who knows what's ahead for me. If I'd listened to my initial prognosis in 2017, I wouldn't be here today.

Surrounding yourself with support is extremely important and that's where MND South Australia have been amazing. Whilst I don't look ahead in a gloomy way, I'm still aware that I need to put things in place to make my life easier for me and my loving husband, Chris. The team at MNDSA have been wonderful in helping me with equipment and advice. Just having a kind understanding voice on the other side of the phone has also been such a relief as the disease has progressed.

MNDSA have also supported me in continuing with my life's dreams. I wrote a children's book last year and have published it this year. It's a bright, beautiful book called 'Azzurra', encouraging children to find their "Inner Dragon" to help them when facing life's challenges.

I'm also very passionate about raising awareness of MND. I was initially shocked at how little most people knew about the disease. Since my diagnosis, I've spoken about the need for more funding and awareness on radio and TV. With my media background, I would like to contribute more in this way.

Having MND isn't something I would ever choose or want, but there are still blessings to be found in every experience, including this one. I'm more grateful for each day. I'm careful to fill my precious time with people and things that I love and which give me joy. Plus, because I believe I have a duty to myself and others to stay positive and not allow fear to change who I am, my time is now so much happier and more on-purpose than it's ever been.

In these COVID times, we've all learnt to pivot. For those of us with a terminal illness - or two - we've been doing this all along. Life is meant to be lived fully and attitude is really the key to making sure that happens.

LIVING BETTER

Caring for your Mental Health

Being diagnosed with motor neurone disease (MND) can be devastating, and managing emotions can become hard

Living with a life limiting illness, and having the daily challenges that come from increasing physical disability, can cause stress and other concerns. Maintaining connections with family and others might get difficult too. Your emotions and moods, general state of mind, and relationships with others, are all important. There are, however, positive ways to deal with emotions and your overall wellbeing.

Doing things each day to look after you can make a positive difference to your mental health and living with MND. Being proactive in exploring MND management options, and looking after your mental health, can have a large impact on your physical health and how you feel each day.

Getting plenty of rest when you can, building on the things which you enjoy, and other strategies, can help make you feel more relaxed and able to deal with MND. Talking with mental health professionals may be a useful source of support as well.

By doing your best to look after yourself, you're likely to feel a greater sense of control, and lift your moods. You're also more likely to enjoy time with others, your interests, and other things important to you.

Who can help?

Not everybody wants to talk about what they are going through. While people living with MND have some things in common, they also have very different experiences of the disease. There is no 'right' way of dealing with MND. Some things you feel and do with MND, however, may be signs that you might benefit from some extra support. These things can include:

- * panic attacks (extreme anxiety and strong physical sensations of fear)
- * persistent irritability
- * problems concentrating
- * being easily distracted
- * persistently avoiding other people
- * angry outbursts
- * difficulty accepting and/or adjusting to the diagnosis and disease related changes
- * persistent sadness
- * persistent feelings of being overwhelmed
- * when feelings interfere with ability to carry out usual activities
- * avoidance of usual activities and connections

These responses are understandable and can be a common reaction to the situation you are experiencing, but the behaviours can have a negative impact on you and those around you. You may find it helps to talk to people who you know and trust about how you feel. It is not always easy to do this, but seeking support is a great first step to feeling better.

If you are finding it hard to talk to people close to you, it may help for you to talk to someone more distant about what's going on, such as:

- * your doctor
- * your MND Association Advisor or Support Coordinator
- * a mental health professional (e.g. counsellor or psychologist)
- * others going through similar experiences (people at support groups for example)

People with MND have individual support needs rather than 'a one size fits all'. Your local MND Association Advisor or Support Coordinator will be able to guide you towards the support you need.

This article has been adapted from the MND Australia webpage 'Caring for your mental health'. To view the entire resource, visit www.mndaustralia.org.au/mnd-connect/living-with-mnd/caring-for-your-mental-health or scan the QR code on the right.





Tips to help care for your mental health

- * **Start slow and small:** when making changes to how you look after your mental health, it can help to change one thing at a time.
- * **Find ways to work around challenges:** living with MND can be a challenge, but you're likely to be already finding ways to adapt and live with the disease, and there are things you can do to manage new or extra challenges if they arise.
- * **Relaxation:** doing things that you enjoy and find relaxing can lift your mood, such as listening to music.
- * **Managing sleep as best you can:** sleeping well is important for managing emotions and wellbeing. However, sleeping with MND can become difficult, so talk to your health care team so that they can support you and work to improve the particular issues that are impacting your sleep.
- * **Stay connected:** try to keep enjoying and maintaining your relationships with your family, friends, and others in your social circle who matter.
- * **Keep active:** with MND, it becomes harder to physically move, but that doesn't mean that you can't find ways of being active that work for you. Don't forget to speak with your OT or physiotherapist if you need some assistance with being active.
- * **Keep learning:** learning new things, or learning how to do usual activities another way, can help you gain confidence and feelings of satisfaction and achievement. Learning may also provide a greater sense of purpose and give you an improved ability to get the most out of life.

Important things to remember

- * Be kind to yourself. Everyone is different and there is no right or wrong way to feel.
- * Feeling overwhelmed is not about being weak, it is about being human.
- * It may take a little while to find a person who you feel comfortable to talk with, but don't give up. It is okay to see different professionals until you find the right person for you. Some psychology service's websites have a section with short biographies of their practitioners which can help guide you in deciding who may be the best person for you to see.
- * Others in your family may be feeling the same way.
- * Others in your family may not understand the changes they see in you, so it may be useful to explain to them what is happening to you.

MND RESEARCH



Exploring the impact of communication and cognition on healthcare involvement and decision making in MND

Communication and cognitive impairments are known to negatively impact health outcomes generally. Also, they are recognised as barriers to shared healthcare decision making. Shared decision making involves patients, their families and healthcare professionals sharing information and knowledge so that decisions and choices match with patients' values and preferences. This process highlights the importance of everyone working together to facilitate tailored management of MND symptoms and to maximise quality of life. People affected by MND (that is, people living with MND as well as family members and carers) face changing needs as the disease progresses and this can impact decision making^[1]. Decision making in MND has been described as an ongoing cycle because people need to react and adapt to ongoing change^[2].

In this study, 19 people living with MND and 15 family members were interviewed one to three times. Participants were asked to describe their experiences of making healthcare decisions. They were also asked how changes in their speech, communication, or thinking skills changed the way they were doing things or changed the way they interacted with healthcare professionals.

The main theme identified in this study was communicating takes effort. This encapsulates the effort required by people living with MND to cope with symptoms or circumnavigate impairments, the effort family members provide in support, and the effort healthcare professionals make to accommodate for changes in communication abilities.

People living with MND described how slurred speech, respiratory weakness, and fatigue makes talking so effortful they sometimes avoid it. This means they ask healthcare professionals fewer questions, provide short answers, or do not fully express their opinions. People reliant on communication aids (e.g. email, writing or eyegaze technology) recognised it was time-consuming which sometimes presented problems in busy clinical environments. People who used communication aids reported frustration if others second-guessed their responses: especially if it was incorrect. People living with MND whose speech was difficult to understand, used the National Relay Service, email, and text messaging to manage healthcare appointments independently.

The support provided by family members was essential for many people living with a communication and/or cognitive

impairment. Examples of practical support for communication tasks included answering the phone, managing medical and clinic appointments, filling out forms, and liaising with community disability support services. People who used communication devices often needed family to set up devices and show staff how to use them. Examples of emotional support were: being present in clinical appointments, providing personally relevant information, and encouraging the implementation or use of high-tech communication devices.

Participants in this study described many ways healthcare professionals adjusted their practice to accommodate a communication impairment. Examples provided were allowing extra time, conducting joint sessions with another clinician, and using email instead of telephone. Without this support, involvement in healthcare appointments would have been reduced. Some participants described occasions where support wasn't provided which negatively impacted their input in decision making.

Being able to explain MND-specific care needs was imperative and it caused anxiety for some participants to have new paid carers or nursing staff unfamiliar with MND. Being able to communicate to facilitate 'difficult conversations' meant that some participants completed medical-legal issues (e.g. documenting Powers of Attorney or Advanced Care Plans) whilst communication skills were intact. Others, however, stated that the onset of communication impairment would be the trigger to start planning.

To summarise, this study shows the considerable effort people living with MND and their carers undertake to maintain or maximise their involvement in healthcare. Much of this effort is largely 'invisible' activity because it occurs outside of medical or healthcare appointments. Despite the effort, healthcare involvement and communication can be compromised. Healthcare professionals and health services can make accommodations or adjustments to minimise any impediment to involvement in healthcare decision-making for people living with MND and their families. These results demonstrate that communication is everyone's business.

Camille Paynter, B.SpPath (Hons)

PhD Candidate, The University of Melbourne

NHMRC/MNDRA Postgraduate Scholarship

References:

1. Hogden, A., et al., Development of a model to guide decision making in amyotrophic lateral sclerosis multidisciplinary care. *Health Expectations*, 2015. 18(5): p. 1769-1782.
2. King, S.J., M.M. Duke, and B.A. O'Connor, Living with amyotrophic lateral sclerosis/motor neurone disease (ALS/MND): decision-making about 'ongoing change and adaptation'. *Journal of Clinical Nursing*, 2009. 18(5): p. 745-754.

UPCOMING EVENTS



Flinders Ranges Trek Challenge Event

Join MND South Australia's "Flinders Ranges Trek" to help provide and promote the best possible care and support for people living with MND.

As part of this incredible adventure, you'll discover the history and majesty of South Australia's Flinders Ranges. Traversing this 600-million-year-old landscape, you'll trek through magnificent river red gum woodland in the shadow of rugged peaks, into rocky gorges, past pastoral ruins, and beside lush, natural watering holes. As each day comes to an end, you'll watch the awe-inspiring landscape change from deep browns to brilliant ochre-orange as the sun sinks behind the horizon to reveal a million-star night sky.

Best of all, with every step you take, you'll raise vital funds for support services and research into the cause, cure and management of MND.

Highlights

- ✿ Explore the awe-inspiring Flinders Ranges
- ✿ Marvel at the rugged beauty of Wilpena Pound and Brachina Gorge
- ✿ Witness the oldest visible geology in the world and swim in Blinman Pools
- ✿ Raise vital funds to provide care and support to people living with MND

Fast facts

Destination: Flinders Ranges

Dates: 29 May – 2 June 2022

Challenge grade: 3/5

Registration fee: \$390 (non-refundable) Register before 5 October 2021 and get \$100 off your registration fee

Fundraising target: \$3,000

Travel package (subject to change): \$2,880 *land only*

Accommodation: Twin-share in 3-star lodge

Register now at: <https://events.inspiredadventures.com.au/events/mndsa-flindersranges-2022/> or scan the QR code on the below.



Glitz and Glamour Gala Dinner 2021

We are extremely disappointed to advise that, once again, we have had to cancel this year's MNDSA Glitz & Glamour Gala Dinner. This decision has not been taken lightly and has been made in consultation with stakeholders and ticket holders alike.

As you know, MNDSA rely solely on fundraising opportunities in order to continue and increase our much needed support, services and equipment to people living with MND in South Australia. In these COVID uncertain times, MNDSA is needed more than ever however we simply cannot put the health of our clients, supporters and staff at risk. Just when we think it's safe to host the event, we hear of another COVID scare and the potential for widespread infection in our communities. We feel that the safest and most responsible thing to do is to postpone the gala dinner indefinitely.

We have launched an on-line Xmas auction with some amazing prizes and experiences that would make great Christmas gifts – this can be accessed on app.galabid.com/mndsa2021

Thank you for your understanding and ongoing support.

“You, Me & MND”

Join us for our next “You, Me & MND” event, which will be held on Thursday 14th October at 11 am on ZOOM. The session will be about the **MNDSA Palliative Care Pathways Project with a demonstration presented by Tracey Watters.**

The Palliative Care Pathway was specifically developed for health care professionals to refer to from the time a client presents with symptoms.

We recommend that you join us for this session, then revisit later the topics that you would like more information on. We also recommend that you share the link with family and friends who would like more information on MND (more information on this project can be found on the outside back cover of this newsletter).

For details of upcoming sessions and to book, please visit: my.mndsa.org.au/events, scan the QR code below or call MNDSA on 08 8234 8448 for more information.



Lumary City-Bay 2021

You don't have to run or try and beat any records to become a Lumary City-Bay Fun Run Hero with us, “Team MNDSA”, on Sunday 7th November.

Walk or wheel (chair) with us on the 3km “walk” and we will give you a FREE WTD T-shirt and bandana when you reach your fundraising target of \$200*

Start your fundraising page here: my.mndsa.org.au/events/tickets/13/city-to-bay-2021 or scan the QR code on the right.

*Conditions apply



GIVING



Linking Arms – Growing Together!

MNDSA Launch New Partnerships Program

We all know the value of people working together to achieve a common outcome. At MNDSA, we have been exploring opportunities to further expand relationships with the South Australian public and the MNDSA Community.

As a result, we are excited to announce the official launch of our latest initiative – the MNDSA Partnerships Program.

PARTNER - We have identified the genuine desire of people wanting to support our work in providing products, services, and personal support for people living with MND, so we are developing a range of new Marketing, Media, and Promotional activities which can facilitate these potential partnerships. We have created a wonderful platform that the general community and businesses can now 'link arms' with, in order to create mutually beneficial partnerships.

SUPPORT - Our new MNDSA Partnerships Program provides several options and financial levels from which either individuals or businesses – no matter how small or large – can choose.

Each partnership level provides the opportunity for participants to increase their own brand awareness, engage with a wider South Australian audience, get involved in events, MNDSA media campaigns, and more!

CONNECT - The MNDSA Partnership Program has been designed to enhance the annual marketing plan of any business. It offers the perfect opportunity to showcase and support South Australian organisations and fulfil the genuine desire to represent in corporate social responsibility. The overall social impact created is an attractive value proposition for all involved.



If you are an individual or business owner who is looking to support a very worthy cause, then now is the time to speak with Jaynie Morris at MNDSA! Call Jaynie on 0449 886 788 for an initial conversation and let us tailor your new Community Partnership today!

MNDSA CLIENT SERVICES

Palliative Care Pathways Project

This project delivers an online tool to help medical professionals recognise and understand the journey of a person with MND. The resource stands to improve the lives of over 2,000 adults affected by MND in Australia at any one time.

This has been supported by funding from the SA Government's Palliative Care 2020 Grants Program and is promoted throughout the CountrySA Primary Health Network. MNDSA sincerely thanks everyone involved in the project for their support and encouragement, and for sharing their time and expertise.

While the GP and primary healthcare team may be able to meet some of the needs of the person with MND, a multidisciplinary approach to symptom management has been shown to improve the quality of life for patients, as well as survival, necessitating the input of other health and social care professionals.

The website - www.mndsapathway.com.au - is an easy-to-use digital tool to guide the GP step-by-step through information and treatment protocols, from presentation of first symptoms to bereavement. It provides MND-specific evidence, information, and consumer resources, setting out the processes for access to specialist care providers and



other supports including MNDSA, the statewide MND Clinic, and palliative care providers.

Culturally adapted information and resources developed for Aboriginal and non-English speaking consumers, and a series of short educative videos, have been developed to assist health care providers in the recognition of MND and provision of care.

At the project outset, we engaged Antikijirita woman, Natalie Austin from Coober Pedy, to co-design 'MND Explained' and create an artistic illustration to help sensitively communicate information about the motor neurone journey.

MNDSA Client Services Information and Advice about MND

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

MNDSA can provide information online, over the phone, and in printed materials to people affected by MND. We offer education support sessions for clients and their carers, as well as health and community professionals, in workplaces, and in schools to raise awareness about MND.



MND SOUTH AUSTRALIA

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