



TALKING MS: HOW JESS AND EMMA STARTED THE PODCAST 'RETHINK MS'

PLUS, MAKING EXERCISE A PART OF YOUR LIFE AND THE POWER OF CREATIVITY

# In this issue

# August 2021

# News

Meet Danielle	03
World-first multiple sclerosis global	03
image database launched	

# **Health & Wellbeing**

How to start exercising (and stick to it)	04
Talking MS: Podcasting with Jess and Emma	06
Chronic Illness and mental health	80
The power of creativity	10
10 minutes with musician and music coach, Jess Frick	12
The balancing act: living a balanced lifestyle	13
MS Community Corner: Managing cognitive symptoms of MS	14
Brain Booster (Sudoku)	14
Brograms and	

# Programs and Workshops

MS Peer Support	15
Weekly Exercise Programs	15

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# **Message from the CEO**

Over the past six months I have been meeting with and listening to people living with MS and thinking about the ways we are delivering services and communications to you.

I've been fortunate to visit various peer support groups over the last few months as well as to travel to the Northern Territory as part of the services our team provided in Darwin and Alice Springs in the past few months. The team has also been to Port Pirie, Port Lincoln and the Riverland. I want to ensure we continue to find ways to provide services to people living in regional areas.

We have also been busy behind the scenes developing a strategic plan for the next three years and I look forward to sharing more of that with you as the improvements that flow from that work start to become clearer.

We are focussed on finding ways to provide more and better supports to people living with MS from the initial diagnosis and throughout everyone's individual journey.

I'm very excited to work alongside you all as we take some important steps forward to strive towards our goal that every person living with MS is accessing the highest standard of services and support they need to live well.

Tim Ryan, Chief Executive Officer

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Northern Territory





We are so excited to welcome Danielle to the MS Society team as the General Manager of Client Services. Danielle will be leading our client services team to deliver services, care and support to people living with MS.

Here's a message from Danielle:

"I have always been passionate about making a difference in the lives of others and driven by my values of compassion, integrity, respect and client-based expertise. I'm looking forward to working within the MS Society SA & NT team to be part of the difference we can make together for people living with MS.

I trained as a social worker and have 16 years' experience within the human services sector, including 12 years in leadership roles across areas such as mental health, disability, trauma, domestic violence, homelessness, and drug and alcohol.

# Meet Danielle

General Manager, Client Services

I am a heart led person and have always been motivated and moved by people, their stories, their experiences and the way they navigate the significant challenges life throws at them.

In my first couple of months here at the MS Society, I have already been out meeting with clients in the north and south of Adelaide, I have travelled to Port Pirie and Port Lincoln for our Peer Mentoring Workshops and will soon be jumping into our hydrotherapy classes! I'm so excited for what is to come and have loved what has already begun.

Some of my favourite things to do in my spare time include spending time with the love of my life and my gorgeous boxer dog Layla, enjoying a nice glass of red, and going to a dance class.

I'm so looking forward to meeting many of you and working with the MS Society's Client Services team to support people living with MS." ■

# World-first multiple sclerosis global image database launched

The first global database of MRI scans of people with MS is now accessible to researchers worldwide, thanks to the work of the Brain and Mind Centre at University of Sydney, MS Base and the Sydney Neuroimaging Analysis Centre.

The new MSBase Imaging Repository will fast-track MS research, particularly in working towards earlier diagnosis and monitoring of MS disease progression.

You can learn more about the MSBase Imaging Repository at **msbir.sydney.edu.au** 





Have you been thinking about getting into exercise but just aren't sure where to start? Or is your MS fatigue making exercise too difficult? MS Physiotherapist, Margot Strelan discusses how to get into a new exercise routine without letting fatigue hold you back.

WITH MARGOT STRELAN, MS PHYSIOTHERAPIST

# How to start exercising (and stick to it)

#### **HOW CAN EXERCISE HELP?**

Studies show that exercise helps to reduce the impact of many common MS symptoms including fatigue, pain, balance, muscle weakness, and improved bladder and bowel function.

Regular exercise is also great for the mind and brain, not just the body. It can improve your mood, improve symptoms of anxiety and depression, and improve your brain's performance (brain health and cognitive function).

# WHAT IS THE BEST EXERCISE FOR PEOPLE WITH MS?

A combination of strength training, cardiovascular (cardio) and stretching is suggested for people with MS.

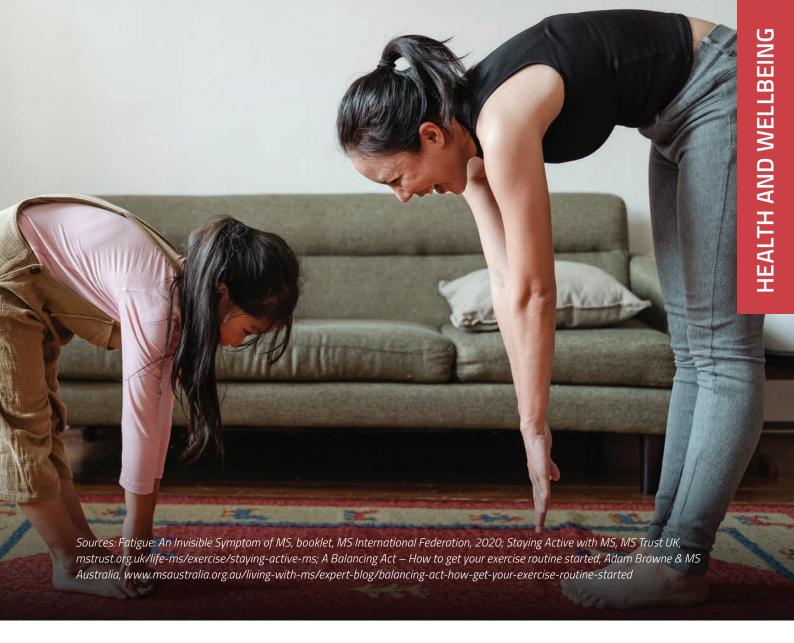
The most important thing is that you choose exercise activities that you enjoy, as you'll be more likely to stick with it!

# NEW OR RETURNING TO EXERCISE? HERE'S HOW TO GET STARTED:

Start by introducing shorter sessions of exercise of 10 to 15 minutes at a time, 2–3 times a week. Once you have a routine you can slowly start to increase the length of time you exercise for and/or the intensity by adding speed or resistance.

Here are some tips to help you get started:

- Set your intentions remind yourself why you want to start exercising and make it a priority.
- Set clear achievable goals for yourself and a reward for when you achieve your goal!
- If you have trouble committing to exercise, try booking to attend an exercise class or 1-on-1 classes with an exercise professional.
- Listen to music to get motivated.
- Exercise with a friend or family member.



- Track your progress with a smart watch or with a calendar/diary.
- Create a dedicated and welcoming space to exercise in your home.

# HOW CAN I MINIMISE FATIGUE DURING EXERCISE?

While it may seem counterproductive to wear yourself out with exercise if you experience fatigue, exercise actually helps to improve strength, fitness and mood, and stops muscles from losing strength over time (deconditioning). All these things improve your body's efficiency and help to manage fatigue in the short and long term.

However, it is possible to exercise too much, so exercise needs to be balanced with rest. Ensure you are getting enough sleep, managing stress and planning your day to take breaks as needed.

If you feel fatigued during or after exercise, you can experiment with the length of your workouts, alternate between different body parts to give them a chance to recharge and break up exercise into manageable chunks throughout the day.

If heat makes your fatigue worse, make sure you are hydrated and keep cool while exercising by sipping on cold water, exercising in a cool room and wearing cooling garments. Exercising in water can also help to regulate body temperature.

► A physiotherapist can help you come up with an exercise plan and reduce the impact of symptoms following a relapse.

Contact MS Assist on 1800 812 311 to book an appointment with an MS Physiotherapist.



Two women, with two very different lives, who came together because they had two big things in common: a multiple sclerosis diagnosis and a desire to help.

Jess is a 27-year-old, new mum diagnosed with MS in 2019 only months after giving birth to her daughter. Jess is studying and planning a career in disability support, specifically for people living with MS. Her goal is to be a life coach for others living with MS, a space to turn to for guidance in the overwhelming stages of a new diagnosis.

Emma is a clinical mid-wife, has two kids (11 and 7 years old) and is an avid runner having completed the London Marathon virtually last year and more recently her 100th Park Run. Symptoms like drop foot, fatigue and heat sensitivity can all threaten to get in the way of her running, but MS hasn't stopped her from reaching her goals.

The two met when they joined the MS Society's People Living with MS Committee with a desire to have an impact on the services and supports that people with MS have available to them. Soon they realised a shared passion to do something more to support young people and those newly diagnosed with MS.

And the podcast and social media platform, Rethink MS was born in February 2021. With over 400 followers in just eight months, Rethink MS is a platform for Jess and Emma to share their experiences and start conversations about the highs and lows of living with MS. They host fortnightly Facebook live podcasts where viewers can interact and join the conversation in real time or watch back later.

We asked Jess and Emma to tell us about Rethink MS and how the project has changed their lives...

#### WHY A PODCAST?

Jess: Being in my 20s a lot of MS-related supports and services unfortunately felt like they were tailored towards older people. Most people in their 20s, 30s and even 40s are on social media, so that seemed like a really great place to start advocating for not only myself but other people with MS.

**Emma:** We wanted to have something interactive. Originally, we were going to record and put it up as a traditional podcast, but we really wanted to put faces to it. So, we've gone with the Facebook streaming.

# WHAT IS THE AIM OF 'RETHINK MS'?

Jess: To spread awareness in all age groups, hopefully reaching and informing young people in our community, hopefully leading to a more inclusive community in the years to come. I want people with MS to know that doors do not close for them. I don't want people with MS to let fear stop them from achieving their goals and dreams.

**Emma:** We want to capture that good life ethos and what that is for you is unique. MS isn't going to get in the way; it might be different. We just want people to absolutely acknowledge that it's difficult, but you always have something that can help you get closer to your goal or meet your goal whatever your goal is.

# HOW HAS STARTING 'RETHINK MS' CHANGED YOUR LIFE?

Jess: I feel more empowered. I feel more motivated and positive about what I'm doing by sharing my experiences. My favourite part about it is probably during the live streams when we get people having really good flowing

conversation and sharing a range of different experiences and providing their strategies. Seeing people come together and help each other who have never ever spoken to each other before makes me feel like I'm on the right path and I'm doing something good for other people.

**Emma:** It gave me something really positive to work on and towards. I'm really proud of persevering with something, it's not always easy. It's really, really scary in a lot of ways to see people I don't know commenting on things that are really quite personal [to me], but I am so proud of it when someone tags the podcast and says they watched.

# WHAT ADVICE WOULD YOU GIVE TO SOMEONE WHO WANTS TO PURSUE THEIR OWN CREATIVE ENDEAVOUR OR SIDE BUSINESS?

Jess: If it's social media and an online journey that you want to go on, even if you're just using it as an outlet, don't hesitate. Just jump in and do it. While you may take a while to build up followers, even if you're sharing and five people are watching – that's five people that you're making a difference to support.

Emma: Having a creative outlet for dealing with MS has been amazing for me. I think that MS and running have taught me that the journey is just as important and even if you're not good at something, that's okay. Just dabble and see where your passion lies. If it doesn't work, it's a good reason to reach out for mentoring or peer support. There are forums and there are people who are dying to teach you.

Jess and Emma's stories and to check out the podcast, follow Rethink MS on Facebook and Instagram.



Living with a chronic condition is hard, but you can reduce its impact on your mental and emotional wellbeing. Do the daily challenges of living with MS make you feel sad or anxious? Know that you are not alone. Half of the people in Australia that live with a chronic health condition experience depression or anxiety, according to research conducted by SANE Australia, a national mental health charity.

PUBLISHED WITH THE PERMISSION OF JEAN HAILES FOR WOMEN'S HEALTH

A chronic condition can affect your lifestyle and your quality of life. But there are ways to reduce its impact on your emotional and mental wellbeing, says Tamara Cavenett, president of the Australian Psychological Society (APS).

#### **GRIEF FOR WHAT WE HAD**

First, it is important to understand the emotional fallout of living with a chronic condition. "We often get angry," says Ms Cavenett. "A lot of us experience grief for the life we had before. It is not uncommon to grieve the loss of your health, and yet it is something that people are most dismissive of."

"They might say, 'other people have it worse. I shouldn't feel this upset. But it [can have] a substantial effect on your work, your personal life and often, your financial life."

#### **EMOTIONAL PAIN**

As humans, we are driven to solve problems. "I need to figure out how to pay this bill — I will do 'X'," says Ms Cavenett. "The problem is quite different when it is a health issue that can be managed by you, but not controlled or fixed. Then it's a matter of learning to live with it. That's part of the reason we talk about it as grief.

"A lot of people ask, 'why me? What did I do to deserve this?' 'It's not fair' is the common thinking around it and that's understandable. You get a lot of anger, frustration and feelings of unfairness around it."

Ms Cavenett says she always urges her clients to acknowledge their feelings. It is important for them to know they can discuss how they feel with their health team, as well as family and friends. Emotional support is vital in making the best of the circumstances.

#### **COPING STRATEGIES**

Psychologists can help, as they can tailor coping strategies and tips to an individual client's needs, says Ms Cavenett. "We have proven strategies that will help you to change how you think, and that can change how you end up doing things," she says. "We often teach skills around relaxation, pain and anxiety management and stress reduction."

Pain, she explains, is influenced by anxiety and mood. She says there are things you can do to improve your mood and therefore lift your pain threshold.

"It's not about injuring yourself, but doing things in a concerted way," she explains. "It is not uncommon to grieve the loss of your health, and yet it is something that people are most dismissive of. You have to work with it. It's about modifying what you do and how you do it to take into account your health condition so that you get maximum quality of life and benefit from it."

"Sometimes it's about shifting the mindset and a psychologist can help with that."

Those who suffer with a chronic condition tend to isolate themselves, assuming others are not experiencing something similar. "It's important to manage your mental health to its best," says Ms Cavenett. "Sixty per cent of Australians with mental health conditions will have one or more chronic health conditions.

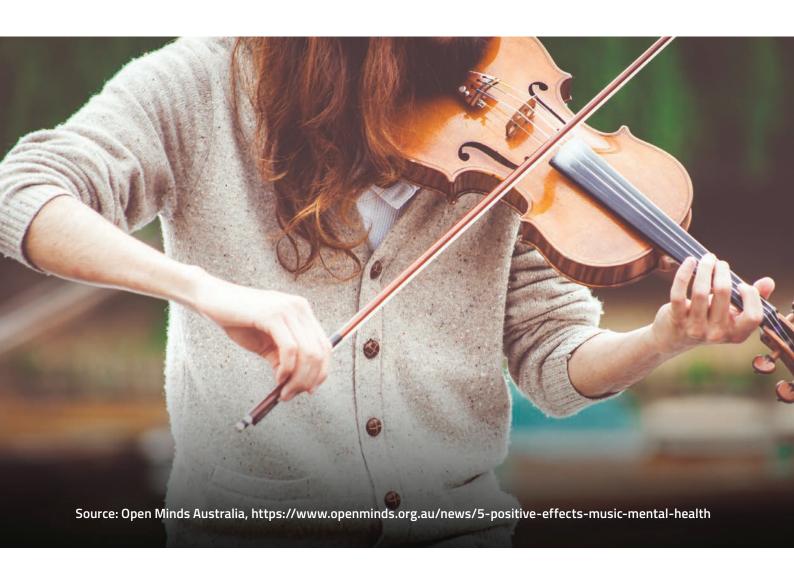
"Mental health is stigmatised. Our understanding of physical health is much better.

"It's important to work on both parts of the system. It's about living our best life with all of our health."

#### TIPS FOR COPING WITH A CHRONIC CONDITION

- Take good notes at your medical appointments. Get in control of the elements of your health condition.
   Learn about it to better manage it.
- It's about taking back control. The more information you have, the more you can work around it. You can jump back into the driver's seat and have a full and rich life.
- Pace what you do in terms of activity. While you may not be able to do the things you used to do, you adjust, creating a new way of living while managing your condition, still achieving what you want to in life.
- You are not alone in this. Get support.
   Find someone who can help you if you need it. That may be a psychologist, a
   GP, a friend or a family member.

Find more information on looking after your mental and emotional health @ jeanhailes. org.au/health-a-z/mentalemotional-health



There is a growing body of evidence in positive psychology literature that describes the benefit of using our creative sides with regards to social and emotional wellbeing.

That feeling of 'getting lost' and losing track of time while completely immersed in a project is very important! These experiences provide an opportunity to get things off our chest and sometimes explore emotions that may have been lingering beneath the surface for some time.

It is my experience that our relationships with creativity are entirely individual and can take any form a person desires.

### **CREATING IS EVEN BETTER TOGETHER!**

Engaging in group learning and accessing the

community is another plus to the creative arts. Music, art and drama are all inherently collaborative.

The connections that are formed in workshops and other learning environments are incredibly deep and learning a new skill alongside others is a fantastic way to meet new people and strengthen existing friendships.

There is a great deal of evidence for the role that learning new skills can play in maintaining cognitive function. Learning helps to keep our brains adaptable and 'on its toes', strengthening our brain's cognitive abilities. Finding a fun, engaging way to learn new skills that opens opportunities to meet new people is even better!

#### WHY MUSIC?

Aside from the expressive elements of creativity, engaging with something that is fun and

Having a creative outlet is key for any person. Scott Marshall, co-founder of Lift Up Voices and a social worker with a background in special education, explains how getting creative can positively impact your life.

WITH SCOTT MARSHALL,
LIFT UP VOICES DIRECTOR AND SOCIAL WORKER



# The power of creativity

enjoyable has immense mental health benefits.

One of the Lift Up Voices organisation's values is that every person deserves an opportunity for their creativity to be heard.

Engaging in the arts has been shown to release dopamine, which is the happy brain chemical. This means music has the power to elevate your mood and empower you for the day ahead. Engaging with music and other art forms can be powerful tools in the treatment of anxiety and depression.

Studies also show that music has incredible positive effects on our brains and cognitive function, increasing our memory and retention.

# ACCESSING CREATIVE ARTS SERVICES AND SUPPORTS

The creative arts are a very exciting space in the disability sector. Increasingly niche providers

are offering innovative ways for people to utilise their NDIS funding to develop skills whilst also pursuing their personal interests.

Lift Up Voices is one of these providers, offering individual and group-based programs that incorporate singing, song writing, production and podcasting in sessions that are entirely individualised to suit each artist's goals.

Lift Up Voices, and many others who work in the creative arts space, are able to fully customise the experience of each artist, regardless of experience or how they perceive their ability level. Adjustments can be made that accommodate any learning style to ensure everyone can be successful.

In closing, I would like to encourage anyone with an interest in the creative arts to pursue something new. Don't allow self-consciousness to hold you back — the time to try is now!

Jesse's passion for music has continued to grow throughout his life starting with singing at home with his family as a child, studying music at university, writing his own songs and recording an EP, to now sharing his passion with others as a music coach at Lift Up Voices. Jesse shares how music has had a positive impact on his life and the lives of the students he coaches.



# 10 minutes with musician and music coach, Jesse Frick

#### WHEN DID YOUR PASSION FOR MUSIC START?

From the moment I was born really. I was always singing. My mum's side of the family are very musical. It's very much part of my life.

# WHAT IMPACT DO YOU THINK MUSIC HAS ON MENTAL HEALTH AND EMOTIONAL WELLBEING?

For me with my disability [multiple sclerosis], I know that my physical wellbeing is closely linked with my mental wellbeing. If I'm not having fun, if I'm having a down day, that's reflected a lot in the way I am physically. Music is a great tool for expression. It's a great therapy — to sing out your feelings. It's like writing in a diary.

# HOW HAS MUSIC HELPED YOU THROUGH DIFFICULT TIMES IN YOUR LIFE, LIKE YOUR MS DIAGNOSIS?

Song writing is a therapy to get my emotions out – to get things down. When I did that CD, to be able to write those stories down; and write down how I'm feeling and express that through music, helped me out greatly.

# WHAT DO YOU LOVE ABOUT BEING A MUSIC COACH?

I love giving my passion for music to other people and my enjoyment of singing. I've always wanted to help out people as well. That's one of the reasons why I did that first CD, so I could give the money back to the MS Society. So this is really combining my two loves of music and helping other people.

# WHAT ADVICE WOULD YOU GIVE TO OTHERS WHO, LIKE MUSIC, BUT ARE NERVOUS OR DON'T THINK THEY HAVE THE TALENT, TO DABBLE IN THE CREATIVE ARTS?

At Lift Up Voices, some people have come in and at first weren't quite as confident at singing and as ready to be as expressive as they could. Now they are the loudest singers. Being the best singer isn't the prerequisite for Lift Up Voices, in my group its really about the love of music and the enjoyment of music. Having fun is what it's all about and being part of a group with like minded people.

When I first started with my song writing, I didn't know what was going to happen, but I've just been loving it and I don't care if nothing comes from it. It's brought me so much joy and it has helped me out so much. You might really surprise yourself with what you're able to do. •



Balancing the demands of a busy lifestyle and MS are not always easy but can be managed by understanding your priorities. MS Nurse, June Mattner discusses habits and activities you can prioritise for a balanced lifestyle. Spend some time looking over this list and adding these items to your day!

WITH JUNE MATTNER, MS NURSE

# The balancing act: living a balanced lifestyle

Having a balanced lifestyle means that your daily routine does not leave your heart or mind feeling neglected. Developing this skill allows you to feel calm, grounded and motivated to deal with anything life throws at you.

#### **SOCIAL**

Share time with people who are a source of pleasure and support to you. Do remember that it is okay to say "no" to an invitation if you are feeling too tired; friends and family will understand.

## **FUN**

Making time for your hobbies and interests can help to take a break from day-to-day stresses and devote some time to yourself.

#### **PHYSICAL**

Exercise releases your body's endorphins which are natural pain and stress fighters. Exercise at least three times per week.

#### **SLEEP**

Aim for seven to eight hours of sleep a night to give your body time to rejuvenate and reenergise for the day ahead.

### **INTELLECTUAL**

Stimulate your mind and learn something new by attending courses, reading a book, listening to the news, checking out websites and engaging in lively discussions.

## **NUTRITIONAL**

Ensure you eat a well-balanced diet consisting of all five food groups over three main meals, and snacks in between, to ensure you have fuel for your everyday activities.

#### **SPIRITUAL**

Spend time examining your beliefs, values and your philosophy for living an enjoyable life and take a moment to be grateful for each day – journaling can be a great tool for this!

# **RELAXATION**

Relaxing the muscles and quietening the mind may take various forms such as yoga, meditation and deep muscle relaxation – enjoy!

## **WORK**

Engage in work or volunteer activities that help you gain a sense of satisfaction and achievement.

# Community Corner

# Managing cognitive symptoms of MS

We asked our MS community for some handy tips and management strategies for cognitive symptoms of MS such as memory, concentration, planning and sensory overload. Here's what you had to say...

"I use the calendar on my phone to remember events and other important information. As long as I remember to check my calendar regularly, it's a great help!" - Carolyn

"I am constantly trying to do any kind of puzzles. This one is difficult, but I take it like a gym – if it does not hurt, I am not doing enough. The good news is that for me it has become easier." – Raul

"My supervisor now emails me clear instructions for projects she wants me to take on instead of grabbing me as I am passing her office." – Trish

"I have a small desk space that has calendars, bills, papers, to do lists, etc. that I will visit at least once a day. [I use] headphones to handle sensory overload and focus." – Jess

"Always a pen and pad in my walker (around home) to write things down immediately. I've found what works for me with sensory overload is time out i.e., a quiet day the next day." – Rosemary

"Post it notes, reminders, timers and checklists. A lot of labels. We've labelled everything in our house. I have a checklist on my workbag." - Emma

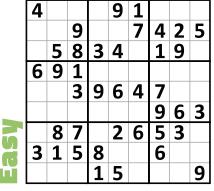
# Brain Booster

### Take a break to boost your cognitive reserve!

Cognitive reserve is the brain's ability to use its nerve pathways more efficiently or to find alternative pathways if the usual ones are damaged. The higher your cognitive reserve, the stronger and more resilient your brain is which can help you cope with cognitive difficulties caused by age or MS.

Boost your cognitive reserve by keeping your mind active through reading, creative activities, or puzzles such as sudoku and crosswords.

Source: MS Trust UK, mstrust.org.uk/life-ms/ wellbeing/thinking-and-memory-problems



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# Weekly Exercise Programs

# VIRTUAL MS EXERCISE GROUPS Tuesdays and Fridays, 9:30am

Improve your strength, mobility and balance in our twice weekly, online exercise classes with an MS Physiotherapist. Exercise at home, with classes running for 45 minutes via Zoom. Exercises can be done standing or seated.

# **HYDROTHERAPY**

## Daw Park, Klemzig and Victor Harbor

Water based, group exercise classes held in three location in Adelaide and regional South Australia.

# GYM CLASSES WITH A PERSONAL TRAINER MS Society SA & NT, Hillcrest

Personalised exercise sessions with a personal trainer using specialised, accessible gym equipment.

# EXERCISE CLASSES Aldinga, Nuriootpa, Payneham, Port Pirie and Reynella

Group exercise classes held in various locations in Adelaide and regional South Australia.

# **MS Peer Support**

## PEER SUPPORT GROUPS

The MS Society SA & NT has 22 MS Peer Support groups meeting at various locations in Adelaide, regional South Australia and Darwin. Groups usually meet monthly over coffee or a meal. Some groups gather to discuss specific multiple sclerosis issues and others get together for activities such as tennis and crafts.

You can see our full list of MS Peer Support Groups at ms.asn.au/how-we-help/peer-support or contact MS Assist on 1800 812 311 to learn more.

# FACEBOOK PEER SUPPORT GROUPS My Society – People Living with MS

This is a private and safe place for people living with multiple sclerosis in SA and NT to chat, seek advice and share stories. Search for the group on Facebook and request to join.

# Family and Friends of People Living with MS

This is a private place for family, friends and carers of people living with MS to chat, share information and connect with others who are supporting someone with MS. Search for the group on Facebook and request to join.



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