

# A PATHWAY BEYOND PAIN

Pain. It's something that we've all experienced in one way or another – from the sharp pain of burning your hand on a stovetop to the throbbing ache of muscle pain.

But for an estimated two-thirds of Australians living with MS, pain is an invisible but very real symptom that can have a significant impact on so many aspects of their life.

And for people like 49-year-old mum, Emma, who's been living with MS for 23 years, the pain also comes without warning: *"Nerve pain is just horrendous. It's like a really bad toothache but in a bigger area of the body. It just stops you in your path."*

While there are many options

for treating pain, such as medications and physiotherapy, not everyone reports effective relief.

We know there are different types of pain, but we don't yet fully understand the nature of MS-related pain, or how it's experienced by those living with it – because it can vary so greatly from one person to the next.

Some people experience aching and burning sensations, while others experience excruciating nerve pain. It can be pain that comes and goes, or chronic pain that never leaves – in some cases, people can experience several types of MS-related pain at once. Whatever form the pain takes, we must

continue our efforts to end it.

A couple of months ago, Emma was out walking with her husband when the pain struck without warning:

*"Out of the blue – all the way down my left leg – the nerve pain just hit me all of a sudden and I fell to the ground. I sat there for about 10 minutes because I couldn't get up."*

*"I always think what would happen to me if I'm out by myself? Or driving a car? I don't know what I'd do. I've had to withdraw myself from a lot of things I used to do...It breaks my heart because I miss being able to be a good mum for my girls and take them out to go do things."*

# FROM THE CEO

ROHAN  
GREENLAND

20  
YEARS OF EXCELLENCE  
IN MS RESEARCH



With a federal election expected within the next six months, MS Australia is vigorously promoting three significant policy proposals to the major parties. We are asking them to commit to the following to help improve the lives of everyone living with MS.

- Establish a national neurological research mission under the Medical Research Future Fund, with a \$30m a year commitment for the coming decade.
- Fund a national MS nurse workforce strategy (\$4m over four years) to address the disturbing shortage of MS nurses across the country. Funding will support a pilot project with a research component to assess the cost-effectiveness of the pilot.
- Fund an MS Biobank (\$8m over five years) to support and accelerate Australian research for early detection and prevention of MS.

These three actions will help propel us toward better treatments, better care and - ultimately - cures for MS and many other neurological conditions.

They are investments that are highly cost-effective, easy to implement, high impact and would be warmly welcomed, not just by the 33,335 people living with MS, but also by their families, friends and carers.

We are reminding our political representatives that MS is on the rise, with a 30% increase in prevalence recorded between 2017 and 2021.

We also remind them that - over that time - the total economic and social costs of MS in Australia has risen from \$1.75bn to \$2.45bn.

Of course, a neurological research mission will help not only MS research, but research across the many neurological conditions which today affect some seven million Australians at a cost to the community of more than \$100bn a year.

And while we will be just one of many thousands of causes demanding attention from our politicians over the coming months, we know that neurological conditions have not, as a group, got the recognition, support and funding they need.

Time for change!

**Rohan Greenland**  
CEO, MS Australia

The pain on its own is more than anyone should have to bear.

Dr Alice Saul is a postdoctoral research fellow at the Menzies Institute for Medical Research at the University of Tasmania. Dr Saul and her team are working hard to better understand the pain people with MS experience, so more effective and targeted treatments can be found.

Dr Saul's research focuses on understanding the different types of pain experienced by people with MS by using data from the Australian MS Longitudinal Study (AMSLS),

which has tracked over 2,000 people with MS since 2002. Dr Saul and her team are analysing the prevalence, severity, duration, and triggers of pain and investigating which pain management strategies are most effective overall and for specific pain types.

And for people like Emma, finding better treatments, would mean everything:

*"We need to give people living with MS hope for medicines that mean you don't have to worry or doubt your body. You don't have to cancel appointments or not be able*

*to go out or take your children places."*

*"Pain management would be everything. It would give me freedom and confidence."*

It's why Dr Saul is so motivated and inspired to progress her research at the Menzies Institute for Medical Research. So they may get a better understanding of the different ways that pain impacts the quality of life for people living with MS.

A vast majority of people living with MS will experience its unique pain - but its causes and best treatments are still little understood.

**Please support research with a gift this Christmas to help accelerate the development of treatments that will help people like Emma live pain free.**



**DR ALICE SAUL**



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# LOW INTENSITY REPETITIVE TRANSCRANIAL MAGNETIC STIMULATION ENHANCES MYELIN REPAIR IN PRE-CLINICAL MODELS

Low intensity repetitive transcranial magnetic stimulation (LI-rTMS) uses a rapidly changing magnetic field to generate small electrical pulses in the brain, stimulating certain areas. It is currently used to treat depression in people where anti-depressants have not been successful.

There have also been a small number of rTMS clinical trials in people with MS, and in these trials, people have reported a reduction in fatigue, muscle spasticity and improved memory. However, how it leads to these benefits is unknown.

## What did the researchers do?

MS Australia-supported researcher Professor Kaylene Young and her team, at the Menzies Institute for Medical Research, set out to investigate whether LI-rTMS could promote myelin repair in laboratory models of MS.

They did this by labelling new and mature oligodendrocytes in the brain of laboratory models of MS with a fluorescent tag to trace the fate of these cells.

Using advanced microscopy and cutting-edge techniques, the team captured how these cells interacted in the brain and investigated the exciting potential for LI-rTMS to boost myelin repair.

## What did the researchers find?

Professor Young and her team found that LI-rTMS promoted the following aspects in laboratory models of MS:

- **It boosted the myelin repair capacity of new oligodendrocytes.** However, it did not increase the number of new oligodendrocytes.
- **It boosted the myelin repair capacity of mature oligodendrocytes in the brain.** This was particularly the case for the corpus callosum, which acts as a communication pathway between the two halves (hemispheres) of the brain.
- **It increased the length and thickness of each section of myelin produced.** This suggests that myelin repair is more efficient. The researchers also found that more nerve fibres were covered in myelin in treated areas.

## What is the significance of this?

This study revealed a significant finding – that LI-rTMS promotes myelin repair in laboratory models of MS by affecting the behaviour of new and mature oligodendrocytes. While this requires further investigation, it presents a promising treatment that could be used alongside other MS therapies.

LI-rTMS is currently in a clinical trial for myelin repair in MS. The TAURUS phase 1 clinical trial results were released a few months ago, and showed that LI-rTMS is safe and well tolerated by people living with MS. The high compliance also indicated that this procedure is feasible for people with MS to adhere to. This trial has now been moved into Phase 2, which will focus on the effectiveness of LI-rTMS in promoting myelin repair and improving several clinical measures including mobility, fatigue and magnetic resonance imaging metrics.

We look forward to hearing the results of this study once it is completed.

## EATING WELL WITH MS:

## A PROGRAM CREATED WITH THE MS COMMUNITY

## TO EMPOWER HEALTHY CHOICES

Diet plays a significant role in managing MS symptoms and may slow its progression. However, many people with MS find it challenging to navigate conflicting online dietary advice.

To address this, MS Australia-supported researchers, Dr Rebecca Russell and Professor Lucinda Black, along with their MS Nutrition Research team, explored ways to enhance nutrition literacy and healthy dietary habits for people with MS.

These efforts, in collaboration with people living with MS, led to the development of *Eating Well with MS*, a six-week digital nutrition education program designed specifically for the MS community.

The program includes text, interactive graphics, videos, and printed resources such as an activity book, recipes, and information brochures.

*“Making dietary changes can give people with MS a sense of control over the disease, but there’s a lot of conflicting information online. This program was developed to fill the gap in accessible, evidence-based nutrition advice,”* Dr Russell said, highlighting the program’s role in empowering participants through trusted guidance.

### What Did the Researchers Do?

In one study, published in *Multiple Sclerosis and Related Disorders*, the feasibility of the co-designed digital nutrition education

program *Eating Well with MS* was tested. This trial involved 70 adults with MS and assessed recruitment rates, program completion, and participants’ engagement with the program.

In another study, published in *Health Expectations*, the researchers conducted telephone interviews with 16 people with MS who had participated in the trial of *Eating Well with MS*. The aim was to explore the factors that influenced their ability to make dietary changes, focusing on their knowledge, available opportunities, and motivation. The interviews were analysed, and the findings identified key factors affecting how participants engaged with the program.

### What Did the Researchers Find?

In the first study, *Eating Well with MS* was found to be well-received. Eighty-four percent of participants completed at least one module, and 54% finished the entire six-week program. Participants rated the program highly, with improvements in their diet quality, nutrition literacy, and food-related behaviours observed after completing the program.

Dr Russell explained, *“We enlisted 70 people with MS to evaluate the program’s effectiveness and participants rated it 6 out of 7 for usefulness, reporting significant improvements in diet quality, meal planning, and the ability to critically assess nutrition claims.”*

In the second study, researchers identified four key factors influencing engagement

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# HOW MS AUSTRALIA IS CREATING A FUTURE THAT'S MORE INCLUSIVE AND ACCESSIBLE FOR PEOPLE WITH DISABILITY

The MS Australia Advocacy team has been working on crucial disability reforms throughout this year, ensuring the needs of people living with MS are front and centre. This work is more critical than ever as Australia moves to reshape the National Disability Insurance Scheme (NDIS) and disability systems to create a future that's more inclusive, accessible, and equitable for everyone.

Following the release of the NDIS Review, the Minister for the NDIS Bill Shorten and the National Disability Insurance Agency (NDIA) have rolled out a range of reforms in 2024. This includes the introduction of a new NDIS Act outlining some of the changes to the Scheme. MS Australia provided a submission on the new Act and urged the government to review and improve their co-design processes, including compulsory co-design in the development of any future Rules or legislative instruments.

In April, MS Australia provided a submission

to the NDIS Provider and Worker Registration Taskforce urging the NDIA to implement a tiered registration process. This approach would enhance participant safety, promote choice and control, reduce administrative and financial costs and tailor registration requirements to the type of services provided. We also supported the introduction of free, accessible and tiered compulsory worker registration. The Taskforce's final report strongly aligned with these recommendations.

In May, we were pleased to see the NDIA establish the Neurodegenerative, Palliative Care and Rare Diseases Advisory Group (NPR), to provide strategic advice to the NDIA on issues relating to Neurodegenerative and Neuromuscular or rare conditions or those requiring palliative care. MS Australia is represented on this working group by our CEO, Rohan Greenland.

The Australian Government has asked the Independent Health and Aged Care

Pricing Authority (IHACPA) to provide advice on reforms to NDIS pricing with the possibility of future NDIS pricing responsibility transferring to them. MS Australia provided a submission in November recommending flexible, transparent NDIS pricing that reflects real service costs. Key suggestions include allowing flexible fund use, outcome-based payments, removing rural travel caps, separate allied health travel funding, and tiered pricing for experienced workers. Regular reviews for progressive conditions and workforce development incentives are also proposed. These changes aim to improve participant access, service quality, and provider sustainability, creating a more adaptable, person-centred NDIS.

In August, the NDIA released a draft list of supports that will be available under the new NDIS Act. MS Australia provided feedback on the list and called on the NDIA to ensure that the list of supports include best practice disability supports

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and be supported by improved training for NDIS planners and assessors. The NDIA has now released the final approved list of supports. As people living with MS navigate this new list, MS Australia will use the NPR to seek clarity and provide feedback to the NDIA.

MS Australia continues to engage in ongoing NDIS updates and improvements including providing a submission on the annual NDIS pricing review. We also provided a submission to the Joint Standing Committee on the NDIS on the NDIS participant experience in rural, regional and remote Australia and were subsequently invited to give evidence before the

committee. Additionally, we are contributing to broader disability reforms, including providing a submission on the review of Australia's Disability Strategy. Currently, we are working on a submission on the development of Foundation Supports, which are disability services provided outside of the NDIS and were a major recommendation of the NDIS Review.

We would like to thank the members of our Lived Experience Expert Panel (LEEP) who provided feedback and case studies for these submissions that draw on their lived experiences as people living with MS accessing and navigating the NDIS

and disability systems. We would also like to thank our Member Organisations who provided feedback and case studies that draw on their experiences as NDIS providers delivering supports and supporting people living with MS to access and navigate the NDIS.

**You can read all of MS Australia's policy submissions on our website.**



**FIND OUT MORE**

## **EATING WELL WITH MS...**

**CONTINUED FROM PAGE 5**

with the nutrition program: (1) seeking or confirming what healthy eating is; (2) juggling time commitments and the need for social support; (3) wanting to improve health; and (4) the differences in food and cooking skills across participants.

These findings emphasised the need for disease-specific, evidence-based nutrition education to support healthy dietary habits in people with MS. Dr Russell said "Our next step is a larger national trial, with the ultimate goal of making this program accessible to all Australians living with MS."

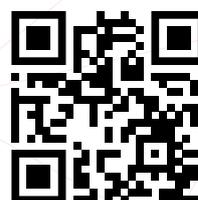
### **What Does This Mean for People with MS?**

These studies highlight the importance of providing clear, evidence-based, MS-specific dietary information. People with MS can benefit from online programs that offer practical support like recipe guides and goal-setting tools, encouraging them to make positive dietary changes. The findings also

stress the value of flexible program delivery, and peer or family support, to enhance engagement and motivation for behaviour change.

*"As people with MS continue to seek out ways to manage their condition through lifestyle changes, 'Eating Well with MS' offers a promising resource for improving their overall diet quality which can impact their quality of life,"* Dr Russell said.

**If you would like to be contacted about being involved in the next study, please leave your contact details in this short survey.**



**FIND OUT MORE**

## MEET THE RESEARCHER

### ISABELLE WELD-BLUNDELL

THE UNIVERSITY OF MELBOURNE



#### TELL US AN INTERESTING FACT ABOUT YOURSELF?

Since moving to a coastal town for my university studies, I became certified in open water scuba diving, and this is how I spend most of my weekends. It's a fantastic way to connect with the outdoors, keep fit, and be part of my local community.

#### WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

I became involved in MS research over five years ago because I wanted to use my research skills to make a meaningful difference in the lives of people with MS. I have seen the impact MS can have on people's lives and feel honoured to be able to work towards improving MS care.

#### WHAT DO YOU THINK HAS BEEN THE MOST EXCITING DEVELOPMENT IN MS RESEARCH?

I find the increasing focus on social and lifestyle factors really promising. We know that factors such as employment, social inclusion, diet, and exercise play a key role in our health. Research in this area has the potential to improve MS care by opening up new avenues for intervention. It marks a shift towards addressing the broader social and lifestyle factors that influence MS outcomes.

#### TELL US ABOUT YOUR CURRENT RESEARCH PROJECT

Social determinants of health such as domestic violence, housing, employment, and social inclusion are not routinely assessed. However, we know that they have a huge impact on health. My project will help us to understand how to screen for the social needs of people with MS. Through meetings with MS patients, carers and clinicians, we will also explore how relevant the existing tools are to MS care in Australia and how they could be better adapted for use in this setting.

#### WHY IS YOUR RESEARCH IMPORTANT AND HOW WILL IT INFLUENCE THE UNDERSTANDING AND TREATMENT OF MS?

My project will help us to better understand how screening tools for social needs may be used in the Australian MS care setting; which is the first step towards addressing social needs in MS care. Screening tools may identify needs that can then be addressed by linking patients to allied health or social services.



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