MS WIRE
NOVEMBER 2023

YOU CAN HELP PEOPLE LIKE ALICE TO LIVE HAPPIER, HEALTHIER LIVES

Too many Australians with MS are not getting the counselling, compassion and support they need to live their fullest lives.

Alice's story sheds light on the essential role that specialist MS nurses like Bridie play in the lives of everyday Australians dealing with the extraordinary challenges of multiple sclerosis (MS).

When single mum Alice was diagnosed with MS, she'd already lost everything. *Her home. Her children. Her job*.

Alice's MS threatened everything - her financial security, sense of self-confidence, and ability to do all the things she wanted to do as a mum. For seven months after her youngest son was born, Alice's health concerns were not taken seriously, and she was misdiagnosed with postpartum psychosis.

Without anyone realising it, Alice was grappling with relapsing-remitting MS. She could not understand what was happening to her or why. She was confused and scared.

She needed support – someone who would sympathise with what she was going through, who could explain what was happening and reassure her that everything was going to be okay.

While Alice's story is unique, her painful experience isn't. Research shows that around one third of Australians with MS are facing challenges that are limiting their independence and happiness, because they are not getting the individual support they need.

MS is a devastating condition that does much more than threaten motor skills. With each worsening symptom, MS impacts the joy, opportunities and standards that enable a life to be lived to the fullest.

From the simplest acts like reading this letter, to the debilitating loss of mobility that can force people out of their jobs and threaten their autonomy, MS affects everyone differently.

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FROM THE CEO

ROHAN GREENLAND

Right now, MS Australia is working with other leading international MS societies in the research space, from Canada, the US, the UK and Italy, to see if we might be able to form a new research collaboration under the new Pathways to Cures research roadmap.

We are particularly keen to see if we can supercharge research around the END MS pillar, one of three in the Pathways to Cures document that seeks a future where there are no new MS diagnoses. This will be done by reducing risk factors through ultra-early detection and early intervention. That means identifying MS in its earliest or prodromal stages to delay or prevent the onset of symptoms.

The question now is, can we develop screening tools and biomarkers to achieve that ultra-early detection and then facilitate effective interventions to stop people from progressing to MS. This is important for a number of reasons, including because we know that damage can be done even in the earliest stages of MS.

This third pillar of the Pathways to Cures roadmap sits alongside two others – STOP MS, which aims at stopping progression for those who already have MS, and RESTORE, which seeks to reverse the damage already done by MS. While we continue to vigorously support research which fits under these two pillars, many have identified the END MS pillar as the area where fewer gains have been made and much work needs to be done.

We look forward to further talks with international counterparts over the coming months to see if we can forge a way forward that will help us get down those pathways to cures, further and faster. Which is, of course, why fundraising for research is so critically important at this time.

So, a big shout out to all our regular donors and fundraisers, including those who very generously supported me as I took on the Berlin Marathon last month, a challenge that had been four years in the planning. Your support spurred me on to the finish! Thank you.

Rohan Greenland
CEO, MS Australia

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Alice's story is a prime example of this. Right when Alice was on the brink of giving up hope, she started receiving personalised care and support from an MS Plus nurse to navigate her local resources. With the expert support, care and capacity that Bridie brought into Alice's life, Alice finally saw an end to the tragedies unfolding around her, and a bright path opened up ahead.

Without the MS nurses helping Alice with her MS, and giving her guidance at that time, Alice would not have been able to cope with managing her diagnosis and understanding her MS.

MS Australia is helping raise awareness about the life-changing benefits of MS nurses and advocating for more MS nurses to meet the growing demand.

As the rates of MS continue to rise nationwide, the support that MS nurses provide is becoming more crucial than ever before.

MS nurses give back the control, happiness and general wellbeing that MS too often takes away.

With the assistance of an MS nurse, people living with MS can receive the specialised care and guidance they need to regain their independence and quality of life.

There is a raw truth at the heart of Alice's story: MS can take everything away.

Our commitment to Australians living with MS is that we will do everything we can to stop it taking away the opportunities that create a fulfilled life.

That means supporting MS nurses, funding medical research into treatments and building awareness of the impact of MS.

But today, our immediate need is ensuring that the expert care of an MS nurse is available to everyone who will benefit from their support, insight and understanding.

More nurses like Bridie can be the key to quality of life, security and self-determination for people living in the shadows of this devastating condition, like Alice.

Thankfully, not everyone will go through the trauma like Alice did with her misunderstandings or misdiagnosis. But, many people in our MS community do experience a deep fear that the things they love and enjoy could be lost to MS.

Please join us this Christmas in supporting our MS nurse workforce. By donating you will help make sure that more Australians like Alice have someone like Bridie standing by their side, helping them face MS with expertise and care.

To donate – https://www.fundmsresearch.org.au/xmas-appeal-2023

MS nurse Bridie

Alice with her children

EXAMINING HOW EARLY RELAPSES SHAPE MS DISABILITY PROGRESSION

Mapping the Course of MS

The aim of this research was to better understand the relationship between relapses and disability worsening in people with multiple sclerosis (MS), especially those who experience relapses when the disease first starts (relapse-onset MS or ROMS).

The researchers used data from a group of 279 individuals who were followed for up to 15 years after their first MS symptoms.

What did the researchers do?

A research team, including several MS Australia-funded researchers, looked at how relapses and disability worsening were connected and whether the use of disease-modifying therapies (DMTs) affected this relationship.

They used statistical models to analyse the data and published their findings in Scientific Reports.

DO OTHER VIRUSES BESIDES EBV INCREASE THE RISK OF MYELIN LOSS?

Multiple sclerosis (MS) is characterised by the loss of the insulating layer around the nerves, called myelin, that helps conduct signals to and from the brain and spinal cord, and the rest of the body.

Previous infection with Epstein-Barr virus (EBV) is well-established as a risk factor for the development of MS.

However, the role of other viruses, and their interplay with EBV, is not clear.

A new Australian study published in the European Journal of Neurology, has examined the role of additional viruses in the risk of MS, against the backdrop of EBV infection.

More specifically, the study examined other viruses as risk factors for the precursor to MS: a first clinical diagnosis of myelin loss (demyelination) in the brain and spinal cord, or FCD.

Other viruses with possible MS association

In addition to EBV, human herpesvirus 6 (HHV-6) is another herpes virus that has been repeatedly investigated as a risk factor for MS, with inconsistent findings.

There are two forms of HHV-6, with the HHV-6B form responsible for a common infection in infants called roseola, or “sixth disease”; but both variants are known to infect nerve cells.

Researchers have also investigated other common viruses, like the varicella-zoster virus (VZV; the cause of chickenpox and shingles). The link between VZV and MS is still uncertain.

Cytomegalovirus (CMV) infection, like EBV, can manifest as infectious mononucleosis and be mild or show no symptoms. Past CMV infection may be associated with a reduced risk of MS in some populations.

What did the researchers do?

The researchers looked for signs of infection with these viruses in people with a first clinical diagnosis of demyelination (204 people), compared to healthy

What did the researchers find?

The research team found early relapses that occurred within the first 2-3 years of MS onset were linked to a higher risk of disability worsening shortly after each relapse. However, they did not seem to contribute to long-term disability worsening afterwards.

Disability worsening was also found to significantly increase the risk of having more relapses each year, and this risk persisted over time, regardless of whether DMTs were used.

They also discovered that using DMTs for a longer duration was associated with a reduced risk of both relapses and disability worsening.

Furthermore, older age and the type of DMTs used played a significant role in determining individual outcomes.

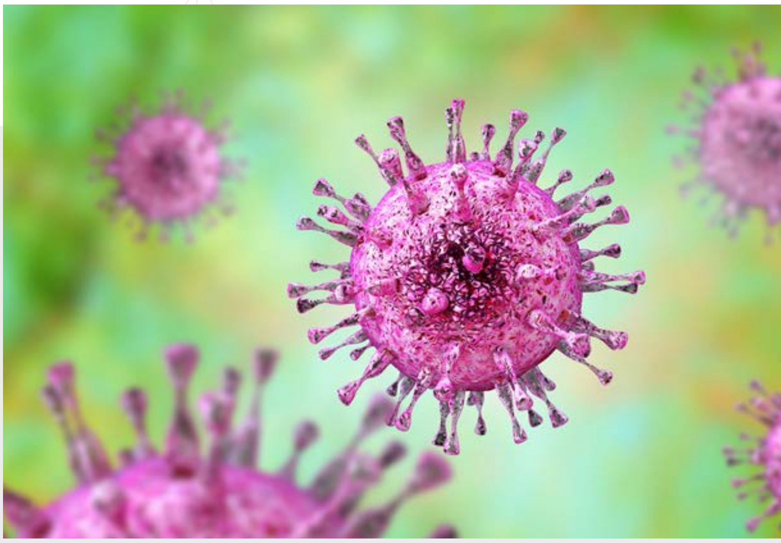
What does this mean for people with MS?

For individuals with ROMS, experiencing relapses in the early stages of the disease may be a sign of potential short-term disability worsening. However, late relapses occurring more than 2-3 years after MS onset may not be as strongly linked to further disability worsening.

Conversely, experiencing disability worsening appears to be a strong predictor of both current and future relapses, highlighting the importance of managing disability to reduce relapse risk.

In practical terms, this research shows that when dealing with MS in its early stages, it is crucial for people with MS to act quickly and decisively when relapses and disability occur. Long-term use of DMTs can also help prevent relapses and disability from getting worse.

It is important for people with MS to report all relapses to their MS care team and adhere to DMT therapy. This way, individuals with MS can lower the risk of experiencing more relapses and worsening disability, ultimately improving their quality of life.



controls matched for age, sex and study region (215 people).

They collected blood samples from people as part of the Ausimmune study, which is funded by MS Australia.

Viral load (DNA) of EBV, VZV and HHV-6 in the blood; as well as levels of antibodies to EBV, VZV, HHV-6 and CMV in serum were measured.

Analysis was conducted to determine whether these viruses were independently associated with the risk of a first demyelinating event, after taking EBV infection and other potential risk factors into account.

What did the researchers find?

Of the various viruses tested, only HHV-6 viral load was associated with a first demyelinating event, in addition to EBV.

More complex statistical modelling that accounted for educational category, serum vitamin D levels, smoking, and EBV status, also found only HHV-6-DNA load to be associated with FCD.

Interestingly, the researchers also found that, in people who carry a specific MS risk gene, higher antibodies to CMV reduced the risk of first clinical demyelination.

What does this mean for understanding MS?

These findings highlight the possible importance of HHV-6 as a risk factor for the onset of MS.

This aligns with laboratory studies linking HHV-6 to MS.

Antibodies to HHV-6 have been detected in the cerebrospinal fluid (surrounding the brain and spinal cord) in MS.

In laboratory models of MS, the addition of HHV-6 virus accelerated the disease and concentrated in areas of brain injury.

HHV-6 has also been shown to slow down the repair of myelin and block the movement of myelin-producing cells.

Overall, this study adds to the evidence on the possible role of human herpesviruses in the onset of MS.

CHAMPIONING RECOGNITION FOR UNPAID CARERS

Unpaid carers are integral to the sustainable support of people with care needs, including people living with MS. However, many unpaid carers experience multiple and complex barriers to social inclusion, economic security, education, and employment due to the significant demands placed on them as 'carers'.

In addition, carers often don't feel recognised by society or government. This is despite legislation aimed at recognising carers, with the Carer Recognition Act 2010 being in place for over a decade.

In June, the Inquiry into the recognition of unpaid carers was opened, aimed at 'strengthening and modernising the Carer Recognition Act'.

The Committee sought to understand the effectiveness of the legislation in raising recognition and awareness of the unpaid caring role and grappled with questions about the value of unpaid care, the needs of diverse cohorts of carers and the importance of carer-friendly workplaces.

MS Australia provided a submission to the Inquiry in August. Our recommendations clearly captured the attention of the Committee, as we were invited to provide evidence at a public hearing in October. Public hearings provide an opportunity for Members of the Committee to ask, often complex, questions.

MS Australia CEO Rohan Greenland and Senior Policy Officer Sarah Clifton participated in the public hearing and explained how, due to the diversity in disease presentation and progression, people living with MS require a broad range of supports that often include care delivered by family and friends.

In fact, 87% of people living with MS have someone (unpaid or informal) who is their main source of support. With over 33,000 people living with MS in Australia, we estimate that there are 29,000 MS carers across the country. Supports may include assistance with everyday tasks such as personal care, life administration, providing transport, and contributing emotional support.

The Committee was keen to hear our thoughts on the definition of an unpaid carer. We shared with the

Committee feedback from our MS Member Organisations, highlighting that many family members and friends who provide care for people with MS don't identify as carers. A carer's self-identification as a carer is crucial to seeking support, information, and resources.

The current definition doesn't capture the experience and diversity of MS carers, and this unintentionally creates a barrier as people don't see themselves in the definition. Particularly with MS, as with other chronic illnesses, there may be multiple carers providing care for a person with care needs rather than one primary carer.

Caring for people with chronic illness comprises a significant group of carers who are more likely to have a prolonged caring role. Their value and contribution are poorly recognised by society and government.

Caring can be meaningful and rewarding, but the time and effort required to provide care requires significant adjustments to a carer's life. These challenges can impact the carer's wellbeing and ability to achieve their own goals.

Without authentic recognition and practical support, unpaid carers are placing their health and wellbeing at risk and may not be willing or able to continue with their caring role.

The Committee wanted to understand the usefulness of the legislation and what MS Australia would like to see in a reformed Carer Recognition Act. We know that many people in the MS community are unaware of the Carer Recognition Act and that carers need more than legislation to improve their lives.

Further initiatives are needed, including public education and awareness, more funding for support programs for carers and strengthening of the reporting obligations on public service agencies on carer support and engagement.

We advocated for embedding the voices of carers through a co-design process, and the Committee members asked questions about the MS Plus Carers Reference Group and Carers Strategy.

While we eagerly await the findings of the Inquiry, the Government has announced two initiatives during National Carers Week that are a step in the right direction for carers.

A new National Carers Strategy has been promised by the end of 2024 with a $3.8 million investment. While light on detail, the announcement looks encouraging, with mention of a consultation process to capture the diversity of carers.

Additionally, the Government launched the Carer Inclusive Workplace Initiative, in partnership with Carers Australia, to ensure carers are better supported to participate in the workforce.

Both these policy announcements align with key recommendations from MS Australia's participation in the Unpaid Carer Inquiry.

MS Australia expresses our gratitude to our state and territory MS Member Organisations for providing their expertise and feedback to this submission.

Through their input, we were able to elevate the voices and lived experiences of MS carers directly to the parliamentarians chairing this Inquiry.

MEET THE RESEARCHER

OLIVIA WILLS UNIVERSITY OF WOLLONGONG, NSW

TELL US AN INTERESTING FACT ABOUT YOURSELF…

I spent my childhood as an elite artistic gymnast, training 25+ hours a week for over 15 years. I won seven consecutive State championships and am a two-time National Champion! I thank gymnastics for the incredible work ethic it has taught me which has certainly translated into my studies.

WHAT HAS BEEN THE MOST EXCITING DEVELOPMENT IN MS RESEARCH?

Research groups all over the world are incredibly dedicated to finding a cure and improving consumer outcomes for those with MS and this is so inspiring. With an obvious interest in lifestyle management, I have loved seeing the development of the MS Brain Health: Time Matters in MS guidance document, which places a necessary focus on the importance of a healthy lifestyle in combination with pharmacologic treatments. The development of these standards and quality improvement frameworks has really shifted the focus towards self-management becoming the mainstream in MS care.

TELL US ABOUT YOUR CURRENT RESEARCH PROJECT…

As no dietary guidelines exist for people with MS, this project aims to rationalise dietary choices and behaviours from the perspectives of both specialist MS clinicians and consumers (what is their lived experience?). This research focuses on brain health and how diet fits into a brain-healthy lifestyle. This research aims to establish preliminary recommendations that support the role of diet in a brain-healthy lifestyle for people with MS.

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

People with MS are interested in how modifying their lifestyle can positively impact disease outcomes. People want to feel like they are in control at a time of great uncertainty! My research will improve our understanding of the role of diet in the holistic management of MS, with the potential to inform future dietary practices of people with MS and enhance the clinical care standards provided by clinicians involved in the day-to-day disease management.

MS HELP FAST TRACK A CURE FOR MS

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Locked Bag 401, Lidcombe NSW 1825, Australia • 1300 733 690 • supporterengagementteam@ms.org.au • ABN 66 004 942 287