ms.
Multiple Sclerosis
Waikato

ManuScript

Working Together to Provide a Service of Excellence
Mahi tatau ki te whakawhiwhi he hapori rawe

Issue 86 – August 2025

Inside:

Finding Strength in Self-Care: Emma's MS Journey

Emma's journey with Multiple Sclerosis began in 2013, not with symptoms, but by surprise, an incidental finding while monitoring the growth of a benign brain tumour. The diagnosis finally answered the nagging questions about why she often felt fatigued and experienced what she describes as a "blanket over the brain" brain fog. It was a turning point.

Determined to take control of her health, Emma gave up smoking and committed herself to nourishing her body through better nutrition and regular exercise. Over time, she lost 20 kilograms and began to treat her body as a temple. This shift in mindset didn't just improve her physical wellbeing, it became a lifestyle. She declined treatment in the early years of diagnosis, choosing instead to focus on holistic living to see if it would ease her symptoms naturally.

Emma embraced strength training and continues to lift weights, feeling grateful for what her body can still do. Cognitive battles, such as memory lapses and fatigue caused by brain lesions, remain part of her reality but she believes these are lessened by the lifestyle she's committed to. Despite having 19 cervical and thoracic spinal lesions, Emma finds many of her symptoms are generally quiet. A calm she credits to her dedication to wellness.

However, with annual MRIs continuing to show new lesion activity, in 2023 Emma made the decision to begin Ocrevus treatment. Since then, only one additional lesion has appeared, a reassuring sign that the treatment may be helping.

Emma with her husband

Emma is based in Hamilton and the proud owner and creator of Soul Divine Massage and Nature's Creations, a body product brand rooted in self-care.

Emma's passion for her holistic wellness business started in 2018, when she began studying Swedish massage and Reiki while still working full-time. Her intention was simple, to help others feel calm and relaxed, and in doing so, she discovered something that nourished her own soul as well. For several years, she balanced this work alongside a demanding career, until 2023, when she made the life-changing decision to step away from her high-stress role after eight years. Trusting the universe to guide her next steps, Emma embraced the shift wholeheartedly. What followed was a profound transformation, the stress melted away, and she found herself grounded in purpose, peace, and joy.

Her journey into creating artisanal body products started in 2022, making them for herself, then family, friends, and massage clients. The response was overwhelming. Encouraged by their feedback, she began selling her handcrafted products at local markets around the Waikato, eventually launching her website Natures Creations in 2025 to reach even more people who value high-quality, mindful self-care.

Continued on P2

MS Waikato Trust supports people affected with Multiple Sclerosis and Huntington's Disease; MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

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SPAN Trust

Emma’s MS Journey *cont from P1*

Every product Emma makes is infused with love, intention, and locally sourced New Zealand ingredients. Her mission is to help others find the balance she has found, in body, mind, and soul. Giving back is at the heart of her business, with a portion of every purchase supporting her annual donation to the New Zealand MS Society, helping others on their own MS journey receive the resources and care they need.

Liz from MS Waikato touches base with Emma every few months for a catch-up. “The support is lovely,” Emma says. “We all experience MS so differently, and it’s comforting to know that if I ever need someone who truly understands the journey and genuinely cares, Liz would be my go-to.”

Emma’s advice to others living with MS?
“Always try to do something nice for yourself. Life is so short, and every act of self-love matters, even something as simple as sitting in the sun for 10 minutes, closing your eyes, and listening to the birds. It quietens the mind and grounds the soul.”

If you would like to find out more about the products Emma has created, you may like to visit her website www.naturescreations.co.nz , or view her Facebook pages. Nature's Creations Facebook page - https://www.facebook.com/share/1F1V5iiB2Y/ and My Soul Divine Massage - https://www.facebook.com/share/18njkTbh1Z/

Carer Support Claim Form Changes

Health NZ / Disability Support Services have made some changes to the way Carers Support Claim Forms are provided. This is an important read for anyone receiving Carers Support.

Those receiving Carers Support should receive notice directly. Carer Support customers who currently submit paper claims will receive this information by post.

This change is effective immediately. Health NZ have apologised that the change was not communicated sooner.

Change
From July 2025 Health NZ / Disability Support Services will stop sending claim forms out by post to Carer Support claimants. If you receive paper forms in the mail this will stop unless you contact and request them.

What is not changed?
The process for submitting claim forms hasn’t changed. You can still email or post your completed Carer Support claim forms. The details for this are included on the claim form.

Why we are they making this change?
Reasons provided for this change are that:

- Many Carer Support claimants now submit their Carer Support claim forms by email and physical posting is less popular than it used to be.
- It is often faster to claim, query, and receive payment online.
- Large volumes of returned mail are received.
- Postal delivery times are less certain than they used to be.

Are paper claim forms still available?
Yes, paper claim forms are still available, but they won’t be automatically sent to you.

If you would prefer to receive paper claim forms by mail, please follow the process they have outlined below.

How to get a Carer Support claim form
You can: Download a blank claim form from:

- Disability Support Services website https://www.disabilitysupport.govt.nz/carers/what-is-carer-support#how-do-you-get-a-form
- Health New Zealand website https://www.tewhatuora.govt.nz/for-health-providers/claims-provider-payments-and-entitlements/carer-support-subsidy#who-can-get-carer-support
- Call on 0800 855 066 or email carer_support@health.govt.nz to request that they continue post forms to you.
- Write on your next claim application that you send us in the mail, that you would still like to receive claim forms by mail

Further support
If you have any questions about this change or for more information about your Carer Support allocation details (number of days remaining and date range), please contact 0800 855 066 or email carer_support@health.govt.nz. Wait times are often reportedly long, so a call back service is available.

It is recommended to keep a record of your claims.

Source – Multiple Sclerosis Society of New Zealand

MS Research

On The Up: Mātai researchers developing new MRI method with better multiple sclerosis detection

Researchers from Mātai Medical Research Institute in Gisborne are helping develop a new MRI scan method, which they say can detect subtle brain lesions in multiple sclerosis patients not seen on current state-of-the-art scans.

According to a recent journal paper published in a special issue of Recent Advances in MRI of Multiple Sclerosis, the new method offers 10 times more contrast, which could enable earlier detection and precise monitoring of multiple sclerosis (MS).

Paul Condron, Mātai charge technologist and one of those who worked on the paper, said the new method was likely to significantly improve how doctors detect and monitor MS, including progressive disease.

“It is a major leap forward in MS imaging.”

He said the first study demonstrating the use of MRI in MS was published in 1981 by a team from the Royal Postgraduate Medical School (UK), including Professor Graeme Bydder.

More than 40 years later, Professor Bydder was continuing his pioneering work on the use of MRI in MS at Mātai.

“Our findings using ultra-high contrast [UHC] MRI surpass standard MRI in both lesion detection and structural clarity,” Bydder said

“This technology opens the door to earlier diagnosis, better treatment planning and potentially life-altering early interventions.

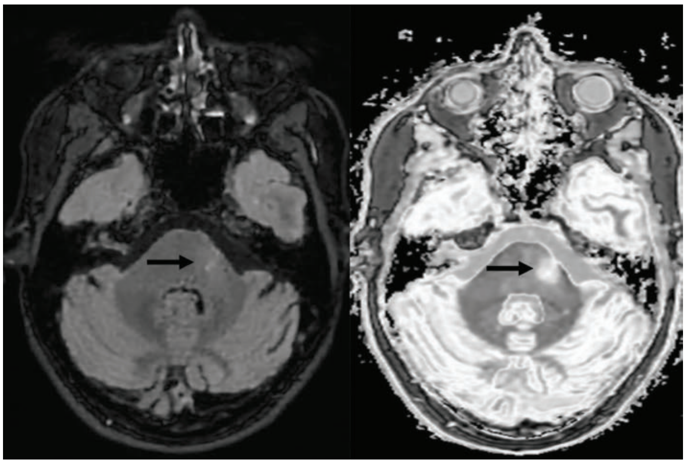
“If we can detect and treat inflammation before it leads to irreversible damage, we could significantly delay progression and reduce the long-term impact on patients and the healthcare system.”

He said the limitations of conventional MRI had long hindered the ability to detect the full scope of MS in people.

“UHC MRI not only reveals lesions that are completely invisible with current techniques, but it also gives us access to new signs of disease activity, including changes at the boundaries of lesions that could redefine how we understand progression in MS.”

UCI MRI refers to the Magnetic Resonance Imaging (MRI) facilities at the University of California, Irvine (UCI).

The new UHC MRI technique is also showing changes in tissue beyond the standard plaque assessment (protein build-up in the brain) that has been at the core of MS brain imaging.



MRI scans from a woman with MS (multiple sclerosis) in remission. In the standard scan (left), there’s a faint, blurry area in the brainstem. In the UHC-MRI scan (right), the same area appears much clearer and larger - showing how this newer imaging approach can uncover more detail than traditional methods. Image / Matai Medical Research Institute

A statement from Mātai Medical Research Institute said that in addition to spotting extra abnormalities in both grey and white matter, the advanced scans provided clearer images of spinal cord and optic nerve damage, which is often difficult to detect.

The scans also demonstrate widespread transient changes in brain tissue during MS flare-ups that are not seen using standard imaging methods.

“MS sufferers often experience symptoms that are difficult to explain, and this may help to understand more fully the broad range of physical, cognitive, emotional and social difficulties that patients experience,” the statement said.

“This has the potential to open the way to a broader range of treatments reflecting the MS sufferers’ lived experience.”

The ongoing research into the use of UHC MRI in MS was supported by the New Zealand Multiple Sclerosis Research Trust (NZMRST) and the JN & HB Williams Foundation, allied with local, national and international research partnerships.

An initial study will include 50 participants, to be recruited in Auckland and Tairāwhiti using clinical networks and community connections.

Some will have established MS and others with symptoms suggestive of MS will be scanned at their first presentation, to assess the sensitivity of UHC MRI in detecting very early disease.

Neil Woodhams, a spokesperson for NZMSRT, said the burden of MS could be greatly reduced if early signs of active inflammation could be seen and treatment

MS Research *cont.*

started before irreversible damage occurs.

“The new technique also may help identify areas of persistent low-grade inflammation that underlie gradual progressive worsening, the main cause of long-term disability in MS,” Woodhams said.

“It could ultimately have a substantial influence on how MS is diagnosed and managed worldwide.”

The impact of multiple sclerosis in NZ
In 2021, there were 4,130 reported cases of MS in New Zealand, an increase from the 2,896 cases reported from 2006.

Despite advances in treatment, diagnosis remains challenging, particularly for progressive MS, where low-grade disease activity continues without visible relapses or new inflammatory lesions.
Mātai aims to advance global healthcare using state-of-the-art MRI technology and personalised medicine for early and precise diagnostics and treatments.

MRI uses magnetic fields and radio waves to generate internal images of the body.

Source – The Gisborne Herald

September is Wills Month

September is Wills Month in New Zealand and is a time when many people may be reflecting on whether their Will still meets their wishes and if appropriate what changes you may like to make, or if you don’t have a Will, it’s a great time to consider writing one.

If you choose to leave a gift in your Will, leaving a gift to MS Waikato is the perfect way to ensure that we are here to support future generations as they need it. It is a way to support MS Waikato that does not affect your finances now while you are needing them to live your life. How you choose to do this is very personal, for some this could be a specific amount, or it may be a percentage, even 1% makes a significant difference. All gifts are used wisely to provide support, education, information and advocacy for our clients and their families, and in accordance with any specific wishes from the benefactor. Of course, your family and loved ones always come first when writing a Will.

If you wish for a donation or gift to remain in the Waikato, it is essential that you stipulate that the gift is for MS Waikato. Simply directing this as a gift to Multiple Sclerosis is not always sufficient to ensure the gift remains local.

If you choose to leave a gift in your Will, we would love to hear about it so we can thank you personally.

Whatever your wishes may be, having a Will is important as it ensures that you are able to provide for your family and loved ones in the way you want to. It gives you control over what will happen after you die, while this is something we often don’t want to think about, having a Will gives you peace of mind that when the time comes, your final wishes will be carried out accordingly.

Without a Will, if your assets are over $15,000, the Probate process would be processed through the high court, with high court costs and processes. The court will decide how your assets will be distributed. This can make a difficult time even more difficult for the loved ones you leave behind.

If you would like to talk about leaving a gift in your Will or have already set up a gift in your Will we would love to hear from you. Please email Janet – janet@mswaikato.org.nz or phone 07 8344740.

Social Group - MS Connect

We have a new group; it is a social get together once a month in the evening. We will meet for a meal and sometimes an activity like 10 pin bowling, a pub quiz, mini golf. If this group is of interest to you, and you would like to receive emails with details, please contact Liz or Karen.

MS Courses

The Menzies Institute for Medical Research has created and hosts several excellent online MS courses, all of which are free to enroll with and complete.

Understanding Multiple Sclerosis
Understanding Multiple Sclerosis (MS) is a free online course that aims to improve understanding and awareness of MS worldwide and empower people to create and contribute to personalized MS management plans.
Starts: 8th September
Effort: 2 hours per week
Duration: 6 weeks

Deciding about DMTs for Multiple Sclerosis
Deciding about Disease Modifying Therapies (DMTs) for Multiple Sclerosis (MS) is a free online course that aims to increase understanding about DMTs and help people living with MS make informed decisions about using them.
The course is always open
Effort 4 – 6 hours online
Duration: Self-paced

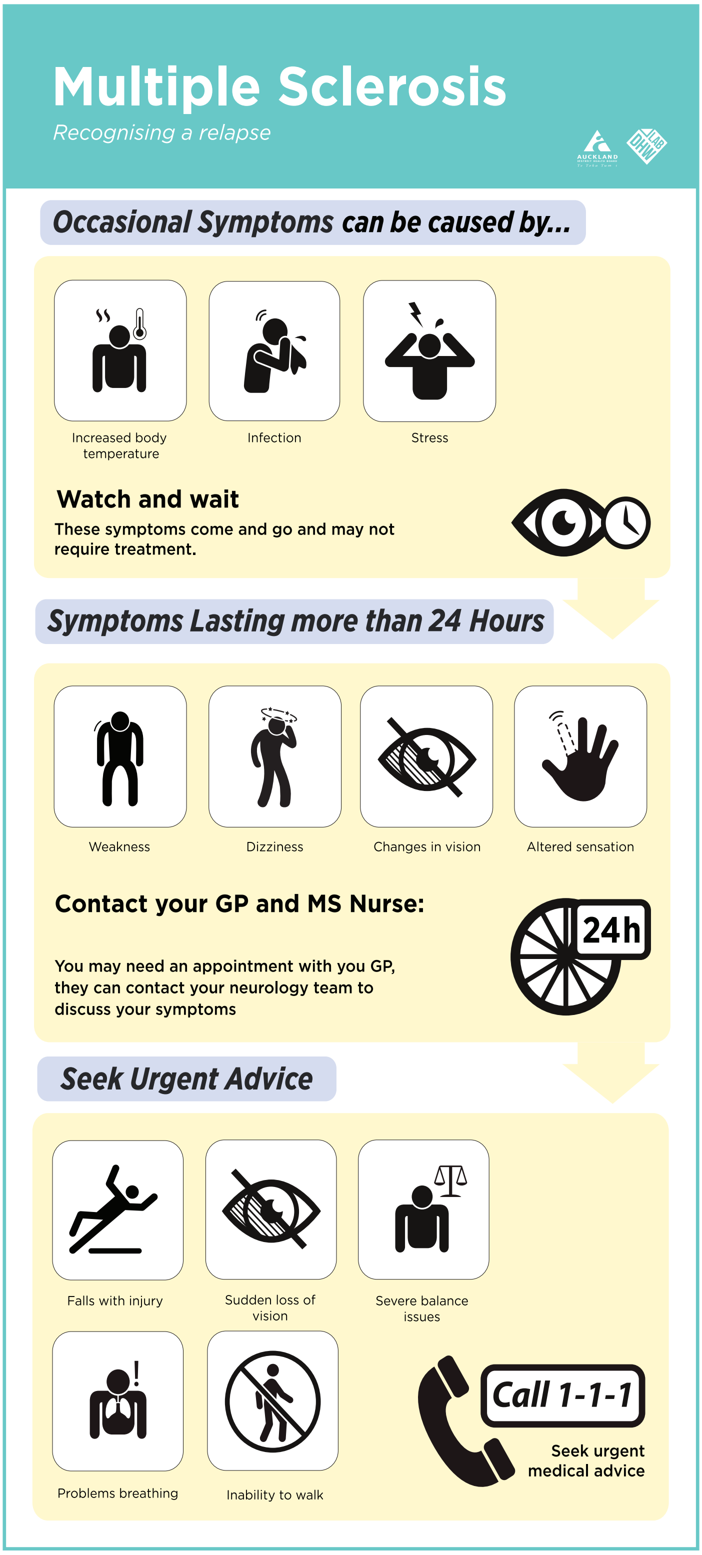
Mental Health and Multiple Sclerosis
Mental Health and Multiple Sclerosis (MS) is a free online course that aims to enhance understanding of mental health and its interaction with anxiety, depression and MS.
The course is always open
Effort 4 – 6 hours online
Duration: Self-paced

Ageing Well with Multiple Sclerosis
Ageing Well with Multiple Sclerosis (MS) is a free online course that explores ageing and how it intersects with MS. The course provides strategies for healthy ageing and helps you plan for the future.
The course is always open
Effort 4 – 6 hours online
Duration: Self-paced

For more information or to enroll on any of the courses visit the Menzies Institute for Medical Research - https://ms.mooc.utas.edu.au/ .

Recognising a Relapse

With today's Disease Modifying Therapies (DMT), relapses are becoming less and less common amongst those receiving treatment. However, it is still important to be able to recognize a relapse if this should happen, the information below will help you choose the right path forward.



Multiple Sclerosis

Recognising a relapse

Occasional Symptoms can be caused by...

Watch and wait

These symptoms come and go and may not require treatment.

Symptoms Lasting more than 24 Hours

Contact your GP and MS Nurse:

You may need an appointment with you GP, they can contact your neurology team to discuss your symptoms

Seek Urgent Advice

Call 1-1-1

Seek urgent medical advice

Sources – MS New Zealand / Auckland District Health Board

How a Smartphone “Detective” is Helping Track HD Progression

Smartphones can help scientists calculate a new clinical measure of HD, called the HD Digital Motor Score. Easier data collection could mean less clinic trips, fewer people needed for studies, and a better understanding of HD.

A team of researchers from Roche and University College London (UCL) have developed a new clinical measure called the Huntington’s Disease Digital Motor Score (HDDMS). This score compiles data collected remotely using smartphones, to track certain signs and symptoms of Huntington’s disease (HD). This new technology helps collect rich datasets and could help reduce the number of people needed to power clinical studies. Let’s get into what the team did and what this means for the HD community.

Gathering clues about the early signs of HD

Trying to spot some of the subtle early signs of HD, or how symptoms progress over time can be a lot of detective work from HD clinicians and scientists. Especially since HD can affect each person differently, the clues are not always big and obvious. Instead, symptoms and the way they change can be like tracking down lots of smaller clues and hints that need to be pieced together to help figure out what is really happening for a given person.

For scientists and doctors studying HD, monitoring the subtle changes in symptoms of the disease is often like this type of detective work. One of the most characteristic groups of symptoms in HD is changes to movement, which can be impacted in many ways. This includes balance, walking, involuntary jerking motions, and how fast people with HD can tap their fingers.

Each symptom is a clue about how the disease is progressing, which is important to understand in detail, so we can better measure the precise changes which come as HD progresses, and how they might differ between people. With many exciting clinical trials underway or in the pipeline, we are keen to see if these new experimental therapies can slow down or halt these symptoms, especially the earlier and more subtle features of disease.

But catching these clues early and accurately has been a huge challenge. Traditional clinic visits for people with HD to see their neurologist only give snapshots in time. This means that subtle changes can go unnoticed until later stages, slowing down research and making it harder to tell if new treatments are really working.

A Digital Detective: The HD Digital Motor Score (HDDMS)

To help solve these problems, a team of researchers from UCL and Roche have developed a new kind of detective tool called the HDDMS. This is a score created from simple movement tests and measurements that can be recorded by anyone with HD via their smartphone, wherever they are.

The measurements collected are part of the HD digital monitoring platform. Just like a detective gathering evidence, participants complete a series of quick motor tests using a smartphone app. These help to measure:

- Standing balance
- Finger tapping speed
- Walking patterns
- Involuntary movements (sometimes called chorea)

The app collects a lot of data as people go about their everyday lives. This means that data can also be collected more frequently than traditional data collection processes, where the person would have to go in to see their neurologist for each test. From all of these tests, the HDDMS combines lots of subtle movement clues into a single score that reflects how well motor function is holding up in people with HD, and how this is changing over time.

A lower score means better motor control; less clues for HD symptoms are found and the detective’s case is still cold. On the other hand, a higher score means more progression, and the clues show the disease is progressing.

Why This New Digital Detective Is a Game-Changer

The researchers tested this digital detective tool using data from over 1,000 people with HD, collected across four different studies. That’s a lot of data!

Here’s what they found:

More sensitive than traditional tools: The HDDMS was about twice as sensitive in detecting real changes in motor symptoms compared to the commonly used clinical score, the composite unified Huntington’s disease rating scale, or cUHDRS. This means that scientists are able to pick up on clues earlier and more clearly than before.

Reliable and consistent: The score is very consistent when repeatedly calculated, just as a good detective would never miss the same clue twice.

Speeds up clinical trials: Because the HDDMS detects changes faster, it could help researchers run smaller and shorter clinical trials. This means testing new drugs might take less time and involve fewer people, speeding up the hunt for effective treatments.

Convenient and remote: People can complete the tests at home in just five minutes and may no longer need to travel to a clinic for long assessments. It’s like having a detective’s magnifying glass in your pocket, ready to spot clues anytime. This is especially great for people with HD who live in remote areas, very far from their neurologist, or have mobility issues.

Professor Ed Wild from UCL, one of the lead scientists on this project, explains:
“Our findings suggest that incorporating the HDDMS in

cont from P6

clinical trials will help to give clearer answers about whether a potential treatment is working, with fewer participants or shorter lead times than conventional measures…. HDDMS is evaluated in a five-minute assessment in people’s homes, [making] it convenient and potentially more meaningful than in-clinic measures of motor impairment.”

The Bigger Picture: Why Tracking Movement Matters
Movement problems are one of the most visible aspects of HD. They affect daily life, making walking, balance, and fine motor skills harder as the disease progresses.

By accurately tracking these changes, scientists get critical clues about how HD unfolds in each person with more precise timepoints through the process. This helps not only in testing new therapies but also in understanding the disease better.
This is a bit like a detective catching a villain earlier in a mystery, before they cause more havoc. The HDDMS gives doctors and researchers a sharper magnifying glass to track the disease’s subtle moves, allowing for faster intervention and better support.

The Road Ahead for the HDDMS
Of course, no detective tool is perfect. The HDDMS has mostly been tested in people who already show symptoms of HD, and more work is needed to see how well it works in very early or more advanced stages of the disease.

Also, while it detects changes quickly, researchers are still learning how well it predicts long-term outcomes, just like how a detective’s case might unfold over years.

Still, the potential is huge! As smartphone and wearable technologies improve, these digital tools could become standard detectives in monitoring not just HD, but other neurological diseases.

Spotlight on Hope
This new digital motor score is a beacon of hope in the HD research world. By turning everyday devices into powerful detective tools, it promises to accelerate research, reduce patient burden, and help uncover the hidden clues of HD progression. All of this brings us closer to effective treatments and better lives for everyone affected.

So next time you pick up your phone, remember, it might just be the detective helping to solve one of medicine’s toughest mysteries.

By Dr Rachel Harding, edited by Dr Sarah Hernandez

https://en.hdbuzz.net/cracking-the-case-how-a-smartphone-detective-is-helping-track-huntingtons-disease-progression/

Support Groups

Support groups are about people coming together to connect, they are people who understand what you are going through with the opportunity to build friendships.

The discussions are not always about MS or HD, the groups talk about all sorts. But they are also a space to discuss challenges and help others do the same. Talking to people who understand can be hugely beneficial.

It’s more than a support group—it’s a place to connect, grow, and even have fun along the way! Talk with Liz or Karen about finding a group that is right for you.

HD Carers Group – Bi-monthly meeting 2nd Tuesday in the month (9th September, 11th November) – Turtle Lake Café, Hamilton Gardens – 10.30am

Exercise Class – Every Monday and Wednesday - Anytime Fitness, Cnr Anglesea and Clarence St – 10.30 – 11.30am, $2 for financial members or $5 for non-financial members. Contact Liz or Karen to organize an initial assessment.

MS Walking Group – Every Saturday - The Veranda Café, Hamilton Lake – 9.00am

Hamilton

MS Support Group – 1st Thursday in the month, (4th September, 2nd October, 6 November) - location varies, contact Liz or Karen for details – 10.30am

MS Connect - Evening Social Group - 2nd Thursday in the month – location varies, contact Liz or Karen for details

Raglan

MS Support Group – 3rd Tuesday in the month, (16th September, 21st October, 18th November) - Orca Café - 11am

Te Awamutu

MS Support Group – Quarterly group meeting Wednesday 10th September, Churchill Café – 10.30am

NOTICE BOARD

MS EDUCATION EVENING

Save the date, Wednesday 17th September at the Link, Hamilton. More information to follow.

MS AWARENESS WEEK

Monday 15 - Sunday 21 September

Can you do something to help raise awareness and/or to fundraise, we would love to hear from you; or do you have a couple of hours to help with a stall at Chartwell Shopping Centre on Thursday 11th September, email janet@mswaikato.org.nz

Do follow and share our awareness posts, we want to get people talking about MS!

Subscripions & Payments

Please note 2025 subscriptions are now due.

The cost is $40 or $20 if you hold a Community Services Card. A subscription form is attached if these have not been received.

Any payments or donations can be made directly to the Trust bank account – 02 0316 0488196 000, please note for confirmation of payee our account name is MS WAIKATO TRUST.

An Eftpos machine is also available, please let staff know if you would like them to bring this with them when they visit.

Thank you for your support.

Entertainment App

MS Waikato are selling the Entertainment app (previously a book), these also make a great gift. The apps contain thousands of dollars worth of vouchers. They can be purchased as a single city, multi city or multi year.

MS Waikato will receive 20% from each app sold. For more information and to view any current offers visit https://nz.entdigital.net/orderbooks/1b54128 or contact janet@mswaikato.org.nz to receive this link.

Healthline

Healthline is a free over-the-phone health service available 24 hours a day, 7 days a week.
If you or someone in your family is unwell, you can call Healthline and speak to experienced nurses and paramedics for health advice and information about what to do next.

Phone 0800 611 116

TravelScoot

We have a TravelScoot available for short term loan. A donation to borrow. For more information contact Liz or Karen.

St John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or are housebound due to an illness or disability. Volunteers phone clients regularly to check that everything is ok.

The service is free, if you wish to enquire about receiving a regular call from a Caring Caller phone 0800 000 606.

Scooter Batteries

If you need to replace the batteries in your mobility scooter we may be able to help with the cost. A generous gift in a will, is assisting with this, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

Dogs in Homes

For the safety of our staff please ensure all dogs are secured when staff visit

Thanks to our Sponsors and Supporters

**COGS – Hamilton City, South Waikato, Waikato West and Hauraki • WDFF Karamu Trust
Rehabilitation Welfare Trust • The Norah Howell Charitable Trust • Glenice and John Gallagher Foundation
Gallagher Charitable Trust • SPAN Trust • Anytime Fitness Hamilton Central • Ngahinepouri golf club • Ruth Mylchreest**

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