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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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ManuScript is brought to you by:



Multiple Sclerosis to Registered Nurse

My story begins in August 2021. I had just turned 35, living happily with my husband Tony and with my lovely twins Harry and Henry. I was born and brought up in India, but as an immigrant to New Zealand, this land has given me a home for me and my family. Our life was going very smoothly, we had a solid plan for the future, and everything seemed to be going as expected. Then, one morning getting ready for work, I noticed something different in my right eyesight. I was looking in the mirror, I found my vision in one eye went completely black. Initially, I thought it was something with my eyes and booked to see my ophthalmologist. I was excited to go to the appointment because I wanted to have glasses like those from my childhood. The twins and I were looking at the glasses frames that we were planning to get. However, after the appointment the ophthalmologist told me that my eyes were looking pretty good it was something behind my eyes. To get a

better understanding of the problem I was referred to the Waikato DHB ophthalmology department.

The ophthalmologist sent me for brain, cervical and thoracic spine MRIs. The result came back and the team informed me that I had three lesions in my brain and two active lesions in my neck. They also informed me that I have optic neuritis, I needed to be hospitalized that night and start the treatment immediately. I still remember it as if it happened yesterday; that I was explaining to our then 9 year old twins what was happening in the family. That night was the scariest night of our life. As my primary treatment, they started with steroids and gabapentin to help with my vision and referred me to a neurologist. Those five days of steroid infusions were some of the most painful days of my story thus far.

As the day was passing my body was showing some more symptoms, like I tried to step out of my car and almost



Multiple Sclerosis to Registered Nurse cont.

fell. My legs felt numb, my ribcage felt like it was being squeezed. As the hospital stay progressed and through the neurological examination they noticed that my right side was weaker. Just like the blink of an eye, the transformation from an independent person to a disabled person was fast for me. As the day's were passing no treatment was affecting me. So, the team of doctors decided to do 7 plasma exchanges, by that time results from the lumbar puncture would be there and they could decide what was happening with me. Months in hospital were traumatising for the kids. Due to the Covid border restrictions during this time, our overseas family was not able to come and help us.

A month after being hospitalized, results came back and the neurologist confirmed that I have Multiple Sclerosis. When I met my MS specialist, they diagnosed me with relapsing-remitting Multiple Sclerosis. After discussing treatment options, because of the aggressive nature of my MS, the team has decided to do 4 weekly Tysabri® (Natalizumab) infusions. My frontal vision came back but the peripheral took a month or longer to fully recover. It took nearly one year to get everything under control.

Throughout my stay in the hospital, whenever I had a consultation with the team and we didn't understand what they said or what was happening with me, I used to run to the nurses to help me to translate. Also, I came across some of the most fabulous nurses who advocated on behalf of us like a family. Seeing that inspired me to become a Registered nurse. To advocate for people like me who don't know what is happening and also support them in their worst time in their lives. For this I approached The University of Waikato. The process of learning to become a nurse seemed daunting in the beginning, but looking back on it now, I can honestly say that it was fun. Now I am working as a registered nurse in the Regional Renal Centre. Working as a nurse is the most rewarding experience I have ever received. Beyond helping the patient, the patients are helping me to see my life in a different lens. Every patient in my unit has a different story or different difficulties that they face in their life. But there is only one moral that they teach me, which is to face your life with a bit of a smile.

On my darkest days, I still allow myself to grieve. There is lots of pain, tears, screaming, anger, and feelings of depression. I accept my ever-changing feelings about living a life with MS. I try to live my life despite MS, and I am constantly working on my coping mechanisms. To balance my work and family, I try to understand my body's needs, and ensure that I am being heard. I have accepted that I have MS, and I have to do things to keep it controlled and at bay; taking medications,



working out, trying to minimize as much stress from my life as possible, eating healthy, holding onto hope for new medication options and maybe one day a cure. In some ways I feel like MS has made me a better person, I have more empathy for others and understand materialistic things aren't important.

I am very fortunate to have wonderful family and friends who support me and a wonderful care team that is always on my side to help me to continue to improve and reach my goals. I'm so grateful that my husband is the most thoughtful partner that I could ever have imagined, always having my back and one step ahead, anticipating my needs. Receiving calls from Karen Bird and Liz Hogan and connecting with the MS Waikato community has also been a huge source of strength for me. Having others who understand what I'm going through; it helps me feel less alone and learning about my MS and how to overcome it has helped me to get back into my life. The exercise classes help me control my symptoms, improving both my well-being and mood. I am looking forward to the next MS family camp, and plan to continue studying to become a nurse practitioner. Life with MS is unpredictable, but I've learned that even in the hardest moments, there's strength to be found. Weakness is our strength somewhere. Even though life with MS is unpredictable, I've discovered that strength may be found even in the most difficult circumstances.

Thara Kurian

5 Stretches for MS Spasticity

Gentle stretches can help you manage spasticity, a common symptom of multiple sclerosis (MS) that causes muscles to feel abnormally tight and stiff. As many as 90% of people living with MS will experience spasticity at some point.

Muscle spasticity and MS can make it harder to move and increase your chances of falling.

Stretching exercises for MS can help with MS spasticity, relieve pain and muscle spasms, improve mobility, and support your independence and quality of life.

Before starting any MS stretches, talk to your doctor or a physical therapist about which exercises are best for you.

How stretching helps MS spasticity

Stretches for MS spasticity can help loosen tight muscles and improve flexibility, which can also reduce the frequency and intensity of spasms that often accompany muscle stiffness.

Symptoms of MS spasticity occur when nerve signals between your brain and muscles are disrupted by MS-related damage.

When nerve signals are disrupted, your body may compensate for the resulting muscle weakness by increasing muscle tone. This causes your muscles to become tight, stiff, or prone to spasms, which are sudden, involuntary muscle movements. MS spasticity can be uncomfortable and painful.

MS spasticity affects everyone differently. For example, you may have a stiff foot or ankle that results in difficulty moving, while another person may have tightness in their leg or hip muscles. The spasms can also vary from one episode to the next.

When MS spasms are more frequent and severe, they may also disrupt your sleep, limit social activities, and make you more dependent on others. All of these can take a toll on your mental health.

Common MS spasticity triggers include extreme temperatures (very hot or very cold), sudden movements, infections, humidity, and tight clothing.

Exercise in general is a good way to support your overall health and manage your MS symptoms.

To complement the benefits of stretching, you can add yoga-inspired moves or light massage to your routine. Yoga stretches for MS can include traditional poses that are modified with props or done while seated (sometimes called chair yoga). There is no right way — it is whatever you can do comfortably.

As MS spasticity often affects the lower body, stretches that focus on the hips, calves, ankles, and feet are particularly helpful.

When you do these stretching exercises, keep your movements gentle and slow to avoid triggering a muscle spasm. Stretch until you feel a slight pull, hold the position

for about 30 seconds, and repeat the stretch three to five times on each side.

Never force your body into any position. Stretches should always feel gentle and controlled, and the right form is very important. Move slowly and listen to your body to prevent strain or discomfort.

As you become more familiar with the stretching exercises and learn how much to stretch without any discomfort, you can slowly increase the time for each pose to up to two minutes.

1. Hip crossovers

The goal of the hip crossover stretch, or belly twist, is to decrease muscle tightness in the hips by stretching and lengthening your hip muscles.

There are many variations, but the basic approach is to:

- Lie on your back on the floor or a bed.
- Keep your arms to the side, forming a letter T shape with your palms facing down.
- If possible, bend your knees into a 45 degree angle.
- Pull your knees together.
- Gently let both knees slowly rotate to one side.
- Hold the stretch for 30 seconds.

2. Hip flexor stretch

Your hip flexors are a group of muscles in front of your hip that help you lift your leg and knee toward your torso, bend forward at the waist, and stabilize your pelvis when moving.

When hip flexors are tight or weak, you may experience issues such as reduced mobility and feelings of discomfort and pain during activities involving the hip joint, such as standing, walking, kicking, or climbing stairs.

This is a good exercise for someone with tight muscles to stretch the hip muscles:

- Sit up tall at the edge of your chair or bed.
- Recline backward.
- You should feel the stretch in the front of your leg where it attaches to your hip. The further you recline, the more of a stretch you will feel.
- Hold the stretch.

3. Calf stretch

For people living with MS spasticity, tight calf muscles can make it difficult to walk.

An exercise you can do after getting dressed in the morning or before going to bed will help you stretch your calf muscles:

- Stand and place your hands flat against a wall at shoulder level.
- Move your right foot back about 12 inches or as far as you can safely manage.
- Bend your left knee and lean toward the wall while keeping your back upright.

5 Stretches for MS Spasticity *cont.*

- You will feel a gentle stretch in your right calf muscle.
- Hold the stretch for 20 to 30 seconds and switch sides.

4. Ankle stretch (heel cord stretch)

The ankle stretch requires only a towel and a chair. The stretch can help with ankle spasticity, which can worsen foot drop, a condition that makes it difficult to lift your foot when taking a step.

- Sit on a bed or a steady chair with your back straight.
- Put your right foot on a stool or something sturdy in front of you. Put a towel or a scarf around the bottom of your right foot.
- Pull on the towel with both hands to stretch your right foot toward you.
- Keep your right knee straight while doing the exercise and hold for 20 to 30 seconds.
- Repeat on the other side.

5. Foot rolls:

Foot rolls using a small ball can help reduce spasticity and, in turn, improve balance and mobility, especially if you have foot drop.

To do foot rolls

- Stand while holding onto a support, such as a chair. You can also do the exercise seated.
- Place a small, soft ball under your toes and press down.
- Slowly roll the ball from your toes to your heel and back again.
- Switch feet and repeat the exercise.
- For best results, a softer ball with some give, such as a massage ball, is better than a hard ball made from harder rubber or plastic, which can cause muscles to tighten even more.

<https://multiplesclerosisnewstoday.com/5-stretches-for-ms-spasticity/>

The Michael Ford Memorial Golf Tournament

Our annual golf tournament took place in March, originally established by Michael Ford, a client who we have sadly since lost, it is now in its 26th year.

With a full field and a beautiful sunny day, the event raised \$7,676.

Overall best Stableford was awarded to Phil Counsell.

Thank you to our generous sponsors and supporters, to the players without whom the tournament wouldn't be possible and the Ngahinepouri golf club who donated the course to us for the day. Thank you also to Sue who ran the gambling hole, our Patron Kay as our Master of Ceremony, to Keith our Chairperson and Joanne Ford who both joined us for the prize giving.

Our sponsors help in a variety of different ways, some making a monetary donation, others donating prizes. They choose to do this to help make a difference; all funds raised remain in our region to assist with the provision of support and education services for our clients and their whanau.

Please do remember our sponsors and support them too.

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Joanne Ford, Phil Counsell, Kay Gregory

Stars in the Sky – Psychosis in HD

New research shines a light on an often-overlooked side of Huntington's disease—psychosis. Understanding the impact of psychosis on daily life and progression of other HD symptoms could be key to providing better care and support.

Imagine battling a disease that not only affects your body but also causes your mind to lose touch with reality, making it hard to see the world as it really is. This is the heartbreaking reality for many people living with Huntington's disease (HD) who also experience symptoms of psychosis. Professor Clement Loy and his inspiring team of researchers from the University of Sydney investigated how psychosis symptoms in HD may affect the lives of these people.

Breaking the Silence

HD can cause symptoms across three main areas: mood, mind, and movement. For some people with HD, one of these areas may be more impacted than the others. What's important to remember is that each person with HD has their own unique journey, much like how every star in the sky is unique. Symptoms and progression can vary from one person to the next.

Each person living with Huntington's disease shines in their own unique way, like a star in the sky, adding their light to the world in ways only they can.

For some people with HD, mood and mind symptoms can be more intense, and this can sometimes lead to a set of symptoms known as **psychosis**. A person struggling with psychosis symptoms may experience hearing voices that aren't there, having hallucinations, believing things that aren't true, or feeling confused about what is real and what is not.

This can add an extra layer of difficulties for someone who is already struggling with other symptoms associated with HD. Psychosis can be a sensitive topic for some, but by opening up discussions around psychosis, it is hoped that the topic will become more widely understood and talked about.

Shining a Light

An important study by Professor Loy and his team investigated how psychosis symptoms may impact daily life and the progression of HD. They aimed to better understand the challenges faced by people with HD, who also suffer from psychosis symptoms. Beyond the mental toll, the researchers concluded that psychosis appears to have an impact on particular movement symptoms in HD.

The researchers gathered information from people who tested positive for the gene that causes HD – both individuals displaying movement symptoms, as well as individuals who were not yet displaying any movement symptoms.

“Studies like this remind us that mental health is just as important as physical health in HD care. By talking openly and honestly about psychosis symptoms, we empower people with HD, their loved-ones, and medical professionals to provide better support and reduce misconceptions.”

Over 1,000 participants were invited to complete questionnaires and assessments to measure mood, mind, and movement symptoms, every year, for 5 years.

- Movement symptoms were measured by participants performing different motor tasks, such as walking in a straight line.
- Mind symptoms were measured through an interview with a researcher. This involved remembering and repeating words and following simple instructions.
- Mood symptoms were assessed through a questionnaire. Questions focussed on assessing mental health and behaviour in participants. For example, do they feel sad, nervous, or frustrated?

Different Stars, Different Paths

Around **1 in 6** people with HD, about 18%, in this study experienced psychosis symptoms at some point during their lives. In those people, the researchers found that they had less independence and ability to carry out day-to-day tasks, reduced cognitive ability, and increased behavioural symptoms. This is perhaps unsurprising given the intense effect that psychosis can have on a person's ability to function, think, and behave.

One of the more surprising findings in this research was that people with HD who experienced psychosis symptoms appeared to experience **less uncontrollable jerky movements or uncontrolled twitching**. These very common movement symptoms - known as [chorea](#) - are often seen in people with HD.

There are a number of coping strategies that you can try to help to manage psychosis symptoms, including: medication management, psychological support, routine & structure, and having open conversations. Remember to always consult a medical professional if you, or your loved one may be experiencing symptoms related to psychosis.

To make sure there weren't external factors contributing to reduced [chorea](#), the scientists adjusted for the use of some medications, like antipsychotics and tetrabenazine, that can affect movement symptoms associated with HD. However, the authors acknowledge that a limitation of this study is the lack of detail around dose and duration of the use of these types of medications. Even still, this finding highlights how some people with HD will experience very different levels of mood, mind, and movement symptoms. This enlightening research by Professor Loy and his team, reflects back to how unique each person with HD is.

This research has raised interesting questions: Could those who experience psychosis symptoms in HD have different **brain chemistry** or **genetics** compared to those who do not experience psychosis symptoms? This is because those with psychosis symptoms did not seem to follow a similar pattern for movement symptoms, compared to those who do not experience these symptoms. Although this study did not provide definitive answers, it does support the idea that HD does not follow a 'one-size-fits-all' approach.

Guiding the Way

For individuals and families affected by HD, the presence of psychosis symptoms can be particularly distressing. Caregivers may struggle to understand the sudden paranoid

Stars in the Sky – Psychosis in HD cont.

thoughts or when their loved-one is hearing or seeing things that aren't really there. The person with HD, who is also experiencing psychosis, may feel confused, frightened, or defensive when their reality does not align with others.

If you are a person with HD or if you are a caregiver for someone with HD and relate to some of the psychosis symptoms discussed in this article, you are not alone. There are a number of coping strategies that you can try to help to manage these symptoms better, which could improve quality of life.

“For people navigating the journey of HD, one message remains clear: you are not alone, and your experiences, both physical and emotional, are valid and worthy of support.”

Potential Coping Strategies for Psychosis Symptoms

- **Medication Management:** Antipsychotic medications may help, though their use must be carefully balanced as they can sometimes worsen movement symptoms. If you want to explore the use of antipsychotic medication, please consult a medical professional, such as your psychiatrist.
- **Psychological Support:** Therapy can help both people with HD and caregivers in managing distressing symptoms.
- **Routine and Structure:** Providing a predictable, supportive environment may help ease feelings of agitation and confusion for people with HD.

- **Open Conversations:** Recognising and discussing symptoms without judgment can help increase understanding and reduce stigma of psychosis symptoms.

Shattering Stigma

Psychosis, particularly when linked to a condition such as HD, remains **a difficult topic to discuss**. There is often fear and misunderstanding surrounding psychosis symptoms. However, studies like this remind us that **mental health is just as important as physical health** in HD care. By talking openly and honestly about psychosis symptoms, we empower people with HD, their loved-ones, and medical professionals to provide better support and reduce misconceptions.

HD effects **both body and mind** in deeply intertwined ways. As research continues to unravel the mysteries of HD, understanding the mood and mind aspects, including psychosis, will be key to providing compassionate and effective care. For people navigating the journey of HD, one message remains clear: you are not alone, and your experiences, both physical and emotional, are valid and worthy of support.

Remember, each person living with HD shines in their own unique way, like a star in the sky, adding their light to the world in ways only they can. As we continue to learn and grow together, let this article be a source of strength, compassion, and hope, illuminating the path for others facing similar challenges.

By Maille (Molly) Gracey, edited by Dr Sarah Hernandez – HD Buzz

Scholarships - Currently open to people with MS

Mastering Mountains

Mastering Mountains offers rehabilitation support and mentoring to people diagnosed with Multiple Sclerosis (MS), Functional Neurological Disorder (FND) or similar neurological conditions to help them overcome a specific obstacle so they can accomplish a self-directed objective in New Zealand's outdoors.

There are two programmes that people can apply for:

1. Mastering Mountains Programme for single-day outdoor goals.
2. Mastering Mountains Expedition Programme for multi-day outdoor adventures that involve at least one other person.

Successful applicants are motivated individuals with an achievable outdoor goal that will improve mobility, encourage a healthy lifestyle, and strengthen their connection to community. In their programme, these people receive rehabilitation support (neuro-physio or personal trainer), outdoor gear and equipment, and mentoring, all aimed at helping them achieve their goal within a year of their application.

Each person's programme package is individualised at the discretion of the Selection Panel. Previous packages have included up to \$2,900 in rehabilitation support, gear worth \$1,000, and mentoring services valued at \$3,100 for a total of up to \$7,000.

Applications are open to New Zealand residents with a neurological diagnosis and are received annually between the 1st of April and the 31st of May. For more information go to the MSNZ website - <https://msnz.org.nz/scholarships-and-grants-2/>

Please note: due to funding constraints, we are only able to offer ONE space on our 2025 programmes.



AGM Updates

The MS Waikato AGM was held on the 27 March; we are pleased to share that we have retained all our Trustees who are keen to continue to serve the organisation.

We are fortunate to have a strong and robust board who bring a diverse range of skills from their different backgrounds. The board continues to be led by Keith Small as Chairperson, and Dave Cordery as Deputy Chairperson. In addition, over the past few months, we have gained two new Trustees - Rachel Webster and Hongxia Tang who have both been co-opted onto the board. Rachel is a lawyer, Hongxia has a background in banking. Our other Trustees are Euan Reeve, Amber Hammill, Bill Shaw and Brenda Johnson.

Our Trustees all work in a voluntary capacity and we would like to express our sincere thanks and appreciation to them for the time they give and the knowledge they share.

MS Research

Study finds specific gut bacteria linked to MS

New research suggests that certain gut bacteria may raise the risk of developing multiple sclerosis (MS), opening up potential new paths for treatment.

A team from Ludwig Maximilian University of Munich studied 81 pairs of identical twins, where one twin had MS and the other did not. By focusing on genetically identical individuals, the researchers were able to control for genetic risk factors and highlight environmental influences instead.

Their analysis revealed two types of bacteria – Eisenbergiella tayi and Lachnoclostridium – were more common in the guts of people with MS. To explore this link further, they transferred gut bacteria from the twins into mice genetically predisposed to develop MS-like symptoms. The mice that became ill had gut microbes pointing back to these specific bacteria.

The findings strengthen the theory that gut health plays a key role in MS, possibly triggering immune system attacks on the brain and spinal cord. While the study relied partly on mouse models and more research is needed to confirm the connection in humans, it provides a clearer starting point for future studies.

The researchers hope their work could eventually lead to treatments that modify gut bacteria to prevent or slow down the onset of MS.

Source – MS-UK

<https://ms-uk.org/news/study-finds-specific-gut-bacteria-linked-to-ms/>

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 (8th July) – 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, (5th June, 3rd July & 7th August) - location varies, contact Liz or Karen for details – 10.30am

Raglan

MS Support Group – 3rd Tuesday in the month, (17th June, 15th July & 19th August) - Orca Café - 10.30am

Te Awamutu

MS Support Group – Quarterly group meeting Wednesday 11th June, Churchill Café – 10.30am

NOTICE BOARD

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

Subscriptions & Payments

Please note 2025 subscriptions are now due. The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed if subscriptions have not been received. Any payments or donations can be made directly to the MS Waikato bank account - 02 0316 0488196 000. 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.

World MS DAY

Friday 30th May
- A global awareness day to raise awareness of Multiple Sclerosis

Library Books

Please remember we maintain a library of books. With books to support MS and HD, a list of titles is available on our website www.mswaikato.org.nz. Please contact us if you would like to borrow a book.

Entertainment App

MS Waikato are selling the Entertainment apps again, 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.

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

Wheelchairs

MS Waikato has wheelchairs available for loan, for all enquiries phone 07 834 4740.

TravelScoot

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

Dogs in Homes

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

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.

Thanks to our Sponsors and Supporters

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