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Multiple Sclerosis Auckland Magazine

July 2022 | Issue 53



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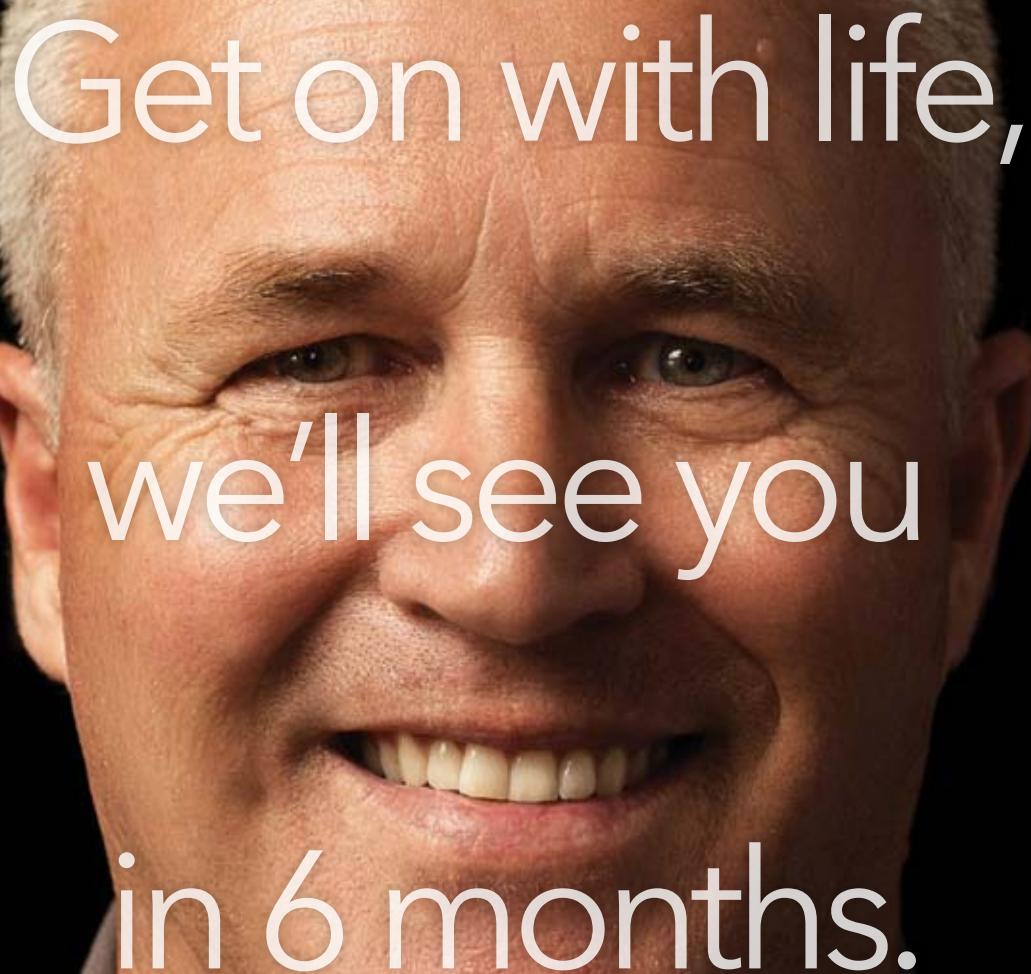
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Welcome

Kia ora koutou.

Warm greetings to you all, and welcome to this edition of Multiple News.

For many across the globe exercise habits were a victim of the restrictions of the COVID pandemic. This edition brings together inspiring stories of exercise and wellness from within our community.

Megan introduces us to her beloved e-bike (page 5) and how it has become an essential element of her everyday life. Tim Tams were amongst Amit's motivational factors for fitness! On page 10 he describes his journey to an impressive 16 kilometre awareness and fund-raising walk. Finally, Amanda shares how powerlifting changed her life (page 20).

The edition is rounded out with a feature by Lisa (Gombinsky) Roach, exercise professional, who outlines the importance of exercises for everyone, and addresses some of the myths surrounding MS and exercise (page 14).

An array of group exercise options, both land and water based, operate across Auckland. There are MS specific classes, programmes for neurological conditions, and more accessible mainstream classes. Check out the 'Exercise Programmes' section of our website and try something new.

Many thanks to all the contributors to this edition of Multiple News. I would love to hear any ideas or stories you may have for future editions.

I'll close with a *whakataukī* (proverb) which echoes the many inspirational stories in this edition. *Kia kaha, kia maia, kia manawanui* (be strong, be brave, be steadfast).

Nicola Bitossi
General Manager

On yer bike!

Megan lives in central Auckland and has a busy full-time job

I squinted at them.

It was a case of who was assessing who now. Had the arthritis specialist and his young counterpart slipped into the drugs cupboard before my appointment? The verdict was repeated, *"For treatment you will need to buy an exercycle and go to physio."*

Where were their magical doctor-y fix-it powers?

I complained to my doctor I didn't want an exercycle. Moreover, I pretended I could get an e-bike. My doctor cheerily replied, *"Buy an e-bike then. One of the nurses here e-bikes from her home in Stonefields to work at Freemans Bay and she loves it."* A hard-working nurse riding such a distance each day sure was impressive.

In 2011 I was diagnosed with MS. The experience meant the osteo arthritis verdict was just another thing.

By Megan Otto





Big thumbs up from brother Justin for Megan Otto and her beloved e-bike.

Months later and nothing else forthcoming in the knee rescue department, I started to frequent cycle shops.

One shop assistant said to me, “*You can’t choose a bike by looking at it you know – you have to ride it.*” And this is how it turned out to be in every cycle shop. They all equipped me with loaned helmets and instructions to take the e-bikes up the steepest hills. My grin grew miles wide every time I rode up a hill with just a relaxed swing of the pedals. Woah horsey! Other e-bikes were less powered and they made me realise I was never going to make the Team NZ grinders team.

One day I asked to try a bike under \$2000. Oh, you don’t want to try that one, it’s not very good the shop woman told me. The seat was wide and padded. The frame didn’t look too heavy. The tyres were fat. The least desirable bike turned out to be just right.

Now as I cycle past cafes, I can actually smell the coffee and if the wind direction is right the mangroves are salty. When it’s a blustery I’m buffeted around like visitor on a fairground ride. The rain needles. When bugs collide with my face, I’m hopeful that they live.

Bicycle assistance can be dialled up or down depending on how much energy I have. The goal is to strengthen the muscles around my knees.

One day for work’s Friday drinks, I collected fish and chips from a pub. After watching me tether my e-bike to a handy stop sign, barman’s eyebrows turned into mini-San Francisco bridges. *“Did you cycle here? Hardly anyone cycles. Back home I had to cycle for a knee injury,”* he continued, *“It took six months but it worked.”* Come what may though, I have inadvertently become smitten with my free and green transport.

Yes, but does it help with MS you ask? I’ve been on the Jelinek diet since being diagnosed. I have the MS Society, Auckland to thank for giving me this life-line which has ‘held’ my MS in check (no relapses since diagnosis 11 years ago). Exercise is part of the Jelinek programme- though you don’t have to look far to see other sources endorsing aerobic exercise as being helpful for MS.

I’ve found cycling has surprisingly made me all-round fitter. The only times I’ve fallen off my bike is when it has stopped! There has been scratches, bruised egos and pride in myself for getting back on the proverbial horse – again and again.

I try to do as many chores as possible on my bike. Having to do something is motivation and thereby the exercise gets done regardless of my sluggish attitude to working out. Probably the best reason to cycle is being able to go door-to-door. A few loops around the supermarket aisles with a bung knee and I expect to see a ticket tape parade to celebrate my achievement. It’s a relief being able to park my cycle right by the front doors (next to the pooches).

The bike has also been a reason to take me and my MS and OA out-and-about. I even visited friends in Hobsonville via cycle because Fullers allowed bikes on the ferry. Though ship-hand was insistent that my saviour must remain outside on the back deck. The spray thankfully flew backwards and bike was none the worse for the nautical adventure.

Admittedly my mobile gym unit is a bit hefty to manoeuvre in and out of lifts, up and down stairs. Though one of my Hobsonville friends said she read an article about women’s health and the gist of it was, *“Lift heavy sh*t!”*.

Sister, I hear you.



From our MS nurses

Criteria adjustments smooth pathways

It seems the winds of change are finally blowing at PHARMAC.

Submissions are currently being called for regarding the funding of disease modifying treatments (DMTs) for those people with MS who have had one relapse only and consequently do not meet current criteria for treatment.

At the present moment two relapses are required to meet the treatment criteria. This has caused much heartbreak for those people effectively waiting for another MS relapse to occur before being able to access a preventative treatment to protect themselves. The stress of this and the worry that the next relapse may bring significant physical issues has been immense for those impacted.

So we wait optimistically for the outcome of these submissions, and will update the Auckland MS community when more is known. If you are someone effected by the current criteria we invite you to contact your CA, GP or MS nurse to discuss this so a review can be arranged.

Those of you out there already on PHARMAC subsidised medications for your MS may recall the angst of the annual assessment at the hospital. Historically, along with seeing your neurologist there was a need to do a dreaded 500 metre ‘walk’ to meet the criteria. This requirement was for many anxiety provoking and more especially so for those whose assessment fell over the summer months when the humidity of Auckland wreaked havoc for those with MS symptoms.

Fortunately the rules around this changed about 18 months ago. The 500 metres has dropped to 100 with the added ability to utilise bi-lateral support (2x sticks) meaning that meeting and staying on treatment is much more achievable. If you do feel that a 100 metres is getting to be more of a strain we advise you speak to your CA at MS Auckland about a physio referral to keep you as flexible and strong as you can possibly be.

Hopefully this has removed some of the concerns around these reviews, as it is so important to use your annual review to check in with your neurologist, so please do prioritise your review, you’re worth it!

If travel is a significant issue which it certainly can be for some, there is also scope to arrange a phone review rather than have one in person. You are able to request this by calling the number on your appointment letter or calling (09) 307 4949 extn: 23241.

Fiona d'Young & Nazila Samadi
Multiple Sclerosis Specialist Nurses
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A life changing experience!

MS: the third person in your relationship



By Nicola Duncan,
Counsellor, Hearts & Minds

For people living with MS, or any chronic illness, often the disease (and children, if applicable) takes centre stage. It may be helpful to take a step back and consider your relationship and how you might protect it going forward.

If you were in a relationship prior to diagnosis, the important first step is recognising that MS changes a relationship. The most tangible and obvious changes include a redistribution of household responsibilities such as chores. Finances may also become tight if household income is reduced. Socialising can also be impacted by many factors including fatigue. Less recognised impacts on the relationship include changes to the sexual activity and ongoing worry about health (by all parties).

All these changes create potential for conflict as a couple navigates their way through new territory. Alternatively, to avoid conflict, sometimes people bottle things up rather than airing them within the relationship.

Common scenarios include the person with MS feeling like a burden and a sense of guilt that they cannot do more around the home; to generate income, with the children, and so on. Conversely, the partner may be reluctant to say if they are struggling with extra responsibilities, for fear of seeming critical or disloyal. What a bind! Although the intention in both of these scenarios is good, it can create a divide between the two.

A helpful tool is as follows: separate the MS from the person. Create a persona for a third person in your relationship/marriage – albeit an unwelcome one! – called MS. Illness does not define the person with MS, so make a strategy to view the person and the MS separately.

By recognising the impact of MS on both of you, it should enable you both to talk about MS freely, and discuss how you will handle it, together.



From our CAs' corner



Resilience has been written about and valued since time immemorial. Its value is transmitted down generations through axioms, mythology, anecdotes, and even children's books.

In essence, resilience can be thought of as a process of successfully adapting to maintain or regain emotional well-being in the face of adversity. It does not mean that distress is not experienced; rather, it is a process through which an individual's thoughts and behaviours overcome distress and optimise positive outcomes.

Unpredictable symptoms, difficult treatment regimes, and uncertainty about the future of multiple sclerosis require people diagnosed with MS to adapt to new life changes and restrictions.

However, several factors can contribute to resilience and quality of life, and these factors are amenable to intervention.



Getting the Basics Right

keep physically healthy, eat a healthy diet, drink enough water, have good hygiene habits, get exercise, get enough time out, rest and sleep, and see a doctor if unwell.

"Every difficulty in life presents us with an opportunity to turn inward and to invoke our own submerged inner resources. The trials we endure can and should introduce us to our strengths..."

Dig deeply. You possess strengths you might not realise you have.

Find the right one. Use it."

Epictetus, The Art of Living

A Support Circle

having a range of positive, supportive relationships e.g., whānau, friends, colleagues, school community, neighbours, team-mates, a cultural community, a faith community, an interest group, and your local community in general. Having a sense of belonging, being included and being connected.



A Sense of Self-Worth

believing in one's own value and worth – being aware of your strengths, skills and qualities.



Life Skills

learning the skills that help us with everyday challenges. Such as; how to problem solve, make decisions, set goals, source information, communicate, manage strong emotions and difficult thoughts, make and keep friends, understand and accept difference, resolve conflict, manage money well, keep safe from harm and ask for help when it's needed.



A Sense of Competence

knowing one's strengths, abilities, skills, gifts – using them and feeling a sense of success and satisfaction – realising no one's perfect, we all make mistakes sometimes.



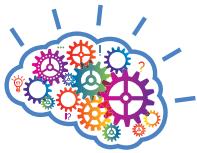
Flexibility

able to bend a little as situations change – being willing to try to adjust and give new things a go.



Creativity

learning to look at things with fresh eyes or from different angles – approaching things in new ways.



A Sense of Humour

able to laugh at things to relieve tension, connect with others and put things into perspective.



Perseverance

willing to keep on trying, despite setbacks – expecting that the end goal can be reached, bit by bit.



A Positive and Hopeful Outlook

being optimistic and expecting to get through difficult challenges okay and enjoy better times – looking beyond the present to a more positive future – having a sense of purpose.



Your Community Advisors



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These are key messages that Community Advisors are promoting and encouraging our members to implement in everyday life. From physical health and healthy diets to a positive and hopeful outlook, from fostering that special sense of belonging, of being included and being connected ... these ideas are embedded in our praxis and promoted at support groups, live events and online webinars.

It is also what keeps us going as professionals: seeing people becoming stronger and more resilient, increasing their ability to adapt to sudden changes and, sometimes... why not?... to find the silver lining. That is resilience after all!

By Luminita Apostol and Catherine Glover
Community Advisors for MS Auckland



The Coast to Coast

By Amit Abhyankar

Amit is an active member and former board member of MS Auckland. He works in the banking sector, and lives in Hillsborough with his wife and son.

A few years ago, I wrote about going on a massive fitness and weightless journey to be able to cross the Tongariro Crossing. Then, Covid happened.

My initial response to Covid was that of being scared as to what was to happen to me considering I am on immune-modifying drugs that I take to combat multiple sclerosis. This meant I went into a bubble and reduced interactions with others, and with that came stress eating and reduction in exercise.

In the space of two-and-a-bit years I put on about 20 kilos. This was largely due to almost no exercise and eating Tim-Tams. There were days when I was watching a movie on the television and I would demolish an entire packet of Tim-Tams.

A few months ago, I reached a point where I realised that this must stop, and something had to be done.



Walking up Maungakiekie.





A well deserved break in Mt Eden to enjoy the city vista.

I approached a few of my friends with an idea to get fitter and exercise with a goal to complete the Coast-to-Coast walk in Auckland. This takes you from the Waitemata harbour to the Manukau Harbour across 16 kilometres of our gorgeous city and we climb through the three peaks of Auckland Domain, Mount Eden, and One Tree Hill.

A date was set for 13 March 2022. A group of us started pushing ourselves to focus on fitness and endurance as for me personally this was never going to be an easy feat.

My wife and I started training for this by walking around the block and slowly increasing to about five kilometres every second day to get our legs used to walking again.

At the start after two kilometres my legs would give in and I would just rest on the next bench or a patch of grass I could see on the side of the road. The more I walked the better the legs got and the more I was able to push myself to go further.

On the day of the walk, I was amazed at the support I received as 16 of us started from Downtown Auckland at 8am. Throughout the journey we had additions into our group with friends and family that wanted to support us and walked a part of the walk with us. The walk surely



gave us what it promised, amazing views of Auckland city. We also took a few detours out from the walk and lots of breaks for hydration and snacks to keep us going.

It was 30,905 steps and 20.49 km that we walked that day. We took five hours for the whole walk and it felt amazing to complete this. I would recommend this to everyone as you get to see our amazing city up close.

Would I do this again? – absolutely I would.



Volunteer profile:

Kevin Miller



What motivates you to volunteer for MS Auckland?

I have been an active member of the Society back to the North Shore Days. Highlights for me have been the annual research days, hydrotherapy classes and connecting with people with MS (PwMS) and supporters.

I have the life and management experience, and following my recent retirement have time to commit, to making a greater contribution to the Society and was delighted to accept the board member nomination. I'm a firm believer that PwMS, or those closely associated with PwMS should be playing key roles in leadership and direction of the Society.

A little bit about me

I'm originally from Christchurch, and in my earlier more active days I even wore the red and black on Lancaster Park in a colts team. We, Christine and I, moved to Auckland in 1976, and have lived in Birkenhead ever since. Our grown-up family, twin boys, fortunately also live in Auckland. We were very active growing up, camping, sailing, dad coaching successful junior boys rugby teams and travelling. I was involved in information technology from the late 70's, banking deregulation in the 80's, executive management in the 90's and latterly as an IT consultant. Late last year I finally retired.

A movie followed by dinner out is a typical weekend treat. We were regular travellers prior to Covid. My last trip was a road trip with my London based sister to Ypres in Belgium, Northern France to see a great uncle's World War 1 grave, then south through France for a week in Brittany.

Anne Schofield had lots of good travel advice in her March 2022 Multiple News article.

MS and me

I was diagnosed with primary progressive MS in 2000, I was playing over 50's touch rugby and sailing at the time and found my balance wasn't what it might have been and I also experienced tingles in my feet. Fortunately, my neurologist diagnosed my MS quickly. I had experienced a single episode of optic neuritis in 1977 but no indication was provided at the time that this may be a precursor to MS. I was to learn later that my younger sister had a similar PPMS diagnosis to mine in the same period, unfortunately her progression has been more significant.

Overcoming Multiple Sclerosis (OMS), a personal experience

My early MS progression wasn't significant, in fact it would be 12 years until I revisited my neurologist, and in 2006 I walked the Routeburn Track. I had read Dr George Jelinek's first MS book, *Taking Control of Multiple Sclerosis*, later to become *Overcoming Multiple Sclerosis*, a volume many of you may have read and may even have met him at a couple of MS Auckland events from earlier research days.

It wasn't until Christine and I attended the first Jelinek Retreat on the Coromandel in 2007 and experienced a full immersion in the elements of what is now the Overcoming Multiple Sclerosis programme. Doing the programme became the guide to a healthier lifestyle and our life with MS.

For me that means

- Plant based and seafood low fat diet plus vitamin D supplementation
- Exercise, my last week has been two aquarobics classes, two walks and a Pilates class
- Mindfulness; acceptance, letting go and focussing on what you can control

Surround yourself with positive people

Latterly I have become the Auckland OMS circle ambassador. The circles are an international network of like-minded people with MS who are following the programme.

One of the opportunities that has come my way because I have MS is the opportunity to participate in the Oceans of Hope Challenge which has provided the opportunity for a week away on iconic yachts Lion NZ and/or Steinlager. I have had the absolute pleasure to share this experience on a couple of occasions and plan to join this year's challenge sailing from Auckland to Bay of Islands on Steinlager.

Sharing this experience with like-minded PwMS is very much a recent highlight. Poignancy for me here, I sold my yacht due to my MS balance problems, and my yachting experiences now are at another level.

I would encourage other members to take opportunities such as this, if they become available, they may present initially as daunting, but the shared experience is incredibly rewarding.

Duncan Grant provided his Oceans of Hope experience in July 2021 Multiple News.

Our focus groups give us meaningful insights

During March, MS Auckland held four focus groups to hear about our members' experiences and needs, and where they see the role of MS Auckland.

The dialogue from the sessions was analysed, themed, and used by the MS Auckland's Board to help inform its strategic review. MS Auckland's General Manager, Nicola Bitossi, says the groups and the individuals concerned provided some excellent insights into the understanding, knowledge and connections around multiple sclerosis. There was a range of MS type, gender, ages and engagement levels with MS Auckland, including time since diagnosis, within the groups.

While the highly valuable feedback on wants, needs and programmes has been woven into the member-facing strategy for MS Auckland, from those dealing with the condition, as it looks ahead, participants descriptions, feelings and emotions provided a deeper context for all those living with MS.

A wide range of words and phrases were used by participants to describe their relationship with MS. Most of the responses were positive and reflective, such as

*'life changing' 'opportunity'
'challenge' and 'resilience'*

There was also some reflection on the unpredictable nature of MS...

"None of us know what's around the corner and that's the biggest challenge from my perspective" said one.

The main challenges of MS were seen as perhaps not so much MS itself but the external issues at play such as dealing with friendships, employment, whānau and other social aspects

Disclosing to others that one has multiple sclerosis also comes with its own set of issues according to the participants.



"It becomes exhausting trying to explain it to people" and similar quotes were common.

This disclosure, they say, can come with judgements and stigma:

"This is something that I'm trying not to let define me, but I have to put in big letters on a form and then get judged for it".

The other theme of challenge relates to mental health and coping, being a burden, loneliness, self-care and depression:

"Owning it and it's part of me".

Other comments reflected some of the direct impacts of MS such as finances, education and symptoms.

Discussions around how MS Auckland's role going forward centred around three clear themes. Connecting and linking like-minded members; providing robust guidance and information; and advocating for member's needs.

The important or transitional points in the MS journey of participants included feeling a sense of shared understanding and ability to talk freely at support groups, feeling educated by the Community Advisor service and ready to get the most out of life.

The focus groups contributed to MS Auckland's service delivery strategy over three years. Connections features strongly, with a commitment to increase opportunities for members to connect with other like-minded members largely via an increased network of volunteers. Another focus is awareness raising in the broader community and developing resources and programmes to support and inform all Aucklanders who are impacted by Multiple Sclerosis.

Exercise for people with MS



By Lisa (Gombinsky) Roach,
Unruly Company

barriers posed by specific conditions. Remembering that people with MS are people who happen to have MS, let's start with general exercise guidelines for people, and then address some MS specific challenges and barriers.

The exercise guidelines for people (with MS) are:

Aim to move your body and elevate your heart rate every day for at least half an hour in addition to your activities of daily living.

Look for opportunities to be more active in your life.

If possible, include daily walking. Do some walking at a pace which is faster than your comfortable pace, include walking up and down hills and stairs, and make sure to walk outdoors, not just indoors or on treadmills.

Do some exercise that is at an intensity that is uncomfortable for you – get a bit out of breath – this is imperative for your cardiovascular health and for the health and resilience of your brain.

Do some strength and resistance work at least twice per week so that as you age you have the strength, stability, and mobility to do the things that are important to you. Weight bear, move your body through space, push and pull things. Exercise hard so you can live easy.

Challenge yourself physically and cognitively – try new things, set goals, have dreams, expect achievement. Don't just settle for decline.

Pay attention to mobility, flexibility, and posture.

Manage your niggles. Work on the things that are causing problems, don't avoid them. Don't let little things turn into big things and don't let disuse exacerbate problems. Get help if you need it and get that help early instead of waiting until a little challenge has turned into a big problem that your body is compensating for. Practice the things that you need to get better at. Do your homework. The improvements and new habits happen with practice and repetition, not when you are being supervised in an exercise session.

Exercise is a great opportunity for socialising and mixing with people. Social interaction is possibly THE most important thing you can do for your health and wellbeing.

Get some fresh air daily

Do things you enjoy, have fun.

As an exercise professional working with people with neurological conditions and disabilities for over 25 years, I am often asked to speak and write about exercise guidelines for people with specific conditions.

I have addressed exercise for people with neurological conditions, people with metabolic conditions, people recovering from cancer, people with dementia and cognitive challenges, people with autism, people with mental health challenges...

My answer is nearly the same every time, because regardless of what condition, illness, disease, or disability a person has, they are still people, and the general exercise guidelines for people wanting to move through life better and to ensure that their bodies and brains age as resiliently as possible despite their condition, illness, disease, or disability still apply: and often are even more pertinent.

Once we understand the exercise guidelines for people generally, we can look at condition specific things that need to be considered or prioritised, and challenges or

MS specific considerations: managing misinformation, heat sensitivity, and fatigue

There are some old-fashioned ideas about the dangers of exercise for those with MS which linger amongst people with MS and many of the health care providers supporting them. People are genuinely scared that exercise might cause an attack, an exacerbation of symptoms, or a more rapid rate of disease progression. This is misinformation – these ideas have not only been proven to be wrong but are arguably dangerous as they add to the existing barriers to exercise for people with MS.

The misinformation does not just come out of nowhere. Exercise can cause temporary inflammation, causes bodies to produce heat, and makes muscles and brains tired. This makes it really challenging to separate the normal effects of exercise from MS symptoms and means that exercise might cause people with MS who already struggle with heat sensitivity or fatigue to feel worse immediately after exercise.

This does not mean that a person with MS should not exercise. It means that it is important for individuals to find a way to exercise that works for them and having flexibility around that as required.

Having an exercise professional or physiotherapist that understands MS is imperative here, so that individual responses to exercise including heat and fatigue can be managed safely, exercise tolerance can be built up slowly, and that there is communication about what is a normal and expected response to exercise.

Specific benefits of exercise for people with MS

It is well documented in research that exercise – in particular, exercise at higher intensity – promotes the resilience of brain cells and neural connections. High intensity exercise encourages the brain to produce chemicals and growth factors that help brain cells push back against disease processes like MS and promotes repair and remyelination. Exercise strengthens the connections between nerve cells, improves the speed and fluency of communication between these cells, and helps maintain the volume of connections between them.

In addition, exercise helps prevent and manage secondary complications like muscle imbalances, weaknesses, and decreased bone density. Exercise promotes functional mobility and independence. It is essential for the integrity of bones, joints, and muscles, reduces fall risk, improves sleep, reduces depressions and anxiety, helps manage pain and fatigue, and reduces risk of other diseases including dementia, cardiovascular disease, arthritis, and diabetes in people with MS.

Exercise is important for all people – but in the face of MS it is an essential tool that must be understood as having the potential to be disease modifying, and as essential to the management of the disease, the minimisation of impairment, and the promotion of overall health, wellness, and wellbeing.

Editor's note: Lisa and colleague Mira are running weekly MS-Fit exercise classes in Hobsonville. Details on 'exercise programmes' on MS Auckland's website, or Google 'Unruly Company'.



Ever-busy Selma Blair says MS is all part of the journey

American multi-media star Selma Blair made headlines in August 2018 when she revealed to the world that she had been diagnosed with multiple sclerosis.

The resulting coverage and ongoing advocacy work by Blair has helped lift the profile of the disease to the larger community: even eliciting comment on the famed MS Auckland Facebook page!

Born in 1972, Blair at the age of fifty has an absolutely enormous body of work behind her in film, television, theatre, music and voice-over as well as her advocacy for numerous organisations including the Staying Alive Foundation and the US National Multiple Sclerosis Society.

In her autobiography, *Mean Baby: A Memoir of Growing Up*, she said for years she had thought that she was suffering from minor illnesses, or even a pinched nerve, but the diagnosis finally explained her disabilities, including her occasional falling, dropping things, foggy memory, and her left side acting like it was asking for directions from a broken GPS. She says she was inspired to reveal the news as a way to thank Allisa Swanson, her costume designer, who had become her unofficial "dresser" for her role in the Netflix series *Another Life*, saying that Swanson "gets my legs in my pants, pulls my tops over my head, (and) buttons my coats."

In a major interview in *People* magazine in 2019, Blair said that when she was diagnosed with MS she had to recalibrate her life in almost every way.

'Since her diagnosis, she experiences daily ups and downs living with the chronic neurological disease, never knowing what to expect from her mind and body when she wakes up every morning — aside from doting on and maintaining a schedule built around her eight-year-old son, Arthur.

'Blair says she is honest with Arthur about her new challenges and is constantly impressed by his resilience.

"He's had to endure a lot; he's seen a lot," Blair told *People*, including watching her fall down stairs or rush to a bathroom if she's feeling sick.

'But Arthur doesn't view his mom's weaknesses negatively, she says. "*He says, 'Mommy's not sick. Mommy's brave.'*"

'The actress says she was recently surprised to learn that Arthur enjoys having her visit his school. "*He said, 'I love when you come to school because you make the kids laugh and you answer all their questions,'*" she recalls. Blair says she doesn't shy away from explaining to the kids about why she "walks and talks funny."

"I explain what's happening and that my voice doesn't hurt, and we have really decent exchanges," she says. *"I had no idea Arthur was proud of that. I thought I'm probably an embarrassment,' but to know I'm not was one of my proudest moments."*

Interviewed this June for *Shondaland*, Blair was asked about what advice she would give to others who are in pain and seeking help for a chronic, invisible illness but just aren't being heard?

"I had decades of miserable symptoms. I'm still awed when I realise I didn't have the right way to explain symptoms. Like weakness; I would say 'tired.' Or a premonitory urge being the real discomfort, and the grunt I make is to alleviate the uncomfortable urge building. That was a relatively new phenomenon after diagnosis. The tics, completely new to me. I didn't even know how to find words for an uncomfortable urge in my body, like a restless leg syndrome that I get from a medication I take.

"I want to get to a nervous-system calm where I have less blocks. When you have chronic pain, fatigue, fever, or illness, it is exhausting for everyone involved. [It's] amazing an MRI could give me the affirmation I needed. All the CAT scans, tests, blood work, and therapists, and never, ever was an MRI ordered, even when my story necessitated one. [It was] a chronic mystery illness."

"So, an MRI — part of the answer. Shuts naysayers up. Diagnosis, then another journey begins. It's all a journey. The disability community has taught me so much about caretaking ourselves and our responsibility to each other in this far-flung society."



Recipe

Lentil and vegetable curry

Warming, nourishing and low cost – vegetable curries are a winner in the winter months. Freeze the leftovers for a night that you don't feel like cooking!

Serves 10. To make: 45 mins - 1hr



Ingredients

1 tbsp oil
1 onion, finely chopped
2 cloves garlic, crushed
1 ½ tbsp curry powder
1 tbsp garam masala
½ cup coconut cream
3 cups water
1 carrot, finely chopped
2 cups pumpkin, peeled and finely chopped
3 cups cauliflower, finely chopped
3 cups broccoli, finely chopped
1 can lentils, drained and rinsed
1 can evaporated milk
¼ cup fresh coriander, chopped

Method

1. Heat oil in a large pot and add onion, cook gently until lightly browned.
2. Add garlic, curry powder and garam masala and continue to cook for a further minute.
3. Add coconut cream and water and bring to the boil then reduce to a gentle simmer.
4. Add carrot, pumpkin and cauliflower and cook until just about tender.
5. Add broccoli and lentils and cook for a further 10 minutes until vegetables are soft.
6. Add evaporated milk and heat until just simmering then remove from the heat.
7. Garnish with coriander

This curry is best served with steamed brown rice.

Recipe from www.heartfoundation.org.nz





Lifting weights; an act of resistance

By Amanda Parish

Amanda lives with her husband and son, is currently completing her Masters in Counselling.

I read somewhere once that the squat is the perfect analogy for life. It is about standing back up after something heavy takes you down.

Maybe that is why after being diagnosed with MS 13 years ago, I was inspired to try powerlifting, and six years later love it more than ever. Powerlifting is about lifting the heaviest weights you can in the squat, the bench press and the deadlift. The competitions are weight class driven, you get three attempts at each lift, and your points are a ratio of what you lift to what you weigh.

I train at DecileOne gym in West Auckland, one of the most welcoming places you'll ever find. I joke that the gym is like my pub. I walk in and spend a fair bit of time on the couch talking to my friends. But then I get the joy of putting on my headphones, being by myself, and experiencing the meditative calm of pushing my body to do things I never thought I would be capable of.

The photos are from my last competition, which was a national's qualifier, and shows the many different faces of competition. Talking to the ref before getting called to lift, getting focused and ready to lift, and lifting.



An impressive 125kg deadlift.

That is a 125 kg deadlift. I weighed in at 55.1 kg for that event.

A standard session for me is around 2.5 to three hours, and I train three times a week. This gives me time to focus on enough rest and recovery in between sessions. Food is important to fuel my training, and I focus on unprocessed carbs and protein, with some fats. My current favourites are charred cauli and broccoli, pumpkin, chicken, with avocado and a side of light sweet chilli sauce. I am very lucky to have a husband who loves cooking and is incredibly supportive of my lifting and knows exactly what my 'macros' need to be.

I also prioritise quality sleep for my lifting and my MS. If I get a rubbish sleep it shows up in how I lift the next day. My MS also likes to be more present when I don't sleep well, eat properly, or exercise. My MS brain likes to kick off at night and tries to trick me into staying awake, so my sleep routine needs to include wind down time, a cool

room and magnesium citrate. I will also massage my feet and foam roll my back before bed to reduce some challenges I have with spasticity.

My coach Carli Dillen has been wonderful at challenging my inner voice which will often tell me I'm not good enough. Having this mindset is not helpful for my diagnosis or when I'm about to lift something that is over twice my bodyweight in a competition environment. To counter this we focus on the idea of marginal gains.

In other words what are all the small things, the five percent, that I can do that will add up to make a big difference. This applies for me in my lifting, my MS and my life. My mindset, my hydration, my meditation, my breathing, my supplementation, my medication, how I organise my routine, who I choose to surround myself with, what I choose to read – all these things contribute to improved performance.

I recently qualified for the New Zealand National Powerlifting Championships in August, and my next goal is to qualify for the Commonwealth Powerlifting Championships which are in Auckland this November. But before then I'm excited to be heading to South Africa as part of the New Zealand Powerlifting team to help coach our athletes competing at the world champs this June. After Commonwealths, I have my eye on qualifying for Worlds myself.

My son loves the fact he has a strong mum, and it gives him confidence in my ability to manage my MS. I will be lifting for the rest of my life, and plan to be a jacked gran in the gym. This is an integral part of my health and wellbeing prescription, alongside my regular visits to our wonderful infusion nurses and my fabulous neurologist.

I have never liked being told what to do. For me, powerlifting is an act of resistance against the societal stereotypes that come with MS about what you can't do. Each time I lift I defy my diagnosis.



Getting focussed and ready to lift. Amanda weighed in at 55.1kg for this competition - a Nationals qualifier.

Step by step

By Peter Tutty

In 1987 I signed up to my first Massey University paper as a fresh-faced 19-year-old, full of hopes and dreams for the future; a first step.

In my final year of being a teenager, absolutely anything was possible. However, 18 months later I discovered that the local pub (The Fitz) was much more fun than morning lectures and as I had run out of money, I withdrew with a touch of sadness for those unfulfilled dreams.

So, I entered the real world and climbed on the bottom of the employment ladder: McDonalds, typesetter, graphic designer, marketing manager- step by step, year by year. After half of a successful career in marketing, MS came to visit one night at the age of 37, and by morning I was blind. Thanks MS, you're awesome!

After a pile of steroids, 20 percent of my eyesight returned, leaving the world being a weird blurry place lacking detail. But...my mind was still sharp, and although my body had daily and long-term issues, MS wasn't going to take me out any time soon. It was going to leave me exhausted from doing simple tasks such as getting out of bed or eating breakfast, but it wasn't going to shorten my life.

I needed a plan

So, I decided to sit around all day and play computer games and watch television. Adapting to a life with MS was going to take some time. This lasted for about five years, then my first grandchild was born in 2010. I looked at him, I looked at myself, and I realised my plan wasn't the best plan for me.

I needed a better plan

I contacted Massey University and surprisingly they accepted that all the work completed in the 1980s was still relevant to my aspirations. I signed up to continue the degree; Bachelor of Arts majoring in psychology and sociology. Just one paper per semester, but time was not the issue. I had too much of that.

For 10 years I persevered, two papers per year generally: step by step, year by year. Then last year I finally filed my submission to graduate and received the happy news. I had finished my journey! After 35 years of waiting, I could finally wear the funny robes with the even weirder hat and stroll across that stage.

Relief, satisfaction, a few tears and even a giggle. Done! Abcdefu MS.



Peter Tutty in his graduation regalia, with his proud wife Kathie.

I needed a new plan

Now I write. Nothing to do with my degree, although the lessons I learnt and the habits I formed will last a lifetime.

I am in no shape to use my degree to start a new career, but I face challenges on a daily basis that the knowledge learnt helps me deal with. Writing, like studying, is my mental gym: my 'use it or lose it' workout. My first book is selling well internationally and I enjoy reading the reviews. Something I was warned not to do. My next book, In Case of Emergency is released in e-book and paperback on 6th July 2022 on amazon. (sorry, just taking the chance for some self-promotion!).

The gym is my 'use it or lose it' physical workout. I attend weekly classes at Unruly Gym with Lisa and Mira and they help my body get a little stronger every week. The classes are changing my life, and I think it is with other individuals with MS. It makes a real difference, not just to the class attendees, but to their partners, family and friends. It makes for more capable people with MS in just an hour each week. We have room left in the class!

So, 19 years on from my original diagnosis, my brain is fogger, my body is weaker, but my happiness is reinforced on a daily basis by the habits I have formed. I want to get out of bed, I want to walk my dog rain or shine (sigh), and I want to make something of my life.

I want to look MS in the eye and say...

*"Not today. Today I choose what I do.
Today I may be held back by you, but I
will do my best to make a difference in
my life in spite of MS. Step by step."*

Some days I just lie in bed and examine the ceiling, wondering if my legs will work when I get out of bed. But hey, you can't achieve every day.

As long as you have a plan. Step by step, year by year. Your goals are achievable. Some will be bigger; some will be smaller. Some will just be opening your eyes and having a smile. The biggest thing holding you back is your desire. **You're in control of that, not MS.**

Massey University, like all universities, has a department dedicated to people living with disabilities. They aim to level the playing field...not to make it easier and not to make it harder, but to smooth out the challenges so a person with disabilities can compete on an equal footing. In my case this included extra time for rest periods in exams, use of computers to sit my exams and even a 'sketcher' staff member to draw diagrams in my exams.



Peter did find his trencher (silly hat).

Hunt for EBV vaccine heats up

In the USA, the National Institutes of Health (NIH) is joining the search for a vaccine to attack the Epstein-Barr virus (EBV). This is a big deal for people with multiple sclerosis, because carrying the virus is thought to play a significant role in the development of MS. Research published earlier this year by Harvard scientists concludes that a previous EBV infection may increase a person's MS risk by 32 times.

Multiple efforts are underway to develop EBV vaccines and therapies. An investigational therapy called ATA188 is among those being researched, and a small study has indicated that this treatment may have an impact on MS. Researchers hope to enrol up to 80 non-active primary and secondary progressive MS patients with evidence of past or current EBV infection in their study's second phase.

Moderna, which produces one of the mRNA-based COVID-19 vaccines, is further along in its quest. The company is sponsoring a clinical trial for a possible EBV vaccine that uses the same mRNA technology as the COVID-19 vaccine. Researchers hope to enrol about 270 participants across 15 sites in the U.S.

Other researchers are investigating whether an experimental COVID-19 T-cell therapy called TVGN-489 can be used against EBV for the treatment of MS.



The NIH study carries with it the considerable weight of this major research institution. The study plans to enrol 40 healthy adults ages 18 to 29, half of whom have evidence of prior EBV infection. Over a six-month period, they'll receive three injections of an experimental vaccine called EBV gp350-Ferritin, developed by the National Institute of Allergy and Infectious Diseases' Laboratory of Infectious Diseases, which is part of the NIH. It targets a glycoprotein found on the surface of the virus and virus-infected cells. This investigational vaccine showed encouraging results in an EBV mouse model about four years ago.

"A vaccine that could prevent or reduce the severity of infection with the Epstein-Barr virus could reduce the incidence of infectious mononucleosis and might also reduce the incidence of EBV-associated malignancies and autoimmune diseases," NIAID Director Anthony S. Fauci, MD, said.

WORLD MS DAY CONNECTIONS



Connecting on World MS Day



Jan Hollway and Neil Woodhams.



Sam Smith.

Did the organisers of World MS Day foresee the isolation and breakdown in connections and community that would occur post-COVID? ‘Connections’ is the theme of World MS Day (30 May) for 2020-2023, and it certainly rings true.

Social media users would have enjoyed the wonderful videos and stories posted by people living with MS in all corners of the globe. A world map highlighting stories and events marking World MS Day around the globe was wonderful to see. Research events, landmarks illuminated for World MS Day, walks and music events were pinpointed around the globe, highlighting all the Connections taking place to raise awareness of multiple sclerosis.

To mark World MS Day, MS Auckland held a ‘Connections’ themed afternoon tea on Sunday 29th May. Given the COVID restrictions in Auckland, this was MS Auckland’s first full community event in almost a year. It was an opportunity for many members to reconnect with each other and with our team in a relaxed environment.

Sam Smith, comedian and MS Auckland’s Ambassador, shared his own reflections on the connections theme and how his connections with family, friends and career morphed following his diagnosis of multiple sclerosis.

MS Auckland’s new strategic direction was outlined by President Jan Hollway and General Manager Nicola Bitossi. Neil Woodhams, President of Multiple Sclerosis New Zealand, was presented with a life membership award for all he has done for MS Auckland and its community over many years.

The day created a tremendous buzz and much reigniting of old connections, the forging of new ones, and anticipation of seeing each other (in person!) again soon.



Support groups

Support groups are for people living with MS as well as their spouses, partners, friends, siblings, children – basically anyone who is affected by MS.



They are fun! They are all about people coming together to connect, share stories, laugh, or shed a few tears, build each other up and make new friends.



Our North Shore café group enjoying meeting in person!

There really isn't anything quite the same as being with a group of people who quite simply just 'get it'.

Most of our groups have returned to in-person format, with many smiling faces at being able to enjoy coffee in the same room. We also have virtual support group options for those who prefer this way to connect.

Our list of groups is below. If you are not yet part of a group and would like to join, please contact your Community Advisor. They can suggest the group that fits best with you, which is usually based on area of Auckland.

Our groups

South / East Auckland

Pukekohe Café Group

Botany Café Group

Manukau Café Group

Men's Group

Date/ Time

First Thursday / Month - 11.30am

Third Thursday / Month - 11.30am

Last Tuesday / Month - 10.30am

Last Saturday of each Month - 10.30am

Central

Mt Wellington Café Group

Stonefields Café Group

Onehunga Group

Second Saturday / Month - 11.00am

Third Wednesday / Month - 10.30am

Third Tuesday / Month - 10.30am

West Auckland & Rodney

Kumeu Café Group

Henderson Garden Café Group

Silverdale Café Group

First Tuesday / Month - 10.30am

First Thursday / Month - 11.00am

Third Wednesday / Month - 10.30am

North Auckland

Mayfield Coffee Morning

Shore Lunch Group

North Shore Café Group

Second Thursday / Month - 10.30am (new venue)

Last Wednesday / Bimonthly - 12.00 noon

First Saturday / Month - 11.30am

Newly Diagnosed

Zoom Meetings

Mt Eden Café Group

North Shore Café Group

Dates and times vary

Fourth Wednesday / Month - 7pm

Third Saturday / Month - 11.30am

For more information on venues and times please contact us

info@msakl.org.nz or on 09 845 5921

Earlier interventions around MS benefit our economy too

A recently released report by the New Zealand Institute of Economic Research (NZIER), commissioned by Multiple Sclerosis of New Zealand (MSNZ) shows that earlier intervention of multiple sclerosis (MS) will not only save New Zealand's health system millions of dollars per year, but it will also contribute millions back into the economy through individual income related earnings.

In 2021 the total estimated employment related loss for individuals with multiple sclerosis was \$82 million. Additionally, the total social cost associated with the prevalence of MS was estimated to be \$266.3 million in the same period.

The report states that understanding the total costs and benefits of a health challenge is good health economics which matters for society because a person's health has implications for families, society, and the economy.

Although the understanding of MS is evolving. The NZIER report provides evidence that earlier intervention and medicines funding access are key to positive outcomes for both people with MS and the economy.

In 2021, around 4,130 people had MS across New Zealand. Predominantly aged from 25 to 50 years old, these people tend to be in their peak earning years and making consequential financial decisions such as home loans and re-financing, household debt and consumption, children and retirement saving plans.

The financial consequences of lost employment and lost potential to earn due to the onset of MS are likely to be significant. Individuals' financial decisions are invariably informed by assumed continued employment and the financial pay-offs associated with career progression.



MS can significantly disrupt these plans and oppose unanticipated costs on households and society.

The report describes how the progression of the disease to the severe disability level can be delayed by between 6 to 10 years with early intervention and the present value of such a delay could be between \$500,000 and \$1 million per case over the delay period.

Slowing the progression of the MS will generate private and social costs savings beyond avoided pain and suffering. Delaying the disease will support people to be more independent, lessen the need for informal care and improve the probability of staying at work.

The population of New Zealand is projected to increase and age in the future, which could contribute to an increase in the number of cases and a greater burden from MS. In the context of an ageing population and MS being a disease of people aged between 25 to 50, it may become more visible in health rankings in New Zealand over the next 30 years.

The prevalence of MS is disproportionately higher among females. Among the New Zealand population, 76% of people with MS were female (3,121), and the remainder were male (1,009). This pattern of higher prevalence among females is a global feature of MS (Wallin et al. 2019; Stenager 2019).

MS is more prevalent in the higher-skilled workforce. The educational achievement of people with MS is higher than the general population. The MS population had higher rates of post-secondary school qualification (54%) compared to the general population (42%) at the time of the NZMSPS (Pearson et al., 2017).

The report combines 2 accepted modelling tools to measure and express the research findings. The Expanded Disability Status Scale (EDSS) to quantify impairment in multiple sclerosis and monitoring changes in the level of impairment over time, and quality-adjusted life years (QALYs) to measure the loss in health quality for individuals.

The estimated total cost of lost QALYs associated with the prevalence of MS in New Zealand was \$26.3 million in 2021.

The health system cost for mild, moderate and severe cases of MS was estimated to be \$14.9 million, \$42.5 million and \$73.1 million, respectively. In 2021, the total health system cost of MS was \$130.5 million. This represents an average cost of \$31,607 per case of MS per year.

The report found that access to medicines in New Zealand is falling behind comparator OECD countries due to a combination of reasons, including:

- Medicines funding is not keeping pace with health spending
- Social costs and benefits being systematically under-counted in funding decisions
- The emergence of effective new medicines is not accommodated by current funding appraisal processes.
- The speed of access to new medicines can be slower in New Zealand than elsewhere.



Earlier interventions with MS will save the country money.

For New Zealand to progress in the assessment of the social cost and benefits of health intervention relating to MS and other conditions, the report proposes the following changes need to be considered:

- Greater use of social-benefit analysis in pharmacoeconomic analyses would provide greater insight into the benefits of emerging treatments for MS.
- Adding cost-benefit analysis to the suite of tools would support more fulsome decisions about how to set budgets to deliver better health and wellbeing outcomes for New Zealanders.
- Commissioning research into the social benefits and costs would support greater transparency.

The analysis measures considered in the NZIER research include comparison of cost-effectiveness analysis and cost benefit analysis.



Research: exercise, aerobic fitness and MS

Recent research in Denmark presented the question; can exercise therapy started soon after diagnosis affect the course of multiple sclerosis?

Previous studies of exercise therapy have included people at least three years after diagnosis. The Danish researchers argue that there may be a "window of opportunity" in the early stages of MS, when exercise therapy might have the potential to modify the course of MS, similar to the benefits seen with early disease modifying drug treatment. To test this theory they evaluated exercise therapy started soon after diagnosis.

They recruited 84 people who had been diagnosed with MS for less than two years. Half of the group took part in supervised high-intensity aerobic exercise training over a 48-week period in addition to their routine care which included taking disease modifying drugs. The other half took part in health education sessions on top of routine care.

There was no difference in relapse rate and overall brain volume loss between the two groups. The exercise group improved their aerobic fitness by 21%, greater than the 10% improvement generally considered to represent a meaningful change. There were also improvements in the microscopic structure of four out of eight areas of the brain important for the control of movement.

The researchers conclude that the results do not show a direct disease modifying effect of exercise therapy but suggest that a study with more participants followed for a longer period might be required to show improvements in relapse rates and brain volume loss.

The positive effects of high intensity training on four out of eight regions of the brain associated with movement control may indicate improvements in neuroprotection or demyelination/remyelination processes.

Background

Exercise therapy, which covers a range of different approaches such as endurance, resistance or aerobic training, has been extensively studied in MS and has been shown to increase general physical fitness and improve MS symptoms. However, these studies evaluated exercise therapy once someone's MS is well-established. In this study, researchers have investigated whether the benefits of early treatment, which are well-established for disease modifying drugs, could also be applied to exercise therapy.

Relapse rate and brain tissue loss assessed by MRI were the main measures of the study. The microscopic structures of several regions of the brain involved in the control of movement were also examined using advanced MRI techniques. Aerobic fitness level and participation in exercise were measured before and after the study.

What was found?

Compared to the health education group, the exercise group increased aerobic fitness by 21%, greater than the 10% improvement generally considered to represent a real change. There were also improvements in the microscopic structure of four out of eight areas of the brain associated with movement.

There was no difference between the two groups in relapse rate, brain tissue loss or number of lesions seen in MRI scans. Both exercise and health education groups increased their participation in exercise, although this was slightly greater in the exercise group.

What does it mean?

Studies of exercise therapy typically include people at least 3 years after diagnosis, at the point where their MS is already well-established. Starting a disease modifying drug early in the course of relapsing MS results in fewer relapses and fewer new lesions, and ultimately less long-term disability. This group of researchers wanted to test whether the same is true for exercise, arguing that we may have overlooked a 'window of opportunity' in the early stages of MS, when exercise therapy might have the potential to modify the course of MS.

The study did not show an effect of exercise on the number of relapses and overall brain volume loss. The researchers suggest that the study may have had too few participants and that 48 weeks may not have been long enough to show effects on these measures; clinical trials of disease modifying drugs typically recruit hundreds of participants and run for two years. So, a larger study which continues for a longer time might show improvements in relapse rates and brain volume loss.

The study did find that the programme of exercise training resulted in a significant improvement in aerobic fitness which will have a beneficial effect on symptoms and well-being of the exercise group, and reduce the risk of the risk of developing other conditions such as cardiovascular disease.

In addition, the positive effects of high intensity training on the microscopic structures of four out of eight regions of the brain associated with movement control indicate improvements in brain and spinal cord structures and possibly on demyelination/remyelination processes.

Citation: <https://onlinelibrary.wiley.com/doi/abs/10.1111/ane.13540>



MS Auckland is grateful to all the individuals, whānau, volunteers and organisations who support our work.

We would like to acknowledge by name our current corporate partners, trusts, foundations and other supporting organisations.

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Rotary Club of Newmarket
Sweep

Remember us with a gift in your will

Most gifts are made by ordinary hardworking people who would like to give lasting support to causes that are important in their lives. A gift to MS Auckland in your will can be as much or as little as you want.

Consider leaving a 1% legacy to MS Auckland in your will; a small proportion for you, but a significant, lasting impact for Aucklanders living with MS.



If you would like further information on writing a will or leaving a gift to Multiple Sclerosis Auckland, or for a confidential no-obligation chat about how your gift can make a difference, please contact Mark in the office on 09 845 5921.

For more information visit www.msakl.org.nz



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TYSABRI
(natalizumab)

TYSABRI® is a Prescription Medicine containing natalizumab 300mg/15mL in a sterile single use vial for IV infusion. **Approved Use:** TYSABRI is used for the treatment of patients with relapsing remitting multiple sclerosis (MS) to delay the progression of physical disability and reduce the frequency of relapse. **Before Use:** Do not use Tysabri at the same time as medicines that modify the activity of the immune system e.g. an interferon or glatiramer acetate. Your doctor should test your blood to check if you have antibodies to the John Cunningham (JC) virus before treatment and periodically during treatment. Like all medicines, TYSABRI has risks and benefits. Ask your doctor if TYSABRI is right for you. If your symptoms continue or you have side effects, see your doctor, MS nurse or other health professional. **During Use:** There have been reports of a rare viral brain infection called progressive multifocal leukoencephalopathy (PML) in patients who have been given TYSABRI. PML is a serious condition and can cause severe disability or even death. The risk of getting PML increases: 1) if you have been exposed to the JC virus; 2) the length of time on Tysabri, especially beyond 2 years; or 3) if you have taken a medicine to suppress your immune system (an immunosuppressant) in the past. The risk of getting PML is greatest if you have all 3 risk factors. If you have not previously been treated with an immunosuppressant and you have received TYSABRI for two years or longer, the level of your anti-JC virus antibody test results may help your doctor assess your risk of getting PML. For those with a lower risk of PML (if you do not have antibodies to the JC virus in your blood OR if you have been treated for more than 2 years and you have a lower level of JC virus antibodies in your blood) your doctor may repeat the test regularly to check if anything has changed. Some of the symptoms of PML are similar to MS. If you or your partner/caregiver thinks your MS is getting worse or notice new symptoms talk to your doctor as soon as possible. If your doctor suspects PML, they will want you to stop treatment with TYSABRI either permanently or until they can confirm it is not PML. Management of patients with PML may require removal of TYSABRI from the blood, usually by plasma exchange. This may lead to further serious complications, including worsening of brain (neurological) function. **Common side effects include:** pain or stinging when passing urine, sore throat, runny or blocked up nose, shivering, itchy rash (hives), headache, dizziness, nausea, vomiting, joint pain, fever, tiredness. **Serious side effects include:** signs of an infection, changes in your personality, thinking abilities or behaviour, yellowing of the skin or eyes, signs of a severe allergic reaction, difficulty breathing or chest pain, easy bruising, spots on your skin, heavier than usual menstrual periods, bleeding from gums or nose, bleeding hard to stop. Serious side effects are rare. **Further Information:** For further information see the TYSABRI Consumer Medicine Information available at www.medsafe.govt.nz or by calling 0800 852 289. Biogen NZ Biopharma Limited, 188 Quay Street, Auckland. TYSABRI is a funded medicine – a pharmacy charge and Special Authority criteria will apply. Normal doctors' charges will apply. **Revision Date:** January 2021.

References: 1. Rudick R et al. JAMA Neurology 2013; 70(2): 172-182. 2. Kappos L et al. J Neurol 2013; 260: 1388-1395. ©2022. Biogen® and TYSABRI® are registered trademarks of Biogen MA Inc. Biogen-150242. TAPS BG1952. Date of preparation: February 2022. BIOG00985/EMBC.

