

multiple news

Multiple Sclerosis Auckland Magazine

March 2021 | Issue 49

Community
Advisors

Nurses

Profiles

Treatment

News

Support

and much more...

the man that's
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A FEELING**

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A few words from Ingrid

Our General Manager

I am so very excited about our first magazine for 2021! You may notice a slightly new look to the magazine. After five years we thought it was time for a bit of a freshen up. We were delighted when Ross Middleton came to us to offer volunteer services in helping us with our magazine. Ross has worked many years in the magazine industry, and while he continues to work part time in his retirement, he offered to join our magazine team as our content manager. We are absolutely delighted to have Ross on board.

We are also pleased that Susan from Underdog Design has continued to work with us over the past five years.

Susan is a brilliant graphic designer and has helped take the magazine from strength to strength.

This magazine is packed with wonderful stories of positive people dealing with their MS. Our cover story, with Simon, I found personally very inspiring. Simon gets on with enjoying the things he loves, not letting his MS get the best of him.

I would like to thank everyone for their contributions to this first edition for 2021. I hope you enjoy the read!

Happy 80th birthdays

to two of MS Auckland's amazing volunteers

Two wonderful women, who have been a part of MS Auckland for many years are celebrating their 80th birthdays in March; Lorraine Street and Joan Thomson. We are so very grateful to these two women and all they have done for the society and people living with MS. Here is a wee bit about each of them:

Joan became involved with MS Auckland when her husband was diagnosed with MS about 20 years ago. Her husband unfortunately passed away quite soon afterwards, but Joan remained involved in helping the society. For about 17 years Joan was part of the MS Auckland Committee. Joan could almost always be seen helping out with events, social occasions, and fundraisers, and continues today as an active member of the Life Buoy fundraising committee. She received the Harcourts Cooper & Co Super Hero Award in 2018 for her community work and in 2020 an MS Auckland Honorary Life Membership.

Lorraine Street's journey with MS spans almost 30 years. She became involved with MS Auckland when her daughter Pip was diagnosed with MS, even though they were told at the time by their neurologist not to get involved with us! Lorraine, together with her husband, John, became the first Ambassadors for MS Auckland. They co-hosted the first Life Buoy for MS event at the Royal NZ Yacht Squadron, where John is an Honorary Member.



Neil presenting Lorraine her Honorary Life Membership.

Lorraine and John were made Honorary Life Members of MS Auckland in 2019. Pip passed away in April 2020 and a wonderful celebration of her life was held in December. Lorraine continues her involvement with the Life Buoy fundraising committee and continues to actively support MS Auckland in her role as Ambassador.



Kirsty, Ingrid, Joan and Carolin, with Joan's Super Hero Award.

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Events for your calendar

MS Auckland Annual General Meeting

Date: Tuesday 20th April
Time: 7:00pm
Venue: Remuera Club, 27-33 Ohinerau Street,
Remuera

The meeting will be followed by a talk from a special guest speaker (please check our website for details), a light supper and the opportunity to mix and mingle.

For catering purposes please RSVP if you are able to attend to: info@msakl.org.nz or on 09 845 5921.

We have some vacancies for the MS Auckland Board this year and are looking particularly for people with skills in any of the following: fundraising; marketing; governance; working in the health sector.

The Board is the governing body of the organisation and meets six times a year. Currently meetings are held over lunch in a central Auckland location, although time and location can be determined by the in-coming Board members. While currently all Board members are up for election annually, we would recommend a commitment for a minimum of two years. If you are interested or know of someone who might be interested, please contact Jan Hollway at msakljh@gmail.com.

We hope you will be able to join us for this year's Annual Meeting. It's a great time to meet the Board, ask questions, get involved, and meet fellow MS Auckland members.

Exercise 4 Health

Day: Every Wednesday
Time: 11:00am to noon (*during school terms only*)
Venue: Trust Stadium Gym,
65-67 Central Park Drive,
Henderson.

An Exercise 4 Health programme began at the end of 2018 at the Trust Stadium in West Auckland. It was started as a pilot project together with Physio Rehab Group and Stroke Northern.

The pilot was deemed a success with 16 people attending the structured exercise sessions.

MS Auckland was able to secure additional funding to continue to rent the space in the Trust Stadium and engage the programme leader, Mira Forrest.

We are also continuing to work with Physio Rehab Group who provide extra support and administration of the programme. Physio Rehab Group are currently charging an extra \$5 per class which they invoice participants at the end of each term

The Exercise 4 Health classes are for anyone.

If you would like more information on the classes or if you would like to try it out for the first time, give Steph or Logan a call at Waitakere Stadium Physio on 909 6632.



The first Exercise 4 Health group 2018

From our MS Community Advisors

Written by MS community advisors
Lesley Amosa and Luminita Apostol

Attitude: is your glass half-empty or half-full?

Back in 1919, an aspiring young cartoonist was fired from his job at a Kansas City newspaper. His editor told him he was not creative enough and should look into work elsewhere. Had the cartoonist listened to his boss and given in to negative thinking, we would probably not have the work of Walt Disney to inspire us today.

Positive thinking that usually comes with optimism and positive solution finding (as in Walt Disney's case) is a key part of effective stress management and it is associated with many health benefits.

But if you tend to be pessimistic, don't despair — you can learn positive thinking skills.

Positive thinking doesn't mean that you keep your head in the sand and ignore life's less pleasant situations. Positive thinking just means that you approach unpleasantness in a more forthright and productive manner: you think the best is going to happen, not the worst.

Researchers continue to explore the effects of positive thinking and optimism on health. Health benefits that positive thinking may provide include:

- Increased life span
- Lower rates of depression
- Lower levels of distress
- Greater resistance to the common cold
- Better psychological and physical well-being
- Better cardiovascular health and reduced risk of death from cardiovascular disease
- Better coping skills during hardships and times of stress

If you want to engage in more positive thinking and experience the health benefits associated with a bright outlook in life, you need to think and behave in a more optimistic and confident way.



Here are some ways to create a new, positive you:

- ☺ Be open to humour. Give yourself permission to smile or laugh, especially during difficult times. Seek humour in everyday happenings. When you can laugh at life, you feel less stressed.
- ☺ Follow a healthy lifestyle. Aim to exercise for about 30 minutes on most days of the week. You can also break it up into 10-minute chunks of time during the day. Exercise can positively affect mood and reduce stress. Follow a healthy diet to fuel your mind and body. And learn techniques to manage stress.
- ☺ Surround yourself with positive people. Make sure those in your life are positive, supportive people you can depend on to give helpful advice and feedback. Negative people may increase your stress level and make you doubt your ability to manage stress in healthy ways.
- ☺ Practice positive self-talk. Start by following one simple rule: Don't say anything to yourself that you wouldn't say to anyone else. Be gentle and encouraging with yourself. If a negative thought enters your mind, evaluate it rationally and respond with affirmations of what is good about you. Think about things you're thankful for in your life.

We have been very impressed with the general positivity and optimism of people with MS. On the following pages you can read the stories of Jennifer and Sandra, just two people who keep their heads up and the smiles on their faces despite everyday struggles or frustrations; amazing people that have chosen a positive attitude and some practical ways to achieve that.

Your Community Advisors



Tatjana
Ph 021 845 903



Luminita
Ph 021 959 187



Lesley
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Negative self-talk



I've never done it before.

It's too complicated.

I don't have the resources.

I'm too lazy to get this done.

There's no way it will work.

It's too radical a change.

No one bothers to communicate with me.

I'm not going to get any better at this.

Positive thinking



It's an opportunity to learn something new.

I'll tackle it from a different angle.

Necessity is the mother of invention.

I wasn't able to fit it into my schedule, but I can re-examine some priorities.

I can try to make it work.

Let's take a chance.

I'll see if I can open the channels of communication.

I'll give it another try.

Jennifer Dickson, 64 years of age, RRMS

Jennifer has had relapsing, remitting MS since 1986. She lives with her husband, Kevin, whom is now retired at Mangere Bridge. Nothing seems too much for Jennifer to do. Below Jennifer answers a few questions that we asked of her.

Who or what inspires you?

My husband Kevin. He worked in the past and couldn't stay home to look after me so this motivated me to do things, which has really helped me. It's made me push myself instead of allowing self-pity.

What motivates you to stay positive?

I love being outside in the yard. I love animals and enjoy cats, horses and dogs especially corgis. I enjoy being outside mowing the lawns, and also using the electric chainsaw. I believe staying physically active has really helped me keep my MS at bay.

What actions do you think have helped you to have a good attitude?

Taking my medications has really assisted me in my recovery. In the past I was in a wheelchair. I am not in a wheelchair now and believe the medications along with keeping physically active has made massive improvements in my body and mind.



When it gets tough Jennifer Dickson slows right down and listens to her body.

What do you do when it feels like things are difficult?

I slow right down and listen to my body. I tend to work through things if I feel down.

Thinking of family and others always helps me feel happy. I like treating people and this always makes me feel better.

Staying connected to family and friends and attending the Support Groups through MS Auckland also helps me feel better when things are difficult. A problem shared is a problem halved.

Sandra Magill, 60 years old, secondary progressive MS

My mother and father have had the most influence on my outlook on life.

They have always been very positive people. When I was at high school my Dad had to go to the USA on business for three months: we all went, a family of four living in San Francisco as locals. Mum and Dad thought it would be a great education for my sister (13) and I (15).

It was truly fantastic and very maturing. I also had an accident at school that year and I can remember Mum saying; *“get on with life, you're ok ... we who love you”*. I was only 16 and went to my school ball just two weeks later! So, I come from good, positive stock.

I have had a great outlook on life since forever. When I come up against a block wall I put on 'my big girl pants' and figure out a way to get through. I have passed this on to my children and they have taken the lesson of positivity well and truly onboard, for which I am truly thankful.

My dad, who is now 85, has always said to me *“make a decision about an issue and run with it”* so I have never been a fence sitter. Whether my decisions have been right or wrong (they seldom are) this is advice I live by.

I hate people being taken advantage of; doesn't matter by whom or by what. If I don't agree with a course of action, I put pen to paper. Over the years I have written many, many letters, even to councils and government.

I am a leader and have had three successful businesses. But never do I expect others to do things I wouldn't. I can remember when one of our businesses was very young and we couldn't afford a factory cleaner; I did it!

I left school and didn't want to go to university so I went to work for Air NZ at the airport on the ground. I was in their employ for nearly 15 years and went through many facets and positions with the airline. I was the youngest single female ever employed in my role at Air NZ. Remember, this was in the days when I had to sign a document saying I would not have children for five years or they would not train me! Imagine doing that today.

Now that I have Secondary Progressive MS I am often asked for opinions and help. I have recently helped two ladies to establish their businesses; one plastering and the other in Doggie Day Care, as the family income had ended



Sandra Magill gives herself plenty of tough love.

with the advent of Covid19. I am extremely proud to have been able to help these ladies.

I stay strong and with a good attitude by surrounding myself with positive people. I find that if you are constantly with 'woe is me' people you tend to be pulled down. The challenge is to turn those people around. I find this very fulfilling.

I do have my down days, but usually after a 'stern talk to myself' I'm fine and have a good coffee and laugh.

I do hope my ramblings have helped you a little.

From our MS nurses



The COVID vaccine and questions around its safety and use in the MS community are a particularly hot topic in the current situation.

The good news is that if you have MS you are at no greater risk of contracting COVID-19 than anyone else. People with MS who have had COVID have recovered well.

That said, you definitely don't want to catch it so please do get vaccinated when you are offered this service, and encourage those around you to do the same.

A number of people have been asking if they should receive the vaccination sooner due to a concern about being immune suppressed. To reassure you all there is no indication that this is necessary.

For those of you who would like to read more the following link will take you to MS specialist's articles about the COVID vaccine. These have been written by MS neurologists from NZ and Australia.

<https://msra.org.au/covid-19-vaccination-guidance-for-people-with-ms/>

<https://www.msif.org/news/2020/02/10/the-coronavirus-and-ms-what-you-need-to-know/>

For people taking MS disease modifying treatment (DMT)

If you are taking an MS medication funded by PHARMAC you are still able to have the vaccination.

Please continue your disease modifying therapy (DMT) unless you are advised by your MS healthcare professional to stop or delay it. Stopping some DMTs abruptly can cause severe worsening of the disease.

Based on data from previous studies of other vaccines and DMTs, getting the mRNA vaccines (Pfizer-BioNTech or Moderna) while on any DMT is safe. Some DMTs may make the vaccine less effective but it will still provide some protection. Again this is why it is vital those around you are vaccinated.

If you are taking the six monthly Ocrevus infusion you should be sure to discuss the timing of this vaccine with your MS team.

Fiona d'Young and Nazila Samadi
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Louise Reed -

By Louise Reed

Reflections on my 10 years serving MS Auckland



Louise enjoying the outdoors.

I have been a member of the MS Society of Auckland committee (and latterly board) since November 2011. At a MS Society lunch in South Auckland I met Neil Woodhams, then president of the society, who approached me about joining the committee. I agreed and became a committee member shortly thereafter. It is hard to believe that I have been involved with the MS Auckland committee for almost 10 years!

My involvement with the MS Society began when I was diagnosed with MS in 2008. When I was initially diagnosed, I had withdrawn from a number of not-for-profit commitments I was involved in because I wasn't sure how was going to cope with my new illness. As time went on, and I found I was managing my MS I was open to the idea of being more involved with an organisation that was helping people like me. Neil's approach to me at the MS lunch to join the committee thus came at the right time.

The committee meetings were every four weeks at the offices of Partners Life in Carlton Gore Road. The meetings lasted for two hours (12pm to 2pm) with lunch provided. Neil's chairing of the meetings ensured that the (large amount of) business of the committee was attended to in a thorough and prompt manner. I learnt a lot from Neil (and more recently Jan Holloway the current president) about how to run an efficient meeting and to ensure that every committee member had an opportunity to voice their opinion and to be heard.

I have also had the opportunity to work with three dedicated general managers of the society; Gary McMahon, Therese Russell and Ingrid Minett. All three managers work tirelessly for the society and its members.

The structure of the society as an incorporated society means the committee is responsible for the governance and strategy of the society. Due to the increase in prevalence of patients with MS in the Auckland region, the society itself has grown substantially. This is reflected in the establishment of the MS Auckland Region Trust to hold bequest funds and other large donations to support the long-term viability and initiatives of the society. In addition, the recent move from a committee to board structures has seen a more corporate and professional appearance to the society and the work it undertakes. Under the governance of the current president, Jan Holloway, that will only improve and develop.

During my time on the committee/ board, I have had the opportunity to meet leading MS medical experts and to be involved at the coal face with advocacy and support of people with MS. I have enjoyed every minute of my time with the committee/board and will miss being kept up to date with the flow of detailed information about what is happening with the MS community.

In order to keep the society improving and reflecting the members it seeks to serve, it is important that the committee/board also changes. That is the reason why I am stepping down from the board; to allow other members of the MS community to come forward and help shape the community which we are a part of. I would encourage members to seriously consider putting themselves forward for election at the next AGM so that you can be a part of your society and its future.

I am excited to see what the future holds for the MS Auckland Society.

Volunteer Profile:

Robin Carner



How long, and in what capacity have you been volunteering for MS Auckland?

I am starting my fifth year of volunteering with the hydro group in Epsom. When I moved here, I was looking into doing some volunteer work as I thought it would be a good way to meet people and help others in some way.

What motivates you to volunteer for MS Auckland?

I am motivated by working with other volunteers who are so kind and friendly, as well as all of the lovely MS people. It makes me happy to think I may be helping others in some capacity.

Tell us of one of your best moments in volunteering for MS Auckland.

It is so hard for me to think of one best moment, every week is the best!

In your opinion, what is the most important work that MS Auckland does?

I think MS Auckland provides a wonderful support group for those with MS; from education to fundraising and support networks. The newsletter provides a wealth of knowledge which is so important. It's good to know you have others around you that you can share your experience with and help you to cope with making the most out of your life.

Best vacation ever?

Ooh, it is difficult to say which is the best vacation as I am fortunate to have been on many good vacations. I love Hawaii for the sun and the relaxed atmosphere, but I'd have to say our family trip to the Middle East in late 2019.

Our entire family (my husband, Ted, and our five children) went to Jordan, Israel and Egypt. We were there for almost a month and we spent Christmas in Jerusalem which was pretty special. The history of the area is also so interesting, and I loved the food there too. Riding a camel and seeing the pyramids and Petra was also amazing. I could go on and on about the trip...



What famous person would you invite for dinner?

I'd have to say Rachel Hunter. She seems like a lovely person who is also stunning. She went from a supermodel to a yoga teacher (which I love!) and seems very grounded despite her huge success. She also seems like a mum devoted to her family which I respect.

If you had to be shipwrecked on a deserted island, but all your human needs — such as food and water — were taken care of, what two items would you want to have with you?

That's easy; a good book and some Tim Tam's!

Any last words?

I am so grateful to be working with the MS Auckland team. Everyone is so kind and their hearts are in the right place.

The people I've met and the friendships I've forged have made my life more enriched.

Lara and her painted stones



Lara has a passion for painting rocks. Beautiful paintings on stones tell a personal story and create positive interactions.

Just over a year ago, Lara was diagnosed with MS. It was quite a journey to the diagnosis for her. She was having symptoms for some time but tended to blame them on her hypothyroidism, until she lost partial vision in her left eye. After massive amounts of steroids followed by the loss of feeling to her legs, she finally had two MRI's plus a lumbar puncture, the result being a positive diagnosis of MS.

Soon afterwards with NZ in lockdown, and with no work and plenty of time on her hands, Lara decided to start doing something she had done a bit in the past and enjoyed; painting rocks.

“I’ve never seen myself as being artistic, like my twin sister, but I’ve always been creative and have painted on rocks a few times for gifts”

She got test paint pots from Resene paints and then with a good supply of paints and rocks from her rock garden and rock collection she was able to get into her painting.

Lara loves walking and being with nature saying, “nature is my medicine”. She is fortunate that they live close to a lovely reserve where she can have walks throughout the day. It was on one of those walks during lockdown that she decided to start putting out her stones for people to take if they wanted. She soon discovered that the rocks would disappear quite quickly, so took to making them a bit harder to find, putting them in trees and fences and other nooks and crannies. She would write on the back of the rocks ‘kia kaha’ and also ‘love me, leave me, or re-hide me’.

Lara has made many new friends and contacts on her walks. On one of her trips with her rocks she came across a man who exclaimed: “Are you the rock lady?” He loved collecting her painted stones and already had nine of them! They agreed that he would deliver her stones to paint that she would then hide in a tree for collection.

On another occasion she noticed that someone else was also painting rocks and leaving them out, however they weren't clear coating them which would enhance the durability of the paint. So, Lara took them home to clear coat and then put them back on the trail for others to find. She bumped into the woman who did the painting and they discovered that they don't live far from each other and are now looking at having painting days together.

Lara also caught up again with her high school science teacher when she saw her taking one of her rocks. Her teacher didn't recognise her but after receiving a few clues she realised who she was, and they had a great catch up.

Some of the stones can take her hours to paint. She starts by painting the whole stone black and then putting it out to dry. Sometimes her paint is ruined by pigeons which means that she has to start all over again. Most of her painting is ‘dot work’. She uses needles, toothpicks, cotton buds, chopsticks, the end of paintbrushes or anything that can give her the size dot she needs.

“I just love painting stones. When I get an idea in my head, I can't wait to paint it on a stone”

Friends and family have been telling her she should sell her rocks. And while she didn't want to at first, she realises that a bit of extra income could help with the cost of supplements that she takes to help her MS. She still hides rocks on her walks but will also sell a few now. Finding a price point was difficult as she knew she couldn't charge by the hour. Some stones can take her seven hours to create.

The NZ lockdown helped Lara reignite her passion for painting rocks and also giving back to the community.

You can connect with Lara and find many of her painted rocks on her Instagram account: [Larakinkiwi6](#)

Changing everything and nothing at all:

By Bonnie Robinson

My journey with MS



Bonnie and husband Brett about to head to the Feb 2020 Round the Bays for 'Team MS'.

When I think about the 18 plus years I have lived with my MS diagnosis I would sum up the journey with these words; MS changes everything and nothing at all. The diagnosis was a shock even though it was not a surprise. I had a sibling with MS, and a couple of aunts in the wider family. I knew the symptoms well, and by the time the health system ground its slow way through the various options; (brain tumor, lupus, motor-neuron, stress etc.), I had already guessed what it was and was relieved to have it confirmed. I had MS. Good to know. Now I could deal with it.

Of course, there was anxiety; I had a three-year-old and a five-year-old, was working almost full-time and my income was essential to our household budget. If I couldn't work or look after them what would happen?

Fortunately, very early on in my journey I connected with the Auckland MS Society. The field worker set me up with some things that help – such as my disability parking card and my total mobility taxi card. But most importantly the field worker suggested I go to an MS information day.

I heard George Jelinek speak about his dietary approach to managing MS and I went home determined to go to

the Gawler Foundation, which at that time was the only place to run his programme. At the last minute I wanted to pull out. I was afraid to hang out with other “sick people.” Fortunately, my husband ignored me, and we went. I've never laughed so much or met such wonderful people as on the MS course. Now I had information, a sense of control back. I learnt to focus on what I still had, which was everything that was important; love, family, a purpose, and not focus on what I had lost or might lose. Hope not fear.

Since that time, I've lived a full and rewarding life. MS doesn't stop me doing anything I really need to do: just some things I might have liked to have done. I've got a great career in leadership, management, and governance. I've travelled overseas. I volunteer in the community and I pursue hobbies that I enjoy. This is a good life for anyone let alone someone with MS.

Some of my good life with MS has come about by design. I have tried to do whatever seems to make a difference to MS – medication, diet, exercise, mindfulness. But I also recognise that a lot of my good life is down to luck. I am lucky that I was accepted for medication early, responded well and have had few serious exacerbations. Lucky that I have a super supportive husband and a medical team (GP and neurologist) who listen. Lucky that the disability that has arisen from my MS is manageable with planning and prioritising of my energy. Lucky also that my work is more intellectual than physical, so I've been able to keep working, and afford some extra help. I know that not everyone is this fortunate in their MS journey and I support the MS Society because of this.

Of course, like everyone with MS, I have bad times when it's harder to stay positive. Humidity is my kryptonite; I dread the summers and fantasize about moving to Antarctica. I sometimes feel isolated because I cannot always go to social occasions due to my energy levels or just knowing I won't physically be able to manage the event. I get bored with managing the whole 'keeping healthy with MS' thing. And I cheat, a lot, on the Jelinek diet and then worry I'll make my MS worse, (but really, if God had intended us to eat this many vegetables they'd taste like chocolate!).

I realised a while back that I no longer remembered 'normal'. I don't remember what it feels like not to have MS. So, in a sense this is no longer a journey. It's my life. And although MS is my disease, not my personality, it is part of who I am. Some of what it has brought is bad and some good. Sounds like 'normal' life after all.

I'm hooked on a feeling

Simon MacLean, our intrepid MS fisherman finds the disorder taking a back seat to the magic.

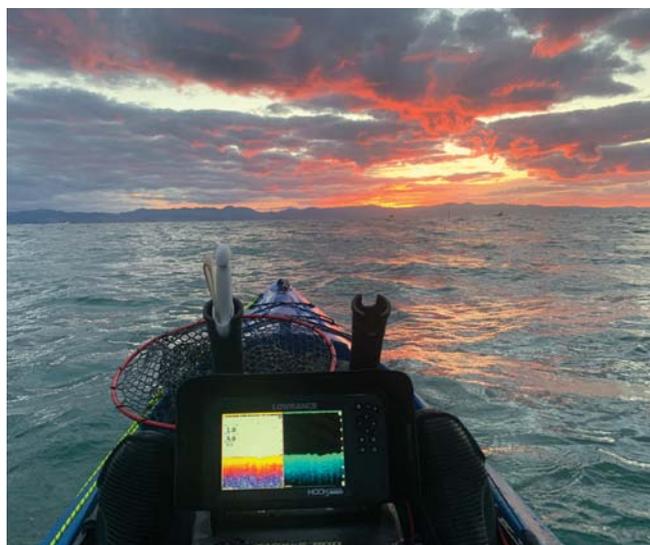
Its 5.30am. After the one-hour drive, I reach the beach with not another person in sight. The sun has not yet risen, and the water is flat and calm. The seagulls have not yet sung their morning song and there is just enough light to see the horizon.

I push my kayak off, paddling away from the beach in search of the fish beneath me. The only sound I can hear is the gentle slap of my paddles and the kayak slowly gliding through the water. Before the sun rises, I cast out my first bait for the morning.

Whack! Something big takes the bait, screaming line off my reel and putting a tremendous bend in the rod. The bow of the kayak is pulled around and I start to be towed forward. After a good fight, I pull a nice snapper up onto the kayak, the first is in the bin.

The sun finally starts to rise over the Coromandel ranges, glowing orange in the morning sky: magic.

I have always been a keen angler and am extremely passionate about fishing. I absolutely love everything about it. Waking up on my 31st birthday with blurry vision in one eye was not exactly the gift I had in mind. Especially given that I need my eyesight to be near perfect for my job as a train driver.



Sunrise overlooking the Coromandel peninsula, taken whilst on the Firth of Thames.



Fish caught from Matai Bay in Northland.

Like a lot of people with MS, I too experienced optical neuritis as a first symptom. And so, my MS journey had begun. My initial fears were that I was not going to be able to continue doing the things I love, like fishing.

Meeting many MS professionals in the early stages, it was apparent that diet and exercise, as well as having a positive mindset, were all key in helping to fight the disease. So, in what felt like a lightbulb moment for me, I decided to combine all of these together, and purchased myself a fishing kayak.

I have always been a happy-go-lucky kind of guy; always seeing the positives in life. I have always stood by a mantra to live your best life, coincidentally also a mantra of MS Auckland. After accepting what I had in front of me, I decided to keep on doing just that. I made a promise to myself, to not let MS get me down, and to catch as many sunrises as I could from my kayak, as well as fish of course.

I realised that it's my own passion that can help me overcome the MS challenges I may face. Harnessing kayak fishing has helped me create a good positive mindset and attitude and gives me a good burst of exercise at the same time.

I have since been on many adventures, ranging from paddling in the far north in Doubtless Bay and Matai Bay, to local missions out from Kawakawa Bay and Orere Point, exploring the Firth of Thames. I was even lucky



Simon fishing from his kayak near Pakihi Island, looking back towards Kawakawa Bay.

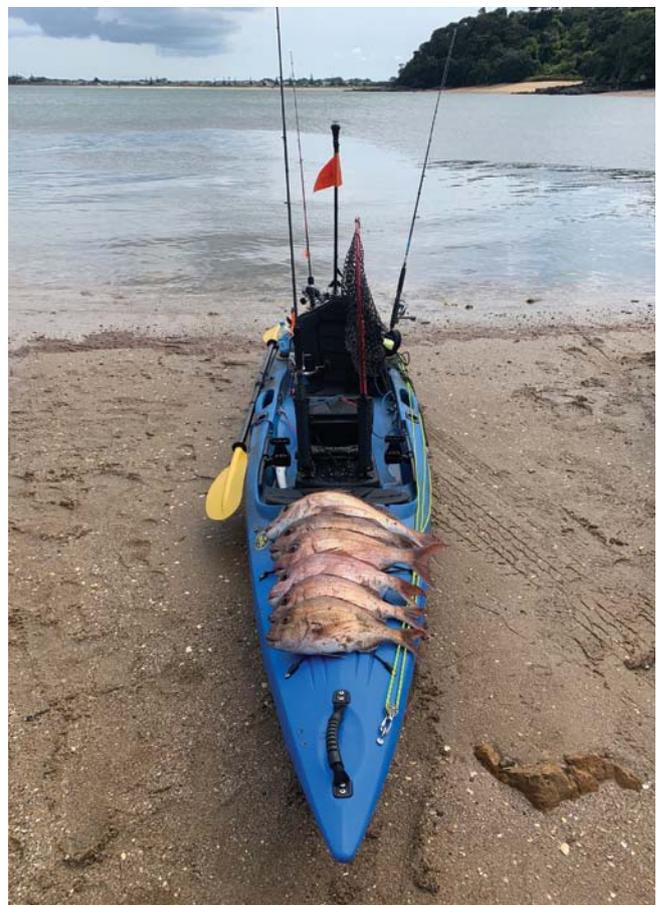
enough to experience a pod of dolphins breaching the surface right next to my kayak on my maiden voyage, something I will never forget. I have also competed in many fishing competitions (yet to place on the podium).

Yes, I am hooked.

Whatever your passion or interests are, I encourage you to keep on doing what you love, turning it into a positive to fight your own MS disease. I highly recommend kayak fishing as a sport to anyone who is keen to try it, and hopefully will see some of you out on the water someday soon.



Dolphins drop in for a chat near Pakihi Island.



Fish caught in a competition in Doubtless Bay, Northland.

You can do anything you set your mind too, until you can't!

The heading at the top of this page is something I truly believe. I was brought up in the era of 'girls can do anything' and I have had amazingly strong women in my life; my mother, sister, nieces, aunties, cousins, friends and work colleagues.

They have all shown me this and have mentored my belief in this every day. I am proud of each and every one of them and I am eternally grateful to have them in my life. They each mean and give me so much.

2020 was a year of huge change for me. I have been dealing with a downward progression in my illness. This hasn't always sat well with me and is pretty darn hard to admit to myself.

A few months ago, I reached out to the MS Society for support and they graciously gave this to me. I had both Tatjana and Luminita pay me a visit, and after general discussions on how I was doing with life and living in general, we talked about some of the things that I was having difficulty with. They provided me with some positive strategies around these things. For me my biggest issues have revolved around my need to do housework and general tasks around the home in order to feel like I am part of contributing to my household.

Their help led to a 'light bulb going off' moment for me and there was the realisation that I was struggling with some of my everyday tasks; but my pride would get in the way of me asking for help with some of these things. They suggested that they could organise a referral for a needs assessment. Being the stoic, headstrong woman that I am, I said, "no way I don't need help". But after letting the idea sit for a bit, I decided it couldn't hurt.



| *Shona Hatton at home.*

A few days later, I had a call from a representative from Taikura Trust who explained to me that they perform the needs assessments in my area for the Ministry of Health (MOH) and that they were wanting to set up an appointment for an interview.

It is important to do some research as to what services are on offer, have some thoughts on how they would be able to help you and to have a clear idea of what you want to achieve as there are several different kinds of supports on offer and they all have their own rules and requirements.

When you have your assessment, it is very important to be honest with the assessor. For me was particularly difficult as I hated the idea that someone might think I wasn't good enough to do something. At the end of the day (as they say) and after a lot of internal debate, I concluded that if I was able to get some help then why not. I could even be providing someone with a job, by accepting help: something that I had never thought about before.

After meeting with the Taikura Trust needs assessor and having a long and comprehensive interview with them, I felt a little more hopeful and they also reassured me that I wasn't wasting their time and that I definitely did have a need for support. I felt happy that I got through it.

A week or so later the assessor rang me and said that she had finished her report and wanted to send it to me for review and to discuss and make any changes that were necessary in order to get my story across. I was pleased about this, grateful to be able to read the information they had gathered and to be sure that they had fully understood what I needed or wanted.

Well, true to their word, the assessment was emailed to me and I read what was written. Yes, I found this confronting and upsetting, but very necessary. To read that in someone else's eyes they saw me as having a disability to perform certain tasks was heart-breaking as it is something that in my own eyes I had never seen. I guess in some ways you put blinkers on to protect yourself. After discussion of the assessment and making a few changes, it was sent off.

About ten to fourteen days later, the Taikura assessor called me and explained that my assessment had been done and that I wasn't eligible for some things, but I was eligible for some help under the 'personal cares' category. I couldn't believe this. I was stoked!

After discussions with the assessor, it was explained that there were two different pathways that this support could be provided. The MOH pathway, where they look after things and provide and manage the services for you or the 'individualised funding pathway', which you get to choose the supports you require and who provides them. I liked the theory behind this, went away, did some research and decided that this was the option for me.

For more information on Taikura Trust go to: www.taikura.org.nz

Study's findings positive for MS potential of nalfurafine

Functional recovery in those living with multiple sclerosis has come a step closer thanks to the latest findings of research led by Te Herenga Waka—Victoria University of Wellington scientists.

Professor Anne La Flamme and Associate Professor Bronwyn Kivell, from the University's School of Biological Sciences, and their team have discovered that the drug nalfurafine has the potential not only to slow the accumulation of disability but also to restore function in an experimental model of MS.

Nalfurafine has been used clinically for years to treat various non-MS conditions such as chronic kidney disease and has been shown to be safe and well tolerated. Additionally, the researchers' findings show its MS-modifying effects are superior to the compound US50,488, which activates the same target but cannot be used clinically because of its poor side-effect profile.

Professor La Flamme and Associate Professor Kivell last year co-founded a spin-out company, Rekovert Therapeutics, with investment from the New Zealand Innovation Booster Fund, a partnership between the University's commercialisation arm, Wellington UniVentures, and Booster Financial Services. Funding for the nalfurafine study came from the Ministry of Business, Innovation and Employment, the Neurological

My first attempt at finding the right host provider was a bit of a failure. I thought they understood me and my needs, but as it turned out, I was wrong. A couple of false starts and a few months down the track with no progress, I called my original needs assessor and told them of my issues. They explained that if I wasn't happy, I could easily change my host provider. I just needed to tell them who I wanted to use and they would handle the transfer paperwork. It really was that easy.

I changed host providers and in less than a fortnight from start to finish, I had had meetings, and was all set up and ready to go.

I have now been using my individualised funding to achieve my goals around home. I know my host provider is just a friendly phone call or email away, to help with any queries or concerns around my funding. They truly have given me piece of mind and have even come up with some great solutions and ideas on things that I hadn't really thought about before, allowing me to concentrate on the things that matter.

Foundation of New Zealand, the Health Research Council of New Zealand, the Great New Zealand Trek, the Kate Parsonson Scholarship, the Wellington Medical Research Foundation, and the National Institute on Drug Abuse.



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TECFIDERA GIVES WOMEN (dimethyl fumarate) WITH RRMS FLEXIBILITY IN FAMILY PLANNING¹⁻³

Tecfidera

9 YEARS

CLINICAL TRIAL & POST-MARKETING EXPERIENCE^{1,4}

EXPERIENCE MATTERS⁵

HOW DOES TECFIDERA EMPOWER FAMILY PLANNING?



TECFIDERA is the ONLY oral treatment for RRMS with an Australian Pregnancy Category B^{11,6-9*†}



No adverse pregnancy outcomes have emerged in over 9 years of clinical trial and real-world experience^{2,3}



TECFIDERA gives patients the freedom to choose their preferred contraceptive method, or to not use contraception at all¹

SPEAK WITH YOUR NEUROLOGIST ABOUT FAMILY PLANNING TO SEE IF TECFIDERA IS RIGHT FOR YOU

*TECFIDERA should be used during pregnancy only if clearly needed and if the potential benefit justifies the potential risk to the foetus. No washout period required before conception. TECFIDERA is not contraindicated in pregnancy.¹

†If you become pregnant while taking TECFIDERA tell your doctor immediately.

RRMS=relapsing-remitting multiple sclerosis.

Reference: **1.** TECFIDERA (dimethyl fumarate) Data Sheet, 5 March 2020. **2.** Gold R *et al.* *Neural Ther* 2015;4:93-104. **3.** Hellwig K *et al.* Poster presented at ACTRIMS-ECTRIMS: September 11-13 2020. Virtual conference. **4.** Gold R *et al.* *Ther Adv Neurol Disord* 2020;13:1-17. **5.** Desai A *et al.* *Eur J Pharm Med Res* 2016;3(5):197-205. **6.** Gilenya (fingolimod) Data Sheet, 20 July 2020. **7.** Aubagio (terifunomide) Data Sheet, 18 August 2020 / Aubagio (terifunomide) Product Information, 17 September 2020. **8.** Fampyra (fampridine) Data Sheet, 31 January 2020. **9.** Mavenclad (cladribine) Data Sheet, 11 May 2020 / Mavenclad (cladribine) Product Information, 15 January 2021.

TECFIDERA (dimethyl fumarate) 120mg and 240mg capsules are a Prescription Medicine for patients with relapsing remitting multiple sclerosis. TECFIDERA® has risks and benefits. For product information check Consumer Medicine Information on www.medsafe.govt.nz. Ask your doctor is TECFIDERA is right for you. Take strictly as directed. If symptoms persist or you have side effects see your doctor. TECFIDERA is a funded medicine - a pharmacy charge and Special Authority criteria will apply. Normal doctors charges apply. Biogen, Auckland.

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Recipe

Breaking the fast

You have probably heard of the old saying “Breakfast like a king; lunch like a prince; dinner like a pauper”.

For many years now breakfast has been considered the most important meal of the day. As the name suggests, it breaks the fast you have undertaken over your sleeping hours and replenishes your supply of glucose to boost your energy levels and alertness.

Some people find they just can't tolerate food first thing in the morning. This may be because of consuming the evening meal quite late at night, or because they just don't find breakfast foods appealing.

Some things to try would be to move dinner time to earlier in the evening; reduce the size of the dinner meal; moving your breakfast to mid-morning; or trying some new breakfast recipes.

This writer has always loved oatmeal however it can get tedious having oatmeal every single morning. Below is a unique oatmeal recipe that is not only delicious, but also very filling. It's like having carrot cake for breakfast, but it is full of ingredients that will get your day started off right.

Carrot cake oatmeal

This recipe takes 10 minutes to make and makes two servings.

Ingredients:

1 cup rolled oats
1 cup non-dairy milk
1 cup water
½ cup shredded carrot
¼ cup raisins
½ teaspoon vanilla extract
½ teaspoon cinnamon
¼ teaspoon allspice
Salt to taste

Toppings:

Maple syrup
Chopped walnuts
Shredded coconut

Or whatever else tickles your fancy!



How to make it

In a small pot over low heat, bring the oats non-dairy milk and water to a simmer.

Stir in the carrot, raisins, vanilla extract, cinnamon, allspice and salt. Continue to simmer, stirring occasionally, until all the liquid is absorbed: seven to 10 minutes.

Transfer to bowls and add your toppings.

Enjoy!

Do you have a favourite Jelinek friendly, or plant based recipe you would like to share for the next magazine?

Please send it to Ingrid@msakl.org.nz. If you can, please also include why it's your favourite and a photo.

The Auckland Council Disability Panel

By Bonnie Robinson

A chance for people with MS to have input into the work of Auckland Council

In the middle of 2020, I was appointed to be a member of the Auckland Council Disability Panel.

I must admit that before applying I had only a vague notion of the panel and its' work. But in late 2019 I saw the advertisement on Seek for panel members and thought, "why not apply. This could be an opportunity to make a difference".

The Council has several demographic panels; older people, youth, rainbow community, ethnic communities and the disability community. The purpose of the disability panel and of being a member is to:

- identify the issues that are important to people with disabilities
- provide advice on Council regional strategies, policies and plans
- help Council effectively engage with people with disabilities

The panel therefore gets to have input into a wide range of the Council's planning and work, from those obvious for people with a disability, like transport, to broader issues like long term plans, how elections are organised to encourage participation, and responses to climate change. It is all about ensuring the voices of people with disabilities, and that includes people with an illness such as MS, are heard throughout the Council.

My motivation for joining was a realisation that the work of local government actually impacts a lot on our day to day lives, and so as a person with disability arising from my MS, the Council is important to how well I can live, work and play in Auckland.

Things like whether bus stops have seats (I can ride a bus, I just can't stand waiting for it or while on it), whether micro-transport (e.g., scooters) rules understand the needs of disabled footpath users, whether buildings are



Some members of the Auckland Council Disability Panel at a recent meeting.

accessible; all these things that affect me day to day are actually influenced by Council. By being on the panel I have a chance to feed in the views and experiences of people such as myself.

It is also inspiring to meet a group of other people with a range of disabilities and to learn from them and to find out more about the work of the Council. Some panel meetings are open – anyone can sign up to attend. See the Council website for meeting dates and times if you are interested.

For now, I'd welcome anything MS Society members might like me to feed into the panel's work. You can contact me via the MS Society. I will also be letting you know if there are issues coming up such as submissions to Council that might be of interest to people with MS.

As they say "decisions are made by those who turn up". The Disability Panel is an opportunity provided by Council for people affected by illness and disability to 'turn up'. I hope the wider MS community will help me to use this opportunity well.

Please send any feedback or comments to Bonnie at info@msakl.org.nz and it will be passed on to her directly. Thank you.

Hydrotherapy

We were very hopeful that after a rather disruptive year last year with pool closures, that 2021 will see things return to normal. Recent brief lockdowns, however have once again disrupted the regular flow of classes.

We are fortunate to have the lovely Laura bring us land exercise classes through Zoom to help keep us active through lockdown. The sessions are recorded and are available on the MS Auckland website. You can find the videos at: <https://www.msakl.org.nz/about-ms/what-we-do/our-resources/exercise-videos/>.

The importance of keeping active cannot be stressed enough and water-based exercise is such a rewarding way of maintaining and improving levels of fitness. There is less stress on your joints when your body is submerged in water. The hydrotherapy classes have also been shown to improve endurance, flexibility, strength and balance, while also improving MS fatigue.

As social creatures, we also enjoy the social aspect of weekly classes. Many new friendships are made over cups of tea after classes.

2021 classes

This year we are offering Hydrotherapy in four pools around Auckland. Unfortunately, we had to make the decision to discontinue at West Wave once again, due to very low attendance. In response to requests from our members for weekend classes on the North Shore, we also ran a Saturday morning class at the Millennium Pool, which unfortunately didn't attract many participants and we will not be continuing with that class in 2021.

Cost of classes

The hydrotherapy classes are heavily subsidised, however there is still a small fee for attendance. If you pay for a term however and then find that you are unable to attend due to pool closures, or your own circumstances then we will either refund you, or let you carry over to the next term with no further payments. If the fees are preventing you from attending hydrotherapy sessions, please talk to



Saturday morning Diocesan swim group.

your MS Community Advisor who will be able to assist you in ensuring that you don't miss out. The cost allows you to attend as many of the sessions you wish each week.

Yearly pass - \$120.00/person

Quarterly pass - \$30.00/person

You can pay directly through our website: <https://www.msakl.org.nz/about-ms/what-we-do/our-services/hydrotherapy/>

Alternatively, you can call the office on 09 845 5921 to make your payment.

First time to a class

If you are new to Hydrotherapy, then you can have your first two classes free. It is important however to let your MS Community Advisor know that you wish to attend. Then she will be able to let the instructor know to expect you and also meet you there to answer any questions you may have.

Before attending a session for the first time, or for more information on the pool groups please contact a Community Advisor or contact the office on info@msakl.org.nz or 09 845 5921.

2021 Weekly Sessions

Tuesday	Wednesday	Thursday	Saturday
Lloyd Elsmore Pool Sir Lloyd Drive Pakuranga	Manurewa Leisure Sykes Road Manurewa	Epsom Girls Silver Road Epsom	Diocesan Girls Clyde Street Epsom
11:00am - 12:00 noon	11:00am - 12:00 noon	10:30am - 11:30am	10:00am - 11:00am

MS under the microscope

Breakthrough technologies deployed to vaccinate against COVID-19 also has led to a promising new approach to preventing the progression of multiple sclerosis. *“It is exciting, definitely exciting,”* said Dr. Yashma Patel, an MS specialist at Valley Neurology in Spokane Valley, Washington State, USA.

So far, the new MS vaccine has been the subject of only a handful of studies in mice, the results just published in the highly regarded journal *Science*. But though they were limited, the results may also open up a new path toward successfully treating a difficult-to-manage disease, according to Patel and Dr. Annette Wundes, director of the Multiple Sclerosis Centre at the University of Washington.

While acknowledging that it’s *“obviously still very early on,”* Wundes said the approach analysed in the *Science* study *“allows a completely new way of dealing with MS.”*

MS occurs when the immune system attacks the central nervous system, damaging the myelin that sheathes and protects nerve cells in the brain and spine. When that happens, it can interfere with or prevent the transmission of messages within the nervous system, leading to the unpredictable onset of symptoms that can include fatigue, weakness, difficulty walking and cognitive problems.

Existing approaches to combating the disease fall into two main camps, according to Wundes. One approach is “chemo-like,” she said, in that you’re attempting to suppress the immune system so it relents in its attacks on the nervous system. While such immunosuppressive therapies can limit the misguided attacks on the myelin, they can also reduce a patient’s defenses against a host of very real threats of disease infection. The other approach, Wundes said, involve modulating the immune system or, put simply, *“strengthening the good guys and weakening the bad guys”* to reduce the severity and effectiveness of the immune system’s attacks on the nervous system.

“We have made huge strides in treating in MS,” Wundes said, *“but to a varying degree, (those treatments) come at the price of higher risk as well.”* Current therapies also *“don’t stop (the disease) and don’t fix anything,”* Patel said.

But the new approach could do exactly that: prevent the disease’s progression and improve existing symptoms without affecting normal functioning of the immune system. It may also stop the disease from ever taking hold in the first place.

A key to achieving these groundbreaking results is messenger RNA, or mRNA, vaccine technology, which was first successfully deployed late last year in a series of new COVID-19 shots.

“When you get a vaccine, any traditional vaccine, you’re given a small amount of a virus, either a live virus or

dead virus,” Patel explained. That injection triggers the immune system to make antibodies so “your body fights it off” and prevents you from getting a full-blown infection, she said. But mRNA vaccines take a fundamentally different approach. Instead of giving you a virus, Patel said, they inject mRNA, which is “essentially a code” that “tells your body how to make” an antigen that triggers the production of antibodies that ward off infection.

One of the successful mRNA COVID-19 vaccines is Comirnaty, which the German biotechnology company BioNTech created with the American firm Pfizer. BioNTech’s CEO, Dr. Ugur Sahin, is behind the effort to employ the same mRNA vaccine technology to combat MS.

The study Sahin published with a team of fellow researchers found that mice administered the MS shot produced an antibody that prevents the immune system from attacking the myelin.

“Basically, what they found is the mice who got the vaccine didn’t display any further symptoms of MS and didn’t see any further damage to the myelin,” Patel said. *“It would basically stop any progression of MS.”*

But while the research published last month is promising, far more work remains to determine whether that promise can be fulfilled. *“It’s hard to say, though, how far it will go,”* said Patel, who noted other therapies that have worked well in mice were either ineffective or dangerous in humans. Wundes agrees that, while the research is *“promising and exciting,”* it’s *“obviously still early on.”*

She said the vaccine will have to work its way through a number of phases before scientists even try treating MS patients with it. She said it will likely be the subject first of further studies in animals and in humans without MS to determine its safety, before it is tried in MS patients to determine its efficacy.

Wundes also said, though, the article published in *Science* indicates that researchers did *“a really good job”* of looking thoroughly at the vaccine’s effect on the mice who were given it. She also said the success of mRNA vaccines for COVID-19 boosts the odds that the MS vaccine will work. Now that the new vaccine-delivery technology is in use, Wundes said, it can be “adapted very quickly to new targets.”

“And if you can apply it to autoimmune disease,” she said, *“that would obviously be very fantastic.”* The benefits would be felt disproportionately in the places where MS is most common: northern Europe, western Canada and here in the Pacific Northwest. *“It does seem like everybody knows somebody with MS,”* Patel said of the Spokane area.

Ultimately, though, no specific cause of MS has been identified. And that means preventing the disease is essentially impossible. Unless, that is, the vaccine works.

Support groups

Our people are continually reinforcing the message about the huge value they place on the MS Support Group meetings held in cafes across our region each week. When we are in lockdown many of the meetings move online to Zoom although face to face is definitely preferred by everyone.

There's nothing quite as satisfying as sitting with a group of people who you don't have to explain your MS to. They 'just get it'. Each support group has an MS Community Advisor who attends whenever possible and can share the latest news from MS Auckland and hear any concerns or issues experienced by members.

Members also share ideas, catch up with each other, and just enjoy relaxing and laughing with friends. Sometimes a tear or two may be shed for those members who are experiencing difficult times or have passed on. Partners, children, parents and even friends sometimes join in the Support Group meetings and also seem to receive as much benefit as the person with MS.



Saturday morning support group.

Below is the list of Support Groups that are currently running. If you are not yet part of a group and would like to join, please contact your MS Community Advisor as they can suggest the best group for you to join, matching your interests with the interests of the groups. They will also make sure they are there for your first visit to welcome you to the group.

Location

South / East Auckland

Pukekohe Café Group - Different Venues
Botany Café Group - Robert Harris Café (Botany Town Centre)
Manukau Café Group - Friendship House (Manukau)
Men's Group - Robert Harris Café (Botany Town Centre)

Central

Mt Wellington Café Group - Coffee Club on Lunn Avenue
Stonefields Café Group - Stonebake Café
(Lunn Avenue, Mt Wellington)
Onehunga Group - Urban Verge Cafe (653 Manukau Rd, Royal Oak)

West Auckland & Rodney

Kumeu Café Group - Different Venues
Henderson Garden Café Group - Columbus Coffee Café
(inside Mitre 10 Mega, 186 Lincoln Rd)
New Lynn Café Group - Columbus Coffee Café
(inside Mitre 10 Mega, New Lynn)
Silverdale Café Group - Kings Plant Barn (Silverdale)

North Auckland

Mayfield Coffee Morning - Kings Plant Barn
(1 Forrest Hill Road, Milford)
Shore Lunch Group - Palmers Planet Café
(cnr Hugh Green Drive/Greville Rd, Albany)
North Shore Café Group - Palmers Garden Café
(65 Greville Road, Pinehill)

Newly Diagnosed Zoom Meetings

Newly Diagnosed Café Groups

Central Auckland
North Shore

Date/ Time

First Thursday / Month - 11.30am
Third Thursday / Month - 11.30am
Last Tuesday / Month - 10.30am
Last Saturday of each Month - 10.30am

Second Saturday / Month - 11.00am
Third Wednesday / Month - Evenings

Third Tuesday / Month - 10.30am

First Tuesday / Month - 10.30am
First Thursday / Month - 11.00am

Second Tuesday / Month - 10.30am

Third Wednesday / Month - 10.30am

First Thursday / Month - 10.30am

Last Wednesday / Bimonthly - 12.00 noon

First Saturday / Month - Mornings

Dates and time vary

Wednesday / Month - Evenings
Saturday / Month - Mornings

**For more information on venues and times of the newly diagnosed groups
please contact Tatjana on tatjana@msakl.org.nz or on 021 845 903**

Complementary and alternative medicines

Many MS organisations globally have a wealth of information about the effectiveness and safety of complementary/alternative treatment strategies and how to integrate complementary or alternative medicines (CAM) into comprehensive MS care.

The National Multiple Sclerosis Society in the USA for example tells us that complementary and alternative medicine includes a wide variety of interventions, from diets and supplements to meditation and t'ai chi, which come from many different disciplines and traditions. Most are considered to be outside the realm of conventional medicine, although others, including vitamin D, exercise, acupuncture and cooling strategies, for example, are establishing their role in comprehensive care through scientific study and clinical trials.

When used in combination with conventional medicine, these interventions are referred to as 'complementary'; when used instead of conventional medicine, they are referred to as 'alternative'. In the United States today, the vast majority of people incorporate one form or another of CAM as part of their MS management, most often in combination with their prescribed MS treatments.

Safety & effectiveness

Many people use CAM because they believe that anything sold online or over-the-counter at a pharmacy or health food store is healthy and harmless. But many products that claim to be safe and beneficial may not be. Unlike conventional medical treatments that are thoroughly tested and carefully regulated by the U.S. Food and Drug Administration (FDA), most CAM therapies have undergone very little, if any, scientific study to evaluate their safety and effectiveness. So some forms of CAM may be completely safe for a person with MS while others may actually pose significant risks — by producing significant side effects, over-stimulating the person's immune system or interacting negatively with other medications a person is taking. Some may provide benefit for a person with MS while others offer no benefit at all.

The American Academy of Neurology released a guideline on the use of CAM in MS. The guideline was developed to address the following questions:

Do CAM therapies reduce specific symptoms and prevent relapses or disability?

Can CAM use worsen MS or cause serious adverse effects?



Disciplines and traditions outside the realm of conventional medicine are often sought out as complementary treatments.

Can CAM use interfere with MS disease-modifying therapies?

Although these are all very important questions, the authors found very few published studies of sufficient quality to provide helpful answers about most of the CAM therapies that are being used by people with MS.

The importance of clinical trials

Carefully-designed clinical trials are the best way to determine the safety and effectiveness of a particular treatment. ***Here's why:***

Because the course of MS is variable, and each person's symptoms tend to come and go in an unpredictable way, the only way to determine if a treatment is effective is to test it against a placebo or an already established treatment, in a large number of people.

Because every treatment carries with it the risk of anticipated and unanticipated side effects, the only way to evaluate a treatment's safety is to evaluate it in a large number of people over a sufficient period of time.

Guidelines for considering or using CAM

What does the treatment involve?

How and why is it supposed to work?

How effective is it?

What are the risks associated with its use?

How much does it cost or is it covered by your insurance plan?

Will it interact with my other therapies?

Keep your healthcare provider informed about everything you are taking (vitamins, herbs etc.) or doing (acupuncture or exercise). Not sharing this important information is like asking your healthcare provider to treat you blindfolded; and knowing everything you are taking will allow your provider to alert you to possible side effects or drug interactions.

Discuss with your healthcare team before changing your treatment plan. You and your healthcare team have developed a comprehensive plan to manage your MS. Adding, stopping or switching one of your treatments can affect the others. Have a conversation with your healthcare team prior to making changes to your treatment plan.

Document the experience. Keep a detailed log of what you take or what is done and any changes you experience.

Complementary approaches to taking care of yourself

Food and diet: MS specialists will generally recommend that people follow the same heart healthy, high fibre, low fat diet that is recommended for all adults. Some other medical conditions – such as high blood pressure and cardiovascular disease may be associated with MS worsening, so a heart healthy diet is very important.



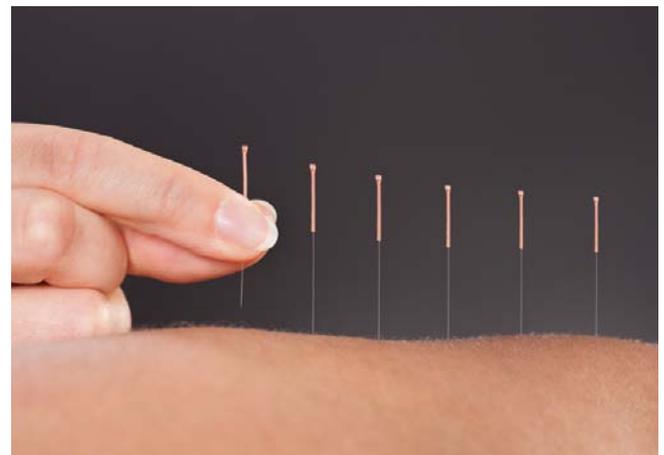
The OMS diet: In New Zealand the Overcoming MS diet is followed by a number of people. This specific dietary approach was developed by Professor George Jelinek based on his own experience with MS. It is a plant-based wholefood diet with the addition of seafood.

Professor Jelinek recommends cutting out all saturated fat, processed foods, eggs, dairy and meats. He also advocates a healthy lifestyle including meditation and exercise, and omega 3 fatty acid supplements with 20-40mls of flaxseed oil or fish oil daily.

For more information on the OMS diet and lifestyle go to: <https://overcomingms.org/>

Exercise: Exercise offers many benefits for people with MS. In addition to improving your overall health, aerobic exercise reduces fatigue and improves bladder and bowel function, strength, and mood. Stretching exercises reduce stiffness and increase mobility. A physical therapist can recommend an exercise plan to fit your abilities.

Stress management: The relationship between stress and the onset or worsening of MS is far from clear – and different types of stress appear to affect different people in different ways. But none of us feel our best when we're stressed, so it's important to find the stress management strategies that work best for you.



Acupuncture: Acupuncture is finding its way into Western medicine, with studies suggesting possible benefits for a wide range of symptoms, such as pain, gait.

*If you want links to more information,
ideas and support systems start at:
Complementary & Alternative Medicines |
National Multiple Sclerosis Society
(nationalmssociety.org)*

Pharmac widens access to funds for MS treatment



From March 1 Pharmac has widened access to all funded multiple sclerosis treatments. 1800 people with multiple sclerosis will be able to stay on their treatment for longer, and some who had stopped funded treatment may now be eligible to restart.

Jeremy Seed (Kai Tahu/ Kati Mamoe) has had multiple sclerosis for eleven years. The former New Zealand Army officer and father of two is relieved that he will be able to stay on his treatment for longer. *“It is really good news. The 500 metre walk was an annual stressor, and I was worried each time I would no longer qualify for my medication. Ironically, stress can exacerbate MS, so not having to worry about it is fantastic,”* says Jeremy.

To ensure ongoing eligibility for treatment, people with multiple sclerosis are assessed with the Expanded Disability Status Scale (EDSS). This is a method of quantifying disability in multiple sclerosis and is used to measure and assess disease progression.

Pharmac’s director of operations Lisa Williams explains, *“We wanted to make sure that all those who were benefitting from the funded treatments were able to continue to get them. To support this, we are widening the eligibility criteria to people with an EDSS score of 0 (as soon as you are diagnosed and have had two qualifying relapses) to 6.0 (inclusive).”* An EDSS score of 6.0 means that someone can walk 100 metres with or without rest and/or assistance. They can use a cane, crutch or brace. Previously, they would have had to walk 500 metres without rest or assistance to stay on funded treatments.

People with multiple sclerosis who stopped funded treatment due to the previous eligibility criteria may now be able to restart funded treatment. People should talk to their specialist to work out if that is an option for them.



“Pharmac is also simplifying the application process for multiple sclerosis treatments,” says Lisa. *“Rather than applying to a group of appointed clinical experts, clinicians will now use the standard electronic special authority process. This will make it quicker for people with multiple sclerosis to access funding for the medicine they need and less burdensome for clinicians to apply.”*

The Multiple Sclerosis New Zealand Society is pleased to see the changes to the special authority. *“We have been advocating for these changes that will keep people on treatment for longer, thereby improving their brain-health, keeping them in work longer, active, and able to support their families and themselves. These changes will also help to speed up the approval process and relieve the pressure on New Zealand’s under-resourced neurology workforce,”* says MS NZ Manager Amanda Rose.

Having recently retired from the New Zealand Army, Jeremy now works for the Returning Services Association (RSA), supporting current and former military personnel and their families. *“Being able to stay on my treatment means I can focus on the things that matter – my family first and foremost, and my new role with the RSA.”*

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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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References: 1. Miller DH *et al.* *N Engl J Med* 2003; 348: 15-23. 2. Kappos L *et al.* *J Neurol* 2013; 260: 1388-1395. ©2020. Biogen® and **TYSABRI**® are registered trademarks of Biogen MA Inc. Biogen NZ Biopharma Ltd, 188 Quay Street, Auckland. **TYSABRI** is a Prescription Medicine. **TYSABRI** concentrated injection solution contains 300 mg/15 mL natalizumab in a sterile, single use vial free of preservatives (pack of 1 vial). **TYSABRI** is a funded medicine – a prescription charge and Special Authority criteria apply. Normal doctors' charges will apply. Biogen-83391 TAPS No: MR7193 BIOG0864/EMBC Date of preparation: December 2020.

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