

# multiple news

Multiple Sclerosis Auckland Magazine

July 2020 | Issue 47



## *Personal reflections on MS and Lockdown*

inside

**ms**  
MULTIPLE SCLEROSIS  
AUCKLAND

Help for today.  
Hope for tomorrow.

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Win! Golriz  
Ghahraman's  
Book – 'Know  
Your Place'

Resilience  
Personal  
Reflections

Three Bean  
Chilli recipe  
*and much  
more...*

**FULLY FUNDED**

from 1 December 2019 for people with RMS who meet pre-defined criteria



Get on with life,  
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OCREVUS only needs to be given every six months after the first dose.<sup>1</sup> If you're one of the 4000 New Zealanders affected by MS, ask your doctor if OCREVUS is right for you.

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ocrelizumab



*Living your life your way with MS*

1. Ocrevus (ocrelizumab) Consumer Medicine Information February 2018 <http://medsafe.govt.nz/consumers/educational-material.asp>

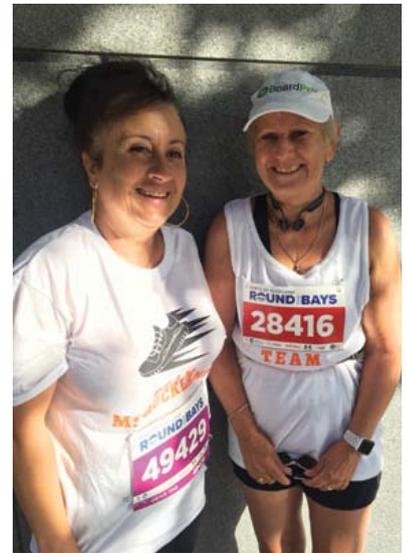
Ocrevus is a PHARMAC funded medicine from 1st December 2019 for patients with relapsing multiple sclerosis (RMS) who meet pre-defined criteria. Patients outside these criteria and with primary progressive multiple sclerosis (PPMS) will need to pay the full cost of this medicine. A prescription charge and normal doctor's fees may apply.

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# our people.

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## a few words from Ingrid.

*Our General Manager*

So much has happened since our March magazine came out. At that time I wrote 'we have one confirmed case of COVID-19' and suggested that it was likely we would see more. Never would I have imagined that by the end of that month we would be in a complete lockdown! March seemed like a year, with new challenges facing us all on a daily basis.

The most difficult challenge was when loved ones passed away during the lock down. Pip McNair, the daughter of our ambassadors and Honorary Life Members John and Lorraine Street, sadly passed away during this time. Our hearts went out to all Pip's family. There will be a celebration of her life later this year.

In this issue people share some of their stories and experiences of lockdown. Our cover photo is of the vibrant Jess Brien, performing at a Street Festival in Toronto, Canada. Learn a bit more about Jess from her story on page 14. Margot, Chris, Christine, and Anne and Tim also tell their stories – all very moving and heart-warming and show how truly incredible people with MS can be.

The lockdown kept the team at MS Auckland busy, while also giving us time to do the work of switching to a new database, developing a new website, and re-thinking our plans for the year. We also recruited a new team member, Tatjana to manage our community services. Tatjana comes with years of experience, and many ideas for enriching what we have to offer the MS community.

At our AGM we thanked Neil Woodhams, who has been our President and active on the MS Auckland Board for 17 years. Neil's involvement and passion for MS will continue with the Research Trust and with MS NZ. Jan Hollway accepted her nomination of President and was unanimously elected for the coming year.

We are very excited about our latest prize offer – a copy of the book by Golriz Ghahraman! It's getting rave reviews. It was just a few months back that Golriz shared her MS diagnosis with New Zealand. See how you can win this book on page 15.

I hope you enjoy the stories and articles we have for you in our July issue. Please continue to send me stories and ideas for our next issue due out in November.

## fundraising update.

*Written by Liz Callinan*

Reflecting over the past 3 months we can only be grateful that we were able to complete such a successful fundraising and MS community event before the restrictions around COVID-19 set in.

Our Round the Bays team event seems like a lot more than 4 months ago! But it has been our only source of fundraising from events so far this year. Like so many other charities COVID-19 has negatively impacted our fundraising efforts and we are unfortunately behind our fundraising targets for this time of year.

But a challenge provides opportunity and chance to do things differently. We are adapting every day and looking at new initiatives to enhance our fundraising and awareness campaigns, so watch this space!

In the meantime let's celebrate our success and congratulate the Round the Bays MS Auckland team for their outstanding achievement!



# events for your calendar.

## Upcoming events

### Recognising Relapses - Zoom Workshop - Friday 28th August, 10:30am

Join MS Nurse, Fiona d'Young from the comfort of your own home, as Fiona talks through understanding, recognizing and dealing with MS relapses. There will be opportunity to ask questions after her talk, or questions can be submitted in advance when registering.

To register for the free event please e-mail [events@msakl.org.nz](mailto:events@msakl.org.nz). You will be sent a link to join the zoom workshop the day before the event.

NEW  
DATE!

### Life Buoy - Sunday 15th November 2020

Date: Sunday 15th June  
Time: 11:30am to 4pm  
Venue: Royal NZ Yacht Squadron  
Special Guest Speaker: Mike King

Unfortunately we had to postpone this popular lunch and auction event, due to the lockdown. A new date has now been set. Life Buoy for MS is our biggest fundraiser each year. The Life Buoy committee will be working hard to plan another successful event. If you have any prizes or special items that you are able to donate to the auction please contact [liz@msakl.org.nz](mailto:liz@msakl.org.nz) or [ingrid@msakl.org.nz](mailto:ingrid@msakl.org.nz) or phone the office on 09 845 5921.

### New Hydrotherapy Class - Saturday's at the Millennium, 8:00am



We've teamed up with Connect Neuro Physiotherapy to provide you with MS hydrotherapy class, 8am Saturday at AUT Millennium. This group will be unique in Auckland as the class will be based on the principles taught and utilized in the innovative and life changing program MS Get a Head Start.

For more information please refer to Hydrotherapy page 21.

*To keep up to date with events at MS Auckland, check out our website [www.msakl.org.nz](http://www.msakl.org.nz) and be sure to sign up for our free monthly e-newsletter.*

**MS Auckland office is located at**  
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# from the MS Community Advisors.

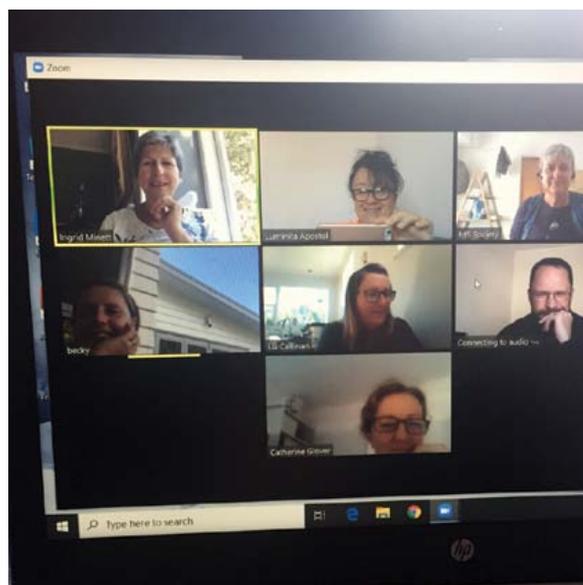
## *How We Got Closer During Isolation*

Written by Luminita Apostol,  
MS Community Advisor

On the 25th of March 2020 New Zealand's alert level went to Alert Level Four, and we experienced our first ever nationwide lockdown. This meant that we all had to stay at home in our bubbles, no travel was allowed, all non-essential businesses and schools were closed and only one person per household could do the essential shopping. For some, this was a good opportunity to have more family time and to work on enhancing personal wellbeing. But, even so, sooner or later it became evident that this was going to be harder than we thought, and this was not a holiday.

Personally, I missed going out and having coffee with my friends, going into the office and seeing my co-workers, and I even missed being able to just drive. I missed life as I knew it.

And then came Zoom. Zoom was able to provide some sense of normality when it seemed like there was not any.



I was able to have my weekly meetings with my co-workers and I was able to continue support groups and all the interactions with people. It is amazing how technology can bring us closer together, even in times when we had to be (physically) far apart. We were able to learn more about one another and chat about our highs and lows for the week. We knew that we could be there for one another, even if it was not face-to-face.

Together we celebrated Easter, celebrated ANZAC day by having an ANZAC biscuit baking competition, celebrated Mother's Day by dressing up, celebrated Queen's birthday with a fancy high tea, celebrated birthdays and anniversaries and also we celebrated World MS Day by having a big zoom meeting with a very special guest.

## Your Community Advisors



**Tatjana**  
Contact 021 845 903



**Luminita**  
Contact 021 959 187



**Catherine**  
Contact 021 959 189

The feedback from the participants at the zoom meetings was encouraging:

***“The support meetings are very good for me. Hearing other people talk about MS helps give context to my condition, as I felt very much on my own before talking to you at the MS Society.***

***I think I was very lucky to connect with the local MS world.”***

***(David – newly diagnosed).***

Now that we are back in Level One, we may not need zoom as much anymore and we can finally see each other. But now we know that we are resilient, creative, brave, empathetic, progressive, supportive, kind, courageous. We can learn new things, we can listen to one another and we can stay positive no matter the situation.

Thank you to everyone who helped make this tough time a little bit easier.

Luminita

## welcome to our new Service Manager, Tatjana!

In June we welcomed Tatjana to our team as our Service Manager, a newly developed role to enhance the services within the MS Community. Tatjana is a qualified mental health professional with a strong counselling and management background. We are so pleased that she has decided to join our team. Since coming on board, Tatjana, has been making an effort to go to as many support groups as possible and meet as many people as possible.

Tatjana comes from the not-for-profit sector where she worked alongside people and whanau affected by mental illness. She worked with individuals and families providing group facilitation, support, education, advocacy and counselling with a particular interest in empowering and motivating people.

Originally from Croatia, Tatjana is experienced in assisting people from diverse backgrounds in dealing with problems they face. With her many years of work/life experiences, Tatjana understands the impact of change on an individual's and their family life.

With the holistic approach to health, Tatjana has been assisting people through their life journey which often involves shedding some old beliefs around oneself



and accepting the new. Tatjana loves the ocean, Italian operas and good food. She is an avid reader and enjoys quiet time and meditation.

# from the MS nurses.

Written by Fiona d'Young

## Resilience



Resilience or the act of being resilient describes a person's capacity to adapt to life's misfortunes and setbacks. Resilience won't make your problems go away but it can give you the ability to better handle what life throws at you in a way that navigates around some of the issues, still allowing you to enjoy life and be less stressed by your situation.

Resilience is a popular concept just now and in the uncertain pandemic times we are all living through warrants some further exploration. As people with MS or people who live with, love and care for people with MS, you are living with uncertainty on a daily basis. Uncertainty is something human's face every day for none of us know what is around the corner.

Resilience is like a muscle. You might not be sure you have it until you start working out and you'll need to exercise, repeat and train to become more resilient.

We have all just lived through a profoundly odd few months, something previously seen only in the terrifying plots of sci-fi movies when a deadly virus breaks out. To have locked down our country and curtailed each individual citizen's physical movement in such an extreme way was completely new territory for us all.

For some of you Level 4 may have been an enjoyable change of pace, an opportunity to reflect on what is important to you, to slow down, eat better, exercise more. Others of you may have had a particularly lonely, or stressful few weeks with anxiety nipping at your heels, strained relationships with partners and immediate family and a persistent knot in your stomach. Or perhaps a combination of both. However you felt is valid and quite ok. There is a psychological weight we have all carried.

Whatever your experience, you've made it to Level 1 with us all. You have flexed your resilience muscle and each and everyone of us have some thing to feel profoundly grateful for.

This pesky pandemic isn't going to blow over anytime soon so there's never been a better time to explore our feelings of gratitude, anxiety, loneliness or worry. Post COVID there will of course be other things life throws at us, so it seems reasonable for us all to do a little homework and continue to develop our resilience.

There are a myriad of websites and applications available to assist with this and its important to note that this is homework for the whole family not just adults. Children have also borne the psychological weight of lockdown through homeschooling, minimal interaction with their peers and felt their parent's fears.

It is easy to see looking at the spikes of mental unwellness in our younger New Zealanders why resilience is worth teaching. We have a generation of children who have lived through COVID lockdown that have the potential to develop significant anxiety and the reality of this and what it means is difficult to predict at this early stage.



### *You may be aware that*

- 1 in 4 adolescents have a mental illness
- 1 in 7 primary school kids have a mental illness
- 1 in 5 adults will experience mental ill health
- 65% of adolescents do not seek help for their illness

These statistics are what drove the founding of 'The Resilience Project' developed in Australia which focuses on teaching resilience to people of all ages. Their website has links to extensive reading lists, an app and advocates using a daily well-being journal. It's well worth a look.

So perhaps we can all start with getting connected, help beat those winter blues and feel that inner glow that comes from feeling we are a part of something. This doesn't mean we need to be part of a 20,000 strong crowd at Eden Park, its hard to transition from physical distancing to a heaving crowd of humanity.

I challenge you to sit back and think about your recent experience, talk to someone you've not yet caught up with about it, call an old friend or come to one of the excellent MS Auckland coffee groups and meet a new one.

I hope we have all learnt that we're part of a big resilient herd and there's always someone around to lean on when you need them.



### *Some recommended websites to explore:*

<https://theresilienceproject.com.au>

<https://depression.org.nz>

<https://healthnavigator.org.nz/healthy-living/r/resilience/>

<https://www.mayoclinic.org/tests-procedures/resilience-training/in-depth/6resilience/art-20046311>

<https://moodgym.com.au/>

<http://beatingtheblues.co.nz>



*Get connected*

*Remain hopeful*

*Make every day meaningful*

*Practice Selfcare*

*Learn from experience*

*Be pro-active*



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Phone – 09307 4949 ext. 25885#*

# meet the MS Auckland 2020 board members.

Our AGM this year held on the 25th of June, two months later than normal, due to the global pandemic and our national lockdown.

10 Board members were unanimously elected to serve for the next 10 months, with the next AGM expected to be held in April 2021.

Neil Woodhams stepped down as President after 17 years of serving MS Auckland. Jan Hollway, who has served for the past year as vice-President, was elected

to take on the position of President. Neil was thanked for his years of service by Jan and presented with a gift from the Society.

Two Honorary Life Memberships were awarded at the AGM – to Joan Thomson and Fran Watts. Read more about Joan and Fran on page 20.

Being on the Board is a volunteer commitment. We are so very grateful to this team for their work and support of MS Auckland.



*Back row (left to right)*

*Julie Adams, Peter Wood (Treasurer), Jan Hollway (President), Robert Irving, Donald Bowie (Vice-President) Louise Reed*

*Front row (left to right)*

*Maureen Wood, Peter Tutty, Judith Herbert, Maxine Pitch*

## congratulations.

Congratulations to Jasper, the winner of the Allied Medical gift basket.

The basket was delivered to Jasper on the 1st of July and he says the items will be a big help to him.

A big thank you to Allied Medical Limited for their generous donation.

<https://www.alliedmedical.co.nz/>



# MS Auckland board member – Maxine Pitch.

Written by Louise Reed

MS and auto-immune illnesses have been a part of MS Auckland Board member Maxine Pitches' family for a number of years. All of Maxine's 5 brothers and sisters have auto-immune illnesses. Maxine's sister (who lives in the UK) was diagnosed with MS more than 30 years ago. However, a diagnosis of MS for Maxine did not come until 2014.

Born in Manchester, England, Maxine came to New Zealand in 1988 with her husband and three children. Maxine and her husband had experienced life outside of the UK before coming to New Zealand, having emigrated to Israel in 1980. They, along with their 1-year old son, Mark, spent 12 months living on a Kibbutz. Maxine said she spent 6 months learning Hebrew but found the way of life on the Kibbutz difficult due to the lack of autonomy.

The family returned to the UK in 1981 at which time Maxie was already 5 months pregnant with their second child, daughter Michala, who was born in August of that year.

Maxine then applied to study law in Chelmsford but found herself pregnant again with their youngest son, Mitchell. It was at that point that she and her husband chose to move countries again and by "throwing a pin at a map" landed up in New Zealand!

When Maxine arrived in New Zealand she and her family became part of the Jewish community in Auckland. A year after arriving in New Zealand, Maxine enrolled at the University of Auckland to study law part-time. Maxine graduated from Auckland law school and was admitted as a barrister and solicitor in 1995 and practiced for many years as a barrister until in 2010 she became a barrister and solicitor as a sole practitioner. Her work load comprises primarily criminal work and also as duty solicitor with the occasional debt recovery and civil litigation work.

Maxine is also an accomplished triathlete. Her biggest achievement was completing the Taupo Iron(wo)man. Maxine has also completed several marathons including London, New York, China and Italy.

Over the years, Maxine experienced a number of symptoms that will be familiar to people with MS including fatigue, leg drop and migraine headaches.



*Maxine with Community Advisor,  
Luminita at the start of Round the Bays*

The culmination of these symptoms ultimately led to a diagnosis of MS for Maxine in 2014 by neurologists at Auckland Hospital. She started on Gilenya in 2015 and says that while she still experiences some MS symptoms, she generally keeps very good health!

In addition to Maxine's busy life, Maxine is also a grandmother to 3 grandchildren – 2 grandchildren in the UK and one grandchild in Sydney.

Maxine became involved with the MS Auckland Board in 2018, just 9 months after her diagnosis. She is also an active member of the Saturday morning hydrotherapy and earlier this year was the top fundraiser for MS Auckland Round the Bays team.

Her contribution and involvement with MS Auckland is greatly appreciated!

# some information on the cannabis referendum.



In this year's General Election, you can also vote in a referendum on whether the recreational use of cannabis should become legal. It is a good idea to gain a good understanding of what cannabis is, what we are voting on and how either outcome will affect the people of NZ.

Cannabis is a naturally occurring drug made from parts of the cannabis plant. It contains many different compounds which are known as cannabinoids. The combinations and proportions of these can differ widely depending on the strain of cannabis plant and how the drug has been prepared.

The two cannabinoids which have been studied the most are tetrahydrocannabinol and cannabidiol. Tetrahydrocannabinol (THC) is responsible for the psychoactive effect or 'high' that is associated with cannabis use. Cannabidiol (CBD) has anticonvulsant properties and there is good evidence that it can treat severe forms of childhood epilepsy. It does not have a psychoactive effect.

Medicinal cannabis is used to refer to the use of cannabis for medical purposes rather than for recreational use. This could cover anything from the raw herbal product through to drugs manufactured to pharmaceutical standards which have been tested in clinical trials and been approved by drug regulators for specific conditions.

There is a large body of research looking at the use of cannabis and cannabis based medicines in multiple sclerosis (MS). The results of the studies have been mixed.

## *The referendum question is:*

**Do you support the proposed Cannabis Legalisation and Control Bill?**

**You will be able to choose 1 of 2 answers:**

**Yes – I support the proposed Cannabis Legalisation and Control Bill**

**No – I do not support the proposed Cannabis Legalisation and Control Bill**

If more than 50% of people vote 'Yes' in the referendum, recreational cannabis wouldn't become legal straight away. There will be opportunity for the public to share their thoughts and ideas on how the law might work.

If more than 50% of people vote 'No' in the referendum, recreational cannabis would remain illegal, as is the current law.

**It is important to note that medicinal cannabis and hemp will not be affected by the outcome of the referendum. Medicinal use of cannabis will still be allowed if prescribed by a doctor, and hemp will still be legal under the Medicinal Cannabis Scheme. You can learn more about the scheme at <https://www.health.govt.nz/our-work/regulation-health-and-disability-system/medicinal-cannabis-agency>**

## *About the proposed Cannabis Legalisation and Control Bill*

The proposed Bill sets out a way for the Government to control and regulate cannabis. This regulatory model covers how people can produce, supply, or consume cannabis.

The Bill legalises restricted access to cannabis. It's main purpose is to reduce cannabis-related harm to individuals, whānau and communities.

You can read the Draft bill here - <https://www.beehive.govt.nz/sites/default/files/2019-12/Cannabis%20Legalisation%20and%20Control%20Bill.pdf>

*To learn more about this referendum and the End of Life referendum, which will also be voted on in the General Election, go to - <https://www.referendums.govt.nz/>*

# Anne & Tim's lockdown adventure on the tall ship – Tenacious.

*Tenacious is a modern wooden sail training ship, specially designed in the 1990s to accommodate anyone over 16 with a disability. When completed in 2000, it was the largest wooden ship to be built in the UK for over 100 years.*

*The ship was built by the Jubilee Sailing Trust (JST) and, along with the Lord Nelson the pair are the only tall ships in the world that are wheelchair accessible through. The JST are an international UN accredited charity offering sailing adventures to people of all abilities and backgrounds.*



It was in December 2018 that I first became aware of Anne and Tim's love of the sea, and especially of sailing Tall Ship's across the Atlantic Ocean. I wrote about their 42 day adventure across the Atlantic in our December 2018 magazine (issue 42).

Since then the adventurous couple have had a few more sailing trips as part of the crew of Tenacious. Their most recent adventure didn't quite turn out as planned. The plan was to sail Tenacious from Antigua in the Caribbean, to Greece. They left New Zealand on the 6th of March. At that time there were 5 cases of COVID-19 in New Zealand. They flew to Houston, Texas, and then on to Antigua. On the 9th of March they boarded Tenacious where, together with about 38 other crew members, they set sail for Greece.

They were half-way across the Atlantic when they were told that Greece had closed its borders and they would not be able to get in. With no wifi or anyway to get news on what was happening in the world, they drifted on the Atlantic waiting for news and instructions as to what they were to do.

They were told they had to change course and head to England. However, they didn't have enough food or fuel to make it there. They sailed to Azores – and I had no idea where this was! Talking with Anne and Tim is like getting a lesson in geography. I learnt that the Azores are an archipelago located in the mid-Atlantic and are an autonomous region of Portugal. Here they were able to tie the ship up, although no one was allowed to get off. Food and fuel were delivered to them by people dressed in full protective gear.

They then headed to England and told they could go into port in South England, but when they arrived the port was filled with cruise ships returning. So once again, they had to turn around.

They had some Irish schoolboys on board whose parents were very concerned, so they headed to Cork, Ireland to drop off the schoolboys and then made their way to Barry, Wales where they were finally able to dock and get off the ship.

Anne and Tim's daughter who lives in England, drove to Barry to pick them up. They had hoped to have a nice long visit with their daughter and grandson, but soon learnt that all overseas kiwis were being urged to come home as soon as possible.

On Easter Monday they flew out of Heathrow on Qatar airlines to Doha on a large aircraft with only about 40 people on board! From Doha they switched planes and flew on to Auckland. In Auckland they were taken immediately into managed isolation in the So/ Auckland Hotel on the waterfront. They were given a nice room with a lovely deck where they could sit out and overlook the water. Anne enjoys knitting and they both had lots of books they could read. Occasionally Tim went out for a chaperoned walk down to the waterfront. Food was delivered and left at their hotel door. Anne follows the OMS diet and found the food choices offered to be quite limiting, however other than that they found the experience pleasant enough, and most certainly memorable!

So now Anne and Tim are grounded. They are keeping busy with a variety of activities that they are involved with, but no doubt dream about their next adventure on the sea!

# Jess's MS shenanigans.

Written by Jess Brien

I've found myself in lockdown on a completely different island to my home hospital.

It sounds foolish but I didn't see that coming. You know what they say... hindsight is 20/20 (hindsight obviously doesn't have optic neuritis!)



Maybe you've seen me around the ward. I'm Jess, I'm 26-and-three-quarters and I was diagnosed with MS in 2014 during my final year of drama school. I'm on Tysabri and things have been ticking away as good as can be, however since September I've been in and out of the Auckland Hospital with MRI's every 4 weeks and too many lumbar punctures and JCV tests. There's a random lesion in my brain and it's, quite frankly, thrown a spanner in the works. I'm still a bit of a mystery to everyone and now, well, now I'm stuck on the wrong island.

I had been cleared by Dr Willoughby to head across the ditch to Adelaide for 5 weeks where I was performing at the Adelaide Fringe Festival. Normally I work as a street performer - juggling eggs and trying to make people laugh under the stage name "Jess the Mess" (that way when my hands seize up and I drop it's funny and on brand!) Unfortunately the aforementioned brain drama meant I wasn't able to do my show as planned, but I picked up some gigs hosting forums, teaching yoga and spruiking outside one of the circus tents. The coronavirus, as we knew it back then, was a frequent topic of conversation but we were feeling optimistic it wouldn't come to much.

It was the final Friday of the festival and me and my partner Jonas were watching the ABC news waiting for the Australian Prime Minister Scott Morrison to decide whether or not unnecessary large groups of people were going to be banned... meaning we wouldn't be working that weekend. Thankfully he decided we were safe from the corona for two more days (again, hindsight!) and bans would come into affect the following Monday. Swiftly after that Jacinda announced mandatory two weeks of self isolation for New Zealand if you weren't home by Sunday and we made the tough decision to stay in Australia. We would see out the remainder of the festival (read: make one last lot of money before going into forced annual leave) and fly back to Auckland as planned the next week.

The most important thing in my life is being in Auckland for treatment. I am fortunate that my job takes me all around the world but treatment is always priority number one. So, with that being said and Air New Zealand's notifications of many cancelled flights, I had one final cuddle with my 7 month old niece and hopped on the first plane out of Australia. Destination: Christchurch.

And that brings me to where I am now. Isolating on my parents farm in Fairlie, about 2 and a half hours south of Christchurch. I'm pleased to report we are all COVID-19 free. The neurology staff at Christchurch Hospital (fun fact: they had the pleasure of diagnosing my 21 year old self) have graciously taken me under their wing for the MRI's and infusions and I feel so incredibly grateful to be taken care of down here amidst this chaos.

However, for someone who constantly moves around the world without any hesitation, I'm starting to feel this odd sort of... well... homesickness.

It's funny the sort of things a global pandemic brings up. The sorts of comforts we miss. I never thought I'd say it, but I can't wait to be back in the Auckland Hospital.

It really is an unprecedented time.

Jess Brien

*Feel free to follow along for more MS shenanigans on instagram @jesssbrien*

## Golriz Ghahraman's book – 'know your place'.

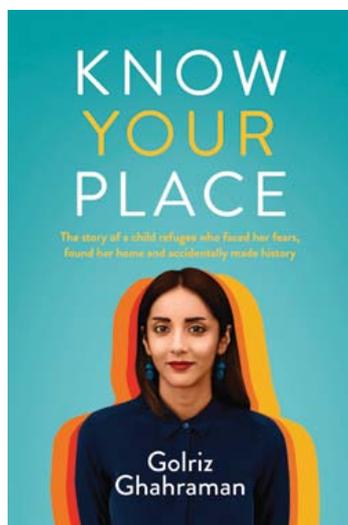
*The following is extracted with permission from 'Know Your Place' by Golriz Ghahraman, \$39.99 RRP (HarperCollins Publishers NZ) on sale now where all good books are sold.*

In politics, as in any field, we bring the whole of ourselves to our work. My first term in politics will always be a little defined by my health. 2018 was the year I was diagnosed with multiple sclerosis (MS). That wasn't something I had spoken about publicly before now, because, to be honest, it was an experience I could barely process for myself for a long while.



Telling people you have MS means being met with terrified silence, or a truckload of questions you don't have the answers to, or an outpouring of grief and love, which in its own way is overwhelming at times. It means reassuring people that you're still the same person. The other reason I was reluctant to talk about it was I didn't feel all that entitled to speak about the MS experience until I had lived with it for a while. Do you get to talk about this illness after one attack, after two? Do you get to talk to it if your symptoms on the daily are mostly 'just' fatigue?

For me, MS comes with fatigue, sight impairment, and numbness and tingling of my feet and legs, a constant reminder that my spinal nerves bear scars — in turn a reminder that my brain does too. It means being less able to travel and sometimes less able to put in the late hours I would like to — stress and fatigue increase the risk of attacks, and hasten the permanent nerve damage.



I've been told from the moment of my diagnosis, by all the medical professionals involved, that this is not the illness it once was. 'No one ends up in a wheelchair,' they say ad nauseam. They mean to be reassuring, but it's hard to have that much faith in medicine when it's your brain and your spine that are affected. I wish they had told me instead, 'It's okay to end up in a wheelchair. You'll still be you, and we'll help you live better by making the world accessible, as it should be.'



**WIN a copy of the book 'Know Your Place' by Golriz Ghahraman.**

Simply by e-mailing [Info@msakl.org.nz](mailto:Info@msakl.org.nz) with the subject heading Know Your Place and give your name, phone number and e-mail address. The winner will be drawn on the 31st of August.

# Chris' lockdown story.

Written by Chris Harmon



*Chris, known also by his nickname Crispy, is originally from Denver, Colorado and has been living in our beautiful country since 2009. He was diagnosed with Primary Progressive MS in 2014, but as he explains to me, he was noticing things and seeking answers for the symptoms he was experiencing for about 4 years prior to his diagnosis. Here is his lockdown story.*

When the first sign of Covid-19 started to become a major concern here in NZ, my employer asked me how I felt about working from home. She knows I have MS and thought it would be best if I wasn't out in the community meeting with clients in public places.

I thought this was a great idea and was very thankful and felt blessed that my employer cared enough about me and my condition to have me carry on working from the safety of my own home. Since 2017 I have been on Ocrevus, which has kept me out of my wheelchair which is a blessing, but which has also taken my immune system to a totally different level, much lower than before. I'm very happy to be on Ocrevus though. Low immune system or in a wheelchair – for me it's kind of a no brainer!

The company I work for assists people with disabilities and other barriers such as anxiety, and depression, find employment, which I am sure is the reason they were so understanding towards me when this crisis became real here to all of us. Little did I know that it would last 12 weeks of me working from home! I have only just returned to the office this past week.

Working from home meant that many of my usual activities and movements, like walking to the car, walking around the office, and meeting with clients in various locations, all stopped. As a result, what I am now experiencing is serious muscle deterioration and loss of strength, especially in my core and in my legs. I did try to walk my very steep driveway a few times a week, and I also have a home gym, which I wasn't very good at using. I was definitely far more inactive over the 12 weeks I worked from home.

The lockdown was hard on me in other ways as well. In April, my father died. It was very hard for me to not be there for my Mum. I still feel sad to be so far away at this time.

I realise that I owe so much to my awesome wife, Alana, for sticking by my side and taking this MS journey with me. We need to thank the ones that journey with us. It is easy to take them for granted without meaning to or even knowing it. To be fair, they live with the same disease as we do.

It is great to be back at work and back in full action. I am starting to feel a lot better but realize that I have a long road to travel yet, even to just get as strong as I was pre-Covid. The old saying – 'Use it or lose it' – is so true! So, my advice to everyone now is to try your very best to stay active, even if it's only small activities. Keep those limbs moving folks!



If you would like to know more about the company that I work for and to see if there is something we can do to assist you in your job searching journey, please feel free to reach out to me at [charmon14u@msn.com](mailto:charmon14u@msn.com)

Kia Kaha, Cheers & God Bless, Crispy

# reflections on MS and COVID 19 lockdown.



Written by  
Margot White

I was diagnosed with MS in January, 2019, two months after starting a new fulltime job, after ten years of working from home as a freelance writer and journalist. Things, including my walking, went more than a bit wobbly in 2019.

MS was not an unfamiliar disease to me. My dearest friend and former journalism tutor, Tony Reid, was diagnosed a year or so after I first met him. Over more than 20 years I saw MS take over his life, much of which was spent in an electric wheelchair.

Tony was one of the country's most esteemed editors and writers. It was particularly cruel that MS attacked his hands first. It made it impossible for him to use a keyboard, on which he'd spent all of his professional life.

Tony had voice-recognition and transcription software installed on his computer, which eventually allowed him to recover his voice, at least enough to write the most vivid and hilarious emails. But as the disease progressed, it became difficult for him to hold a knife and fork and in the end, turn the pages of a book.

He died in hospital a month before lockdown, on Valentine's Day this year. As Jill, his wife of over 50 years said, it was just as well he died before lockdown; at least she and his family were able to be with him.

Tony faced his disease with courage and humour and his friendship was and is one of the greatest accomplishments of my life. We had much in common, but sharing a neurological condition was something we could both do without. As he reminded me MS is an idiosyncratic disease, and how it plays out in each individual is unpredictable. He tried to reassure me that 'his trajectory' would not be 'my trajectory'.

As MS symptoms go I am, so far, probably at the milder end of the spectrum. I have an uncoordinated gait, can't stand for long, and as the neurologist put it, have 'difficulty initiating movement'.

Tony would often talk about his symptoms by prefacing his sentences with "what you don't understand is..." I would privately object. What? Did he think I wasn't listening? That I lacked empathy? I now know where he was coming from.

As is the case of many diseases, we have limited vocabulary for MS, the grief and fear and mourning that accompanies the diagnosis, for ourselves and for the loved ones whose life and future has now been changed as a result of our disorder. Even the symptoms are hard put into words.

Such as what's happening to my feet, what it's like to not quite feel ground beneath your feet, when every uncoordinated step you take reminds you there might come a time when you won't be able to put one foot in front of another.

And 2020 began with the arrival of Covid-19, which has and continues to have a devastating impact; half a million people have died of it, others have died of something else without friends or family around them, the global economic impact has to be revealed as do the psychological costs. So forgive me for my subjective response, but my world had already spun on its axis, and lockdown obliged the world to temporarily join my surreal bubble. It was, for me, a period of reprieve.

But while our borders were shut, the world got a bit wider for me. Theatre companies made productions available on line, as did symphony orchestras and opera companies, film festivals and the Auckland Books festival. I met up with friends for drinks on Zoom, even had a Book Club meeting on Zoom. Things that had become difficult for me over 2019 became easier.

From a work perspective I worked harder than ever, but better. I work at an organisation that covers a large geographical area, which can be daunting for someone with an emerging and mostly invisible (at this stage) mobility issue. On Zoom I could meet from the comfort of my own chair without worrying about getting there, or drawing attention to my 'difficulty initiating movement'.

Lockdown, in short, gave me a chance to recover some confidence, in my ability to work, to engage with others, to consolidate a sense of self. When we moved to Level 2, and then 1, people were relieved to leave their bubbles. Me too, mostly, but there was much about the 'all in this togetherness' of lockdown that made me feel part of the world...or maybe that others were, for a time, obliged to be part of mine.



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**References:** 1. Data on file, Biogen. 2. Desai A *et al.* *Eur J Pharm Med Res* 2016; 3(5): 197-205.  
3. TECFIDERA (dimethyl fumarate) Data Sheet, 2 May 2017.

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# recipe.

## Three Bean Chilli

Contributed by Ingrid Minett

This recipe is a favourite in my household. From about mid-autumn until late spring we'll make this at least twice a month. Chilli is such a satisfying meal, and this recipe generally lasts over a few nights. It seems to improve with age, making it a brilliant left-over kind of meal. We've even made this chilli for guests and it's always as much of a hit for meat-eaters as it is for vegans.

The best part is that it's super simple to make. Here's the recipe if you want to give it a try.

### Ingredients:

- 2 tbsp sunflower oil
- 1 large onion, chopped
- 3 carrots, chopped
- 2 green peppers, seeded and chopped
- 3 cloves of garlic, crushed
- 1 to 2 tsp chilli powder (depending on how hot you like it)
- 1 tsp smoked paprika
- 1 tsp ground cumin
- 1 tin kidney beans
- 1 tin pinto beans
- 1 tin black beans
- 2 tins chopped tomatoes
- 100g of tomato puree
- 125g mushrooms, sliced into quarters
- 2 cups of frozen corn
- 1 tbsp dried oregano
- 2 tsp unsweetened cocoa powder
- 750 ml vegetable stock (or beer)
- Salt



### Directions:

Heat the oil in a saucepan, then add the onion and cook for 5 to 7 minutes until the onion is soft. Add the carrots, peppers and garlic and cook for 3 minutes. Add the chilli powder, smoked paprika and cumin, then cook for another minute. Stir in all the remaining ingredients. Bring to the boil, then reduce the heat and simmer for at least 20 minutes. Alternatively, bake it at 180 degrees Celsius for 20 minutes. The chilli matures with longer cooking.

Once you have the basic recipe, you can play around with the recipe. I like adding in dried mushrooms and about a quarter cup of savoury yeast flakes. Try different kinds of beans, and different kinds of peppers. I recently substituted leeks for the peppers (since I had lots of leeks and no peppers) and it was delicious. You really can't go too far wrong with this recipe. 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](mailto:Ingrid@msakl.org.nz). If you can, please also include why it's your favourite and a photo.*

# profile on volunteers.

## – Joan Thomson and Fran Watts

At our AGM in June two of our very long term volunteers, Joan Thomson and Fran Watts were awarded Honorary Life Membership for their years of service to MS Auckland.

### *About Joan*

Joan's husband, Bruce, was diagnosed in 1993 at the age of 56 with MS. He lived with MS for only 8 years, sadly passing away in 2001. Joan remembers that when he was diagnosed there was very little for him, other than the tremendous support he received from MS Auckland.

Bruce was the first MS patient his GP had ever had, and the neurologist who diagnosed him just sent him home. It was the Field Workers at the time who Joan remembers being so very excellent. They organised a men's coffee group, and often met at Joan and Bruce's house for support and friendship. The Field Workers also organised for Bruce to see a continence nurse and a dietitian.

It was the Field Worker that talked Joan into attending the MS society's AGM. And it was at that AGM, that Joan was elected onto the Committee. She continued on the Committee for about 24 years until 'retiring' in 2019. Over the years Joan has given so much to the Society. She was always the first to put up her hand to help at events and workshops. Nothing was ever too much for her. Her biggest involvement has been, and continues to be with fundraising. She is still on the Life Buoy for MS committee, and together with a small group of hard working volunteers, they put together the biggest fundraising event for the Society each year.

### *About Fran*

Fran was diagnosed with MS on the 20th of July 2001. It wasn't long after that she became involved with MS Auckland, only 'retiring' from the committee in 2019 after 17 years.

Fran is a great advocate for the Overcoming Multiple Sclerosis lifestyle, and has attended two OMS retreats – one in 2004 and one in 2014.

She became the secretary for the Society and held that post for many years. Her other most notable contributions have been in supporting the fundraising projects for the Society. She made a huge contribution to a Bike the Bridge fundraising event, and every year also organises a site for the annual Street Appeal.

Fran says "the MS Society has been there for me the whole time. Being on the committee and helping out where I can is a way for me to give back. The Field Workers in particular have been wonderful and are always there for me to provide help or advice".

Much of Fran's life can be read in her book published last year – 'I can until I can't'. This is an excellent story of hope and inspiration. Fran has donated back to MS Auckland with some of the proceeds of the book sales, which can still be purchased through her website - <https://www.franwattsbook.com/>



*Fran and Joan*

# hydrotherapy.

We are pleased to announce that our very popular Hydrotherapy classes are now able to safely start up again. As one avid participant told me – ‘my hydrotherapy class is what I missed the most during lockdown’.

If you haven’t tried the hydrotherapy classes yet, then why not give it a go? You can attend two classes at no charge to try it out and see if it’s for you.

If you are new to hydrotherapy please contact either a Community Advisor or the MS office. Let them know which pool you wish to attend so that they can let the group leader know you will be attending, and so that you can be met at the pool and welcomed to the class.



## *New Class starting Term 3*

We are really excited to be able to offer a new Saturday morning class at Millennium Pool starting on Saturday 25th of July. This class will be unique in Auckland and will be based on the principles taught and utilized in the life changing programme – MS Get a Head Start. The trained therapists leading the class will support you to ensure you receive maximum benefit from each session.

**Please register for this class by contacting Liz at the MS office on 09 845 5921 or by e-mail at [liz@msakl.org.nz](mailto:liz@msakl.org.nz)**

## *Cost*

\$120 for the year

\$30 per quarter

Payment can either be made on line into our bank account: ASB 12 3047 0088939 00 be sure to put you name and Hydro as a reference. Or by credit card by calling the office on 09 845 5921.

## *Re-start up dates for Hydrotherapy*

Epsom Girls Pool	Thursday 2nd July
Lloyd Elsmore Leisure Pool	Tuesday 21st July
Manurewa Leisure Pool	Wednesday 22nd July
West Wave Pool	Friday 24th July
Diocesan School Pool	Saturday 1st August (due to repair work)
AUT Millennium NEW CLASS!	Saturday 25th July

## 2020 Weekly Sessions

<p>Tuesday</p> <p>.....</p> <p><b>Lloyd Elsmore Pool</b> Sir Lloyd Drive Pakuranga</p> <p>11:00am - 12:00 noon</p>	<p>Wednesday</p> <p>.....</p> <p><b>Manurewa Leisure</b> Sykes Road Manurewa</p> <p>11:00am - 12:00 noon</p>	<p>Thursday</p> <p>.....</p> <p><b>Epsom Girls</b> Silver Road Epsom</p> <p>10:30am - 11:30am</p>	<p>Friday</p> <p>.....</p> <p><b>Westwave Aquatics</b> 20 Alderman Drive Henderson</p> <p>10:00am - 11:00am</p>
<p>Saturday</p> <p>.....</p> <p><b>Millennium Pool</b> 17 Antares Place Rosedale</p> <p>8:00am - 9:00am</p>	<p>Saturday</p> <p>.....</p> <p><b>Diocesan Girls</b> Clyde Street Epsom</p> <p>10:00am - 11:00am</p>	<p><i>Before attending the class for the first time, or for more information please contact your Community Advisor or Liz at the MS Auckland office on <a href="mailto:infor@msakl.org.nz">infor@msakl.org.nz</a> or 09 845 5921.</i></p>	

# Christine Ball – fulfilling a dream!

Early 2017 I told my husband and daughters that I was applying to enrol for full time study to complete a Bachelor of Counselling degree. In doing this, I would finally be realizing part of a dream that I had held for many years. I had wanted to be a primary school teacher, however, these plans had been interrupted with my diagnosis of Multiple Sclerosis.

Life was taking a different course, and instead I worked in financial and administration roles, got married and started a family. Time progressed and our daughters had now grown up, completed degrees, were leaving home and I realised that to work in areas that now interested me required professional training. The opportunity to fulfil my earlier dreams with the possibility to work in schools was now.



Becoming a student meant major adjustments. I had timetables, assignments with deadlines, piles of reading to absorb and lectures to attend. A large yearly planner adorned the wall of my study, colour coded for assignment dates and semesters. Adventures with downloading articles, saving documents, requesting library books and reorganising my schedule was needed. Dramas with submitting weekly tasks on time, writing essays and receiving back marked assignments was challenging to say the least.

Student life was messy at times with the reality of hard work and I often needed to remind myself why I had taken on this adventure. Being accountable to supportive friends helped to steady my focus and my mantra of 'living life well with MS' remained strong. Part of our course content required attending personal counselling and having time to work with my MS story allowed me to recognise areas of disappointment. The young Christine aged 18 who received the relapsing remitting MS diagnosis was given time to be heard and understood differently.

Living with the label of MS and having a condition that had changed my life, now had time to be aired and refined. What does success look like? Can I do things differently? The 'should' and 'could' statements that I had carried were changing to "I am doing well" comments.

Having access at College to use a disabled carpark on days when life was difficult and tiring, was humbling but supportive. I was encouraged by my MS Field worker to apply for the Dorothy Newman scholarship for retraining purposes and to my surprise was successful.

Accepting change and moving with new ideas or approaches are powerful moments of truth.

Learned skills and theories used in counselling have been helpful for me now as I look for employment. Having my practicum at an Intermediate School was my dream, spending time with young students in our current school and family culture was great and this is the area is where I hope to continue working.

The final chapter of this story is still being written, with Covid-19 restrictions having different impacts on community and opportunities that can be accessed.

Learning to be real in situations, handling anxiety and changes which are beyond my control in healthy ways reminds me of previous MS relapses. Counsellor degree completed before turning 55 was my goal, delayed graduation ceremony to now follow and the new journey of 2020 continues to excite me.

Thank you, family now watch this space!

# support groups.

While we enjoyed our Zoom support groups, it is also so very nice to be able to meet up again with friends at a café.

Support groups are fun! We have 15 of them happening all over Auckland. They are open to anyone with MS as well as their partners, friends, parents, carers, siblings or children. There are so many benefits to being part of an MS Support Group including making new friends, meeting others living with MS, feeling less isolated, and exchanging tips and ideas on living well with MS.

If you are interested in joining a group, please contact one of our Community Advisors to let them know. They will assist you in finding a group that would suit you and be there to welcome you to the group. They may even look at starting up a new group in your area.



This is how our Men's group, that meets in the Botany Town Centre got started – someone asked if there was a group just for men with MS. There wasn't one, so one got started about 2 years ago and continues to meet each month.

Location	Date/ Time
<b>South / East Auckland</b>	
Pukekohe Café Group - Different Venues	First Thursday / Month - 11.30am
Botany Café Group - Robert Harris Café (Botany Town Centre)	Third Thursday / Month - 11.30am
Manukau Café Group - Friendship House (Manukau)	Last Tuesday / Month - 10.30am
Men's Group - Robert Harris Café (Botany Town Centre)	Last Saturday of each Month - 10.30am
<b>Central</b>	
Mt Wellington Café Group - Coffee Club on Lunn Avenue	Second Saturday / Month - 11.00am
Stonefields Café Group - Stonebake Café (Lunn Avenue, Mt Wellington)	Third Wednesday / Month - 10.30am
Onehunga Group - Urban Verge Cafe (653 Manukau Rd, Royal Oak)	Third Tuesday / Month - 10.30am
<b>West Auckland &amp; Rodney</b>	
Child Friendly Group, Huckleberry Café, Portage Road, New Lynn	Second Monday / Month - 9.30am
Kumeu Café Group - Different Venues	First Tuesday / Month - 10.30am
Henderson Garden Café Group - Columbus Coffee Café (inside Mitre 10 Mega, 186 Lincoln Rd)	First Thursday / Month - 11.00am
New Lynn Café Group - Columbus Coffee Café (inside Mitre 10 Mega, New Lynn)	Second Tuesday / Month - 10.30am
North Café Groupies - Kings Plant Barn (Silverdale)	Third Wednesday / Month - 10.30am
<b>North Auckland</b>	
Mayfield Coffee Morning - Kings Plant Barn (1 Forrest Hill Road, Milford)	First Thursday / Month - 10.30am
Shore Lunch Group - Palmers Planet Café (cnr Hugh Green Drive/Greville Rd, Albany)	Last Wednesday / Bimonthly - 12.00 noon
North Shore Café Group - Palmers Garden Café (65 Greville Road, Pinehill)	First Saturday / Month - 11.30am

# world MS day, the MS international federation and quality of life with MS.



The infograph on the following page on the Quality of Life with MS was taken from the MS International Federation and can be found on their website - <https://www.msif.org/>

The MS International Federation is a global network of 48 MS organisations, people affected by MS, volunteers and staff from around the world. Their mission is 'to inspire, mobilise and bring the world together to improve the quality of life of everybody affected by MS and to end MS forever.'

The first World MS day was initiated in 2009 by MS International. They choose a theme to focus on for each three year period. The theme for 2020 – 2023 is 'connections'.

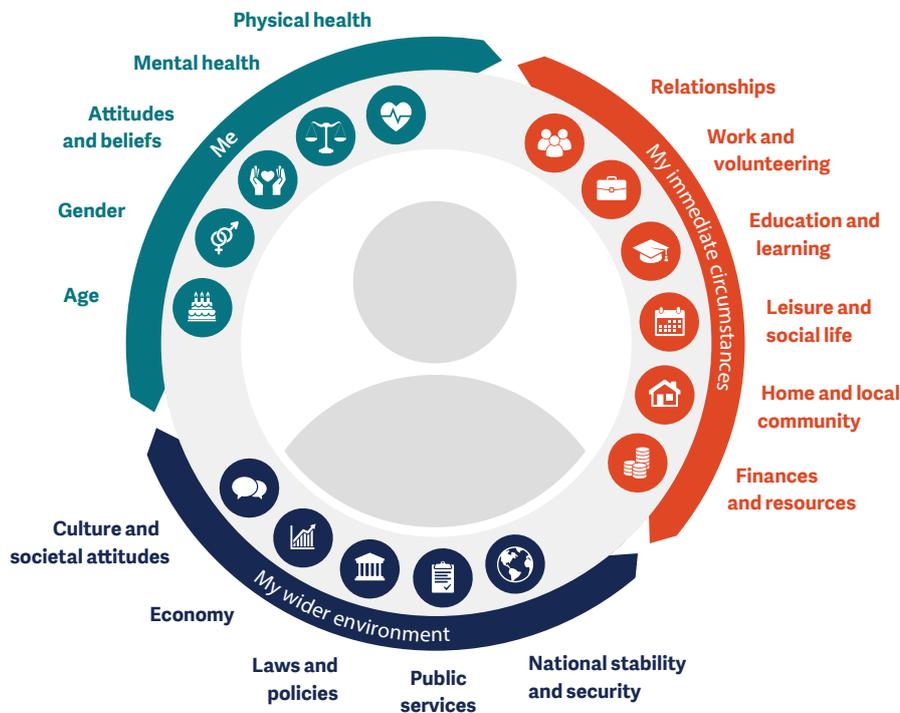
In celebration of World MS Day this year, MS Auckland invited Dr Sally Shaw to speak in a Zoom webinar on the Connections theme. That talk was recorded and is available on our Facebook page. In her talk, Sally briefly drew attention to the following infograph. It is worth having a look at this graph and understanding what influences your quality of life and also how it can be improved.

The MS International Federation's atlas of MS shows that there are about 2.3 million people worldwide living with MS. Many of these people have little access to support. In many ways we can consider ourselves fortunate to be living in New Zealand.

# QUALITY OF LIFE WITH MS

## What influences quality of life?

Many factors influence a person's quality of life, both inside and outside their direct control. These factors vary from person to person, from place to place and change over time. Multiple Sclerosis (MS) can impact these factors at any time.



## How can quality of life be improved?

The seven principles below are based on the insights and experience of people affected by MS and agreed by the MSIF movement. There is no priority amongst the principles – it is for individuals and organisations to decide what is most important to them at any time. No country can claim to have achieved them all. They are our call to action for continuous improvement in every country.

The seven principles	Examples of factors they can influence
Empowerment, independence and a central role for people affected by MS in decisions that affect their lives	
Access to comprehensive and effective treatments and care for the changing physical and mental health needs of life with MS	
Support for the network of family, friends, loved ones and unpaid caregivers	
Work, volunteering, education and leisure opportunities that are accessible and flexible	
Accessible public and private spaces, technology and transport	
Financial resources to meet the changing needs and costs of living with MS	
Supportive attitudes, policies and practices that promote equality and challenge stigma and discrimination	

\*People affected by MS includes people with MS, their caregivers, family members and friends closest to them.



(The following article was taken from [mstrust.org.uk](http://mstrust.org.uk))

Reflexology is a complementary therapy that involves having gentle pressure applied to the soles of your feet or your hands.

It's thought that different points on the feet are connected to different areas of the body, such as particular organs. Reflexologists believe stimulating these points can encourage natural healing.

As well as providing the calming effects of touch, reflexology can promote relaxation and improve wellbeing.

According to a survey, reflexology is one of the most popular complimentary therapies used by people with MS. Although the quality of research is considered low, some studies have found that reflexology can improve pain, fatigue and mood in people with MS.

Reflexology has been investigated in a variety of studies to see whether it can help with MS symptoms. In one study, 71 patients were randomised to either reflexology treatment with manual pressure on specific points of the feet and massage of the calf area, or to non-specific massage of the calf area only. 53 patients completed the study and there were significant improvements in the mean scores of paraesthesia (abnormal sensations such as pins and needles), bladder symptoms, muscle strength and spasticity.

In another study, 73 people received either reflexology or basic foot massage weekly for ten weeks, primarily as a treatment for pain. Both groups showed benefit in pain, fatigue, depression and spasms with no clear difference between reflexology and massage. The effect on pain lasted for up to 12 weeks.

More recently, three separate studies compared the effects of reflexology and relaxation on fatigue, pain and psychological symptoms (anxiety, stress and depression) in women with MS. In each of these studies, reflexology was given to 25 women with MS for four weeks, twice a week for 40 minutes. Results were collected through a questionnaire completed before, immediately after and two months after treatment. In all of the studies, reflexology was found to reduce the severity of these symptoms and was considered an effective technique.

*To learn more about reflexology and to find a registered Reflexologist near you go to: <https://reflexology.nz/>*

# our supporters.

MS Auckland is grateful to all organisations, families and individuals who support our work.

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*Special thanks also to our wonderful volunteers who give us their time, expertise and support.*

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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](http://www.msakl.org.nz)*



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