

multiple news

Multiple Sclerosis Auckland Magazine

November 2020 | Issue 48

Mike King, at Life Buoy for MS



Photo by
Zanthe Vorsatz

inside

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Gratitude

Brain Health

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our people.

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a few words from Ingrid.

Our General Manager

2020 is drawing to a close. What a tumultuous year it has been! It will be interesting to hear what the history books will have to say about 2020!

This issue has some great stories from people in our community, including two newly diagnosed members, Duncan and Mandy, a story from a long time diagnosed member, Christine, and a story from a new member who doesn't have MS, but something very similar, Shona. Jess Brien writes on the Science of Gratitude. Jess is very active on social media and has started a podcast called 'That's so Chronic'. It's a great podcast! The Sam Smith interview, in my opinion, is particularly good and well worth tuning in for.

Self-care is so very important, but it is too often neglected, especially if we are having to look after family members or friends. Our newest community advisor, Lesley, together with Luminita, write about the importance of self-care and provide a few tips on things we can do to look after ourselves. After all, if we don't look after ourselves how can we look after others?

Our cover story this issue is our big annual fundraiser – Life Buoy for MS. This event was supposed to take place in June, but due to Covid-19 it had to be put on hold. This event is so very important to us, and we are so very grateful that the community got behind it again this year to help make it the successful event that it was. It would not have happened though without the hard work of 5 very special volunteers – Lorraine Street, Raewyn Henry, Joan Thomson, Christina Cairns and Celia Snedden. We could not do all we do without our amazing volunteers. Becky talks to volunteer Christina Cairns to find out a bit more about this wonderful lady.

Fundraising has had its challenges this year, especially with our annual street collection having to be cancelled. Along with MS societies across New Zealand we participated in an on-line fundraising campaign instead this year called 'Face of MS'. At the time of writing we

had received donations of just over \$5,100 from this campaign. We will be running it all year, so please have a look at sharing this campaign with your friends. The lovely Anu, is our face of MS, and what she shares in her story is inspirational. The link is - <https://fundraise.msnz.org.nz/faceofms/MS-auckland>.

This is our last issue for 2020 and I would also like to thank my Board members and Staff for their dedication and hard work over the year. I feel fortunate to be working with such kind and talented people. Despite all the challenges we faced we have achieved much and have had a very fulfilling year.

Wishing you all a joyous holiday season and all the best for 2021!

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Anu

"While there is no cure for Multiple Sclerosis yet, your donation can help me, and others, manage our MS and live our best lives."

Anu

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events for your calendar.

Upcoming events



MS Auckland office will close at 5pm on Wednesday the 23rd of December and reopen on Monday the 11th of January.

Wishing you and yours the very best for the Christmas and holiday season. Ingrid, Mark, Becky, Tatjana, Luminita and Lesley

End of Year Christmas Lunch

We hope you will be able to join us this year for our annual end of year Christmas lunch. Bring your partner or family members and meet up with old friends or make new friends.

Date: Sunday 13th December

Time: 12 noon to 3pm

Venue: Remuera Club – 27-33 Ohinerau Street, Remuera

Cost: \$25/person which includes a scrumptious buffet lunch with tea and coffee. A cash bar is also available.

To book your tickets please e-mail info@msakl.org.nz or call the office on 09 845 5921.

Round the Bays 2021

Are you in for another challenge? Auckland Round the Bays will be held on the 28th of February next year. We are looking at getting together once again with our friends at Vision PT and putting a team together for this event.

Let us know if you are interested in participating this year by e-mailing events@msakl.org.nz.

Vision PT now offering the 'MS get a head start' programme



Vision PT now has their first qualified MS Get a Head Start programme facilitator, Carl Paddick.

Carl is keen to start leading this innovative programme. The first set of classes, scheduled to start just after labour day, will be offered at a special price with both Vision PT and MS Auckland subsidising the cost of the programme to help make sure that cost isn't a barrier.

Carl, originally from the UK, joined Vision PT one year ago. He has been in the health and wellness industry for 16 years now, both on land and sea, and is also a qualified sports massage therapist. He has a real passion for working with people and supporting them in achieving their goals.

His interest in MS was initiated a number of years ago in the UK when he worked with a woman who had MS. He wished then that there was a programme he could utilize to support the woman in managing her MS. When Carl found out about MS Get a Head Start programme initiated by Gilly Davy in 2013 he was keen to learn more. He became a qualified trainer this year and speaks very highly of the training he received and the 6-week programme that he is now qualified to lead.

The programme runs over 6 weeks, with 2 one-hour sessions a week, for a total of 12 sessions.

MS Get a Head Start is an exciting opportunity for people with multiple sclerosis. It does require a dedication to two training sessions a week for six weeks, but the long-term benefits are certainly worth the time and effort.

Carl is looking forward to meeting with the MS community and rolling out the MS Get a Head Start programme. Check our website for future dates for the programme or send an e-mail to tatjana@msakl.org.nz to be notified when the next programme will be available.

from the MS Community Advisors.

The importance of self-care

*Written by MS community advisors
Lesley Amosa and Luminita Apostol*



We are all members of the human race and all that entails. But when it really comes down to it, we are also all individual entities and responsible, first and foremost, for ourselves. There is an old adage that if you cannot take care of yourself then nobody else will.

Some people think self-care is selfish, but is it? For us as community advisors, self-care means to care for yourself and to take some time out of your day to look after your own wellbeing. Self-care is about 'filling your tank' with physical, emotional, social, or spiritual well-being. When our tank is full and running over, we feel better and we can be ready to also give to others.

We are all unique and how we manage our self-care depends on what we value as individuals and what we require to thrive and grow in our lives.

Having MS means constantly looking at ways to take care of ourselves as we listen and respond to the signals our body sends us.

Do you feel you get fatigued easily? Do you feel yourself getting grumpy with loved ones? This may be a sign that your tank is getting low or running on empty and that it is time to take a break and recharge. By doing this you will feel better emotionally and will find yourself dealing with the problems or issues that may have come your way throughout the day.

Setting limits or boundaries is a good example of the type of self-care that we believe many people need to practice. If an individual has been used to doing a lot of activity and keeping busy, it can be hard to set limits and to say things like, "I can't do that right now". However if we know that an activity will take a lot out of us and that we will pay the price for it later, it is good to start recognising this ahead of time and to set limits so as to avoid over-commitment and burn-out.

This might also mean learning how to say 'no' when asked to do things. This goes not only for people with MS but also for family members who care for a person with MS.

A simple way to recharge can be by just getting outside in the sunshine for 10 minutes or so. This is a great way to get some vitamin D too! Find a nice place to sit. Perhaps take a cup of tea or coffee with you, and just listen to the birds. It is amazing how quickly nature can revive us. Or, if the weather is not so favourable, just taking time out to sit and reflect and perhaps use your journal. These are all ways to enhance your emotional health and lift your mood.

Social connections are also particularly important and have been shown to be a key driver of well-being and resilience.

MS Auckland support groups are a great way to keep connected to MS friends and to get advice and support from others during difficult times; or just getting together to relax and enjoy each other's company.

Watching what you eat also can improve mood and is another way of practicing compassion and kindness on ourselves. Are you nourishing your body with living foods, such as fruits and vegetables? Or does your diet consist largely of processed and refined foods? Diet plays a key role in our health and in our feeling of wellbeing.

What about exercise? Exercise has been shown to improve mood, lower stress levels and anxiety. It can be gentle exercise, such as walking, stretching, yoga, tai chi or even gardening. MS Auckland provides exercise classes, with hydrotherapy being the most popular. If you have not given it a go yet, perhaps it is something you could consider as part of your revitalised self-care strategy.

Here are some self-care tips and activities you may want to try:

- Connect with people who encourage you and make you feel good
- Start a daily journal
- Get outside in the sunshine
- Watch funny You Tube videos and make laughter part of your day (share them with your MS friends)
- Find an exercise you enjoy and make movement a significant part of your day
- Practice saying no and setting limits on what you can and cannot do
- Spend time alone and just be in the moment
- Listen to your favourite music (and sing out loud!)
- Maintain good bedtime routine and get adequate sleep
- Think back and do those things you used to that brought you joy

Your Community Advisors



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Luminita
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Lesley
Ph 021 959 189

We are reminded of the quote by Buddha: "You yourself, as much as anybody in the entire universe, deserve your love and affection".

Take care of yourself and if you need to talk to someone on how to get in the road to self-care, please just give us a call. We will be only too happy to help.

Lesley Amosa our new community advisor.

Written by Lesley Amosa

Kia ora. I'm Lesley. Let me tell you a bit about myself. I was born in Lower Hutt, New Zealand and adopted by a Scottish couple who emigrated with my younger sister and I to Brisbane Australia. I grew up as a toddler in Australia, so sorry about the slight Aussie accent clobber! I moved back to New Zealand in 1998, with my two children.

My husband Bill and I enjoy spending time with friends on the weekends and going out for a coffee and dinner, occasionally using the 'First Table' booking system (everything half price)! I enjoy reading, arts and crafts, painting and generally being creative. I have recently taken up running which I do early in the morning, I enjoy the quietness at 4:30am or 5am.

One of my previous roles was with Creative Abilities. We worked with people with physical and intellectual impairments. I worked in a busy centre which ran different day classes for those who attended. We also had day trips out into the community. It was a good fun place where there was lots of laughs and a great community feel. I started work with this organisation intending to give to others, however, it did not take long for me to see they actually gave so much back to me.

My next role was working in the mental health sector for a company called Pathways. I was with Pathways for almost 10 years as part of their mobile team and worked individually with people in the community supporting them with their wellbeing and assisting them to achieve

their goals. Most of these goals were around health, fitness and getting connected to other services in the community. This was also a terrific job which gave me a lot of satisfaction and I felt that I had something to contribute to my clients lives and they also contributed to mine.

Immediately before my current role at MS Auckland I was with a company called Supporting Families. I worked with families and enjoyed the groups that we had monthly and meeting the different family members that would come to our office for ongoing support. I enjoyed hearing their stories, learning about their lives and seeing how I could best support them with the changes they were wanting to make to improve their lives and those of their loved ones.

Now I am on the next stage of my journey, I am very excited about getting around to contacting and meeting as many people as possible at MS Auckland. I have enjoyed seeing what happens at hydrotherapy and going out to the support group meetings. I thank you all for being so warm and welcoming to me. I think I have joined at a great time. I'm amazed by all the Christmas parties that will be organised and being included in such joyful festivities and getting better connected. I am also very blessed to be part of the MS Auckland team. What a great place to work!

Best wishes to you all,
Lesley

from the MS nurses.

Written by Fiona d'Young

Brain Health: Time Matters in MS

Our understanding of the human brain continues to evolve. If you follow MS websites or social media activity you may have heard of brain health. Many of you will be incorporating brain health recommendations into your day to day life already. Well done if you are! It is undoubtedly becoming an area of significant interest in MS care and research.

Neurological reserve also called brain volume, is a component of brain health. Having a good neurological reserve is essential as this allows the brain to work harder and compensate for other areas that are damaged by MS.

Only around one in 10 MS lesions cause a relapse¹ that is followed up on by a health professional. Other brain tissue damage can be occurring below the surface that, although not noticeable in your daily function, can be depleting your neurological reserve. This is vital to know about and to understand. But it is not all bad news. There is a raft of possible actions you can take daily to enhance your brain health.

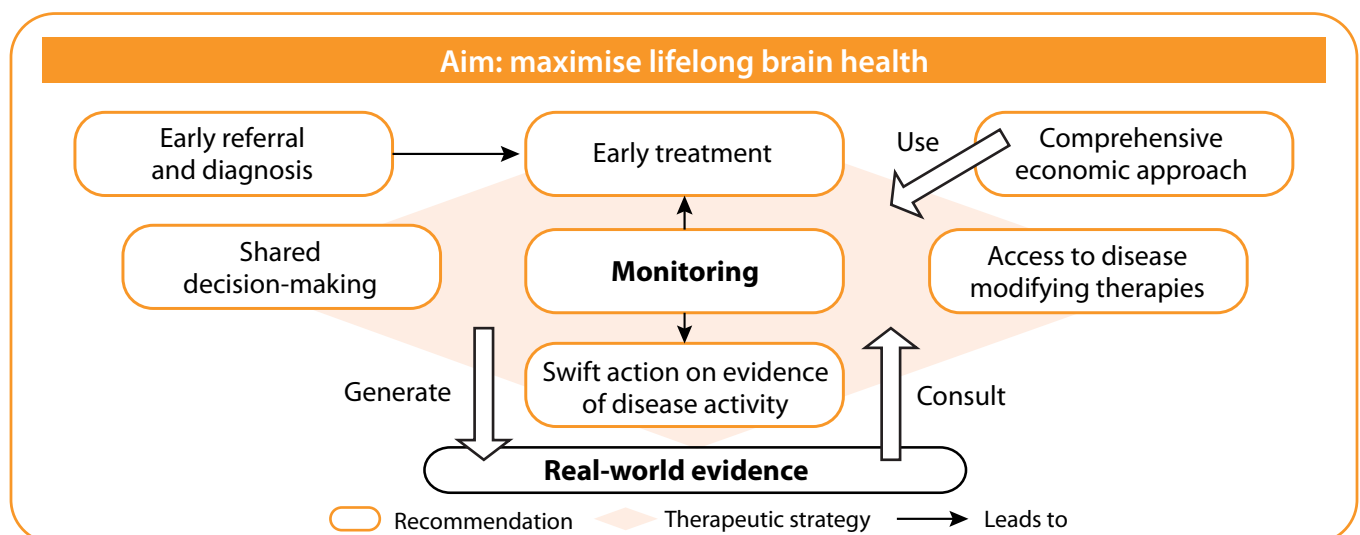
Engaging in positive lifestyle choices can help to keep your brain as healthy as possible. Having a healthy brain that functions well is something we should all strive for.

Here are six positive steps you can take for brain health, whatever your MS diagnosis:

1. Keep as active as you can
2. Keep your weight under control
3. Keep your mind active
4. Avoid smoking
5. Watch how much alcohol you drink
6. Keep taking your prescribed medications (eg. conditions like high blood pressure and diabetes can have a negative impact on your MS)

If you have not visited www.msbrainhealth.org it's an excellent website and well worth visiting. You will find resources and documents that can be downloaded and saved for further reference. These can be helpful to share and discuss with whanau.

Outside of the suggestions around healthy lifestyle choices, the website encourages people with MS to work closely with their MS team and GP to maximise lifelong brain health. This includes being mindful that new symptoms are reported, and regular reviews are arranged.



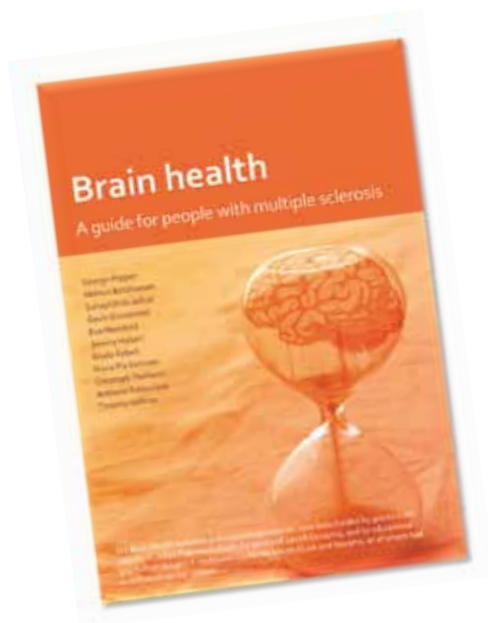


A small amount of brain tissue loss is normal in healthy adults, but in MS this happens faster than usual



When you see your MS team, the following points are worth considering.

<ul style="list-style-type: none"> ■ Keep an MS diary and share information with your MS team 	<ul style="list-style-type: none"> ■ Be part of the decision-making process together with your HCPs
<ul style="list-style-type: none"> ■ Discuss strategies for managing your MS 	<ul style="list-style-type: none"> ■ Prepare for your appointments by making notes about topics you would like to discuss
<ul style="list-style-type: none"> ■ Ensure that you feel well informed about the results of your clinical assessments and MRI scans 	<ul style="list-style-type: none"> ■ Explain to your HCPs what matters to you
<ul style="list-style-type: none"> ■ Ask whether it is appropriate to switch to another DMT 	<ul style="list-style-type: none"> ■ Look for other resources to help with these conversations
<ul style="list-style-type: none"> ■ Ask the health care professionals who oversee your treatment how they plan to monitor your MS 	<ul style="list-style-type: none"> ■ Connect with MS Auckland who can provide information and community support.



Brain health recommendations for MS were developed following an international consensus between people with MS, carers, neurologists and health economists. References for further reading are listed below.

References

1. Kappos L, Moeri D, Radue EW, et al Lancet 1999;353:964-52
2. Giovannoni G, Butzkueven H, Dhiib-Jalbut S et al Multiple Sclerosis and related disorders. 9 (2016) S5-S48

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Our office will be open up to and including the 24th of December. Our out of office details will be on our phone and e-mail.

We will be running a bit of a reduced service over January.

MS Auckland President – Jan Hollway.

Written by Louise Reed

Jan Hollway became the President of MS Auckland in June 2020. Louise met with Jan to find out a bit more about our new President.

Jan met her husband Roger (who is originally from England) when he answered Jan's advertisement for a flat mate.

The couple married in 1981 and have two children; James who is 38 and Lauren who is 33. James is a Professor in International Relations at the Graduate Institute in Switzerland. He is married and has a 4 year old daughter, Sophia. Jan says she chats to Sophia every day over Facetime and loves that she can be involved in Sophia's life even when she lives on the other side of the world. Jan's daughter, Lauren is a trained nurse and currently works in IT for NSW Healthcare in Sydney, Australia.

Jan and Roger have spent time living in both Auckland and Napier, depending on their work commitments. Jan owned her own private training company which was sold in 2017.

In 2000 Jan and Roger moved to Howick, Auckland as Roger was transferred for work.

In 2012 they demolished their property near Half Moon Bay and began building a new home. It was during the house build that Roger was diagnosed with MS. As a result of Roger's diagnosis, Jan and Roger made the decision to follow the George Jelinek Overcoming MS programme.



When Jan and Roger came to Auckland, they became involved in the H28 Yacht Owners' club. Jan said it was a fantastic 10 years of sailing. Jan was also involved in a women's crew competing weekly on a Young 88 and was involved with the "Tuesday night sailing" group for 5 or 6 years. Jan and Roger were booked for the Ocean of Hope sailing trip in Turkey in October, and with that cancelled may be able to pick that up again in 2021.

Jan now plays bridge at Interclub level and has recently taken up portrait drawing. She continues to walk regularly, having completed the 700km Spanish Camino in 2016.

Being involved in community groups is something Jan has done throughout her life. Currently she is also involved with the Uxbridge Community Projects Incorporated, an organisation where she has been the Vice-Chair for 3 years and the Chair for the past 2 years.

Jan says that she is approaching her role as MS Auckland president with an eye to the future so that the society is not just doing the "now" but is planning for the future needs of people with MS in Auckland.

Jan's strategic thinking and commercial experience is an invaluable asset to MS Auckland, particularly given the current challenges raised by the COVID-19 pandemic. Her leadership during the pandemic has been of great assistance to the Society and the Board in creating and implementing appropriate policies to guide the society. Thank you, Jan, for your invaluable contribution to MS Auckland and the Board.

another wonderful night of laughter!



Nick and Tony outside the Comedy Club



Hiria from Harcourts Cooper & Co assists Sam with the raffle prize draws



Sam Smith

MS Auckland Ambassador, Sam Smith, once again put together a fabulous night of Comedy on the 6th of October to raise funds for MS Auckland. This event is usually held during MS Awareness Week, however due to COVID-19 restrictions, the event had to be postponed three weeks. We were just one day away from moving up a level, so we still had to commit to safety precautions and reduced numbers of attendees. However those lucky enough to come along were treated to a great night out, and while funds were slightly down from last year, it was still a wonderful overall result!

This was the 4th year running that Sam has done this for MS. Each year he asks a number of his mates to volunteer their time for the show and over the four years we have seen some wonderful new talent, and some 'old' favourites.

Each year Sam MC's the event, introducing his friends to the stage to perform. But he also performs a set as well and tells me that it gives him an opportunity to try some of his new stuff. This year, as every year, he was accompanied by this guitar, showing off his talent not just with jokes but also with music.

The first year that Sam put the show on he was in a middle of an MS relapse, and was barely able to see. This year though he was feeling great and looked better than ever. His performance throughout the night was brilliant.

Sam is wonderful in the way that he talks about MS. His objective is to raise awareness of the condition and make people living with MS feel confident and strong and understand that they are so much more than their MS.

A big thank you to Sam, and his amazing friends who joined him in 2020 to raise funds for MS:

Tony Lyall, Lana Walters, Nick Rado Natalie Samy and Jeremy Corbett.

Also a big thank you to ***Harcourts Cooper & Co***, who have got behind and sponsored this event each year.

There were also two raffle prizes, one donated by MacPac, and the other by Phytomed Medicinal Herbs.

the science of gratitude.

Written by Jess Brien

During Lockdown 1.0 - I hate to admit it - I was one of those people who did an online course. Fortunately/unfortunately it is a personality trait of mine. When I was at primary school a teacher wrote on my report card, "Jessica is like a sponge. She soaks up information." So it was no surprise I jumped at the chance to do a course with Yale University with this new stay-at-home time.

It was called The Science Of Wellbeing and was being delivered on Coursera - an online learning platform. I forfeited receiving a certificate at the end of the course so that it would be free. I figured I have a Bachelor of Performing Arts in Musical Theatre and no one has ever asked to look at that certificate so this should be fine. I will be putting this on my CV though. I mean it's Yale University! So fancy!

I wasn't alone. Nearly 3 million people (at last count) have signed up for this course. With the world feeling the effects of COVID19 it comes as no surprise that people are searching for tools to enhance their happiness.

I won't get into the details of the course too much but I do want to share one piece of learning.

And that is... Gratitude.

Being thankful and appreciative of what you have. It's not a new concept. You've probably heard of it before or know that you should be doing it. But why? I learnt that scientists have proven that gratitude can increase your mood and lower your stress levels. A study in 2010 showed that writing down five things you are grateful for as opposed to five things that annoy you every day showed an increase in daily exercise by one hour a day. Studies have also shown a positive effect in relationships and at work. But the most interesting to me is that gratitude is a killer of envy. Practicing being grateful will help stop social comparisons which, whether we like it or not, are contributing to our overall happiness.

Living through a pandemic is hard work. Some days I wake up, already sore and fatigued, read the news, and feel like the world is burning to the ground. I won't lie to you, it can be hard to find three things to be grateful for. But then I see the sunshine outside or remember that I have all of the ingredients to make pancakes, or realise that my hands aren't seizing up today, or see that an e-book has become available at the library, or realise that pizza is only a phone call away from being delivered, or remember that I have a lot of people who care about me. It may seem small and even silly to begin with, but writing down three things you're grateful for every morning really does set your brain up to have a good day.

So that's your challenge! For the next seven days write down three things you're grateful for every morning or night and see if you notice anything. I've found that tying it to a routine I already do (like my morning coffee) helps me remember. If you're feeling stuck or find you're constantly writing the same thing you can focus on something different each day, like people, environment, food, health...

Feel free to send me yours or let me know how you get on, I'm on instagram @jesssbrien or email hello@jessbrien.com



Jess Brien - Science of Wellbeing course (bringing back the title pages we used to do in primary school)



podcast 'that's so chronic' highly recommended!

Fellow Auckland MS-er Jess Brien hosts a new weekly podcast called 'That's So Chronic'. A series of interviews with people from around the world who are thriving - and sometimes only just surviving - with chronic illnesses, life changing injuries, and potentially disastrous diagnoses. Recent episodes include our very own Sam Smith on MS, Hayley Sproull on Polycystic Ovarian Syndrome, Morgan McKenzie Moore on coeliac disease, and an interview with a patient and a local Auckland GP all about medicinal cannabis.

Search "That's So Chronic" on social media to keep updated, press subscribe on Apple Podcasts and follow on Spotify (or wherever else you get your podcasts) so you never miss an episode!



PS: Some exclusive information for MS Auckland is that upcoming episodes include Claire Chitham (Shortland St, Outrageous Fortune) on Crohn's Disease, Rachel on receiving aHST in Singapore for her MS, and Lee Weir (The Rock FM) on Type 2 Diabetes ... just to name a few! We can't wait!

gratitude, the short film by Louie Schwartzberg.

There is a lovely YouTube clip on Gratitude by Louie Schwartzberg. Here are the words to that clip. I recommend that you watch the clip as well, as it is far more powerful when seen together. <https://www.youtube.com/watch?reload=9&v=cpkEvBtyL7M>

You think this is just another day in your life. It is not just another day. It is the one day that is given to you – today. It is given to you – it's a gift. It's the only gift that is given to you right now and the only appropriate response is gratefulness.

If you do nothing else but to cultivate that response through that great gift that this unique day is, if you learn to respond as if it were the very first day and the very last day, then you will have spent this day very well.

Begin by opening your eyes and be surprised. You have eyes you can open. That incredible array of colours that is constantly offered to us for pure enjoyment. Look at the sky. We so rarely look at the sky to really know how different it is from moment to moment with clouds coming and going. We just think of the weather and even of the weather, we don't think of all the nuances of weather. We just think of good weather and bad weather. This day right now is unique weather. Maybe a kind that will never come in that form again.

The formation of clouds in the sky will never be the same as it is right now. Open your eyes. Look at that.

Look at the faces of people who you meet. Each one has an incredible story behind their face. A story that you could never fully fathom. Not only their own story, but the story of their ancestors. They go back so far. And in this present moment, in this day, all the people you meet, all that life from generations, from so many places in the world, flows together and meets you here like a life-giving water, if you only open your heart and drink. Open your hearts to the incredible gifts that civilization gives to us.

You flick a switch and there is electric light. You turn a faucet and there is warm water and cold water and drinkable water. It is a gift that millions and millions in the world will never experience.

So this is just a few of a number of gifts to which we can open our heart. And so I wish that you will open your heart to all these blessings and let them flow through you that everyone we meet on the street will be blessed by you. Just by your eyes, by your smile, by your touch. Just by your presence. Let the gratefulness overflow and bless all around you.

Then it will really be a good day.

Mike King throws out the Life Buoy.



Mike King

After a mid-year postponement, MS Auckland's major fundraising event, Life Buoy for MS, for 2020 was celebrated in November at Auckland's Royal NZ Yacht Squadron headquarters on Westhaven Marina. Multiple sclerosis in the region receives only about eight percent of its funding from the government making Life Buoy vital to its continued provision of services and support.

The postponement did little to dent the ebullient positivity of the occasion as invitees including leading Aucklanders again turned up with loose pockets, wallets unclipped and cards in hand. Such was the pleasure in having an awesome event to attend after a stultifying year that funds were raised in record amounts.



Sir Graham Henry and our ambassador Sam Smith

Of course, you do not give generously without having key figures on hand to loosen those purse strings. This year it was Scotty (Sumo) Stevenson of television sport fame acting as master of ceremonies, Martin Cooper of Harcourts Cooper & Co as the auctioneer with the twitchy gavel and last, but by no means least, the forthright and heroic figure of Mike King ONZM as the guest speaker.

There would not have been one person in the room, presided over by the sentinel-like America's Cup, not deeply moved by Mike's address. Sure, he elicited a frequent selection of belly laughs and his language sometimes veered towards the 'blue', but it was all in the noble cause of getting his message across. In openly and honestly discussing aspects of mental health and suicide, he struck a powerful chord with those in attendance. More importantly, he gave people hope and a strength to move forward. The plethora of fulsome hugs he received in the wake of his address was ample evidence of its value.



Harcourts Cooper & Co Ladies

In welcoming everyone to the event, Ingrid Minett, general manager of MS Auckland made special mention of all the wonderful people whose hard work and dedication went to making Life Buoy a success. This included all the volunteers and helpers, the committee who managed the event, the generous sponsors and of course the hundreds who put their hands in their pockets. Ingrid also made special mention of two very special MS people who had passed on this year, Pip McNair and David Barnes.



Standing ovation for Mike King



The Prize Table



The beautiful Pascoes Ring

The 'live' auctions conducted by Martin together with the 'silent' auctions on the tables raised a whopping \$46,250. The table pledges, which every invitee happily contributed to, raised a record-breaking sum of \$23,725. Pledge contributors automatically entered a draw for a stunning platinum diamond ring donated by Pascoes worth \$6,100. This was won by Alistair Gilchrist. Every participant left with a special gift bag from Kiwiherb which specialises in 100 percent natural, premium quality herbal health products. Everyone was a winner!

Photos on the day were kindly taken by David Barker and Zanthé Vorsatz. The selection on these two pages is from Zanthé - www.zanthevorsatzphotography.com



Checking out the Auction Book

volunteer profile – Christina Cairns.

Christina has been an active Life Buoy committee member over the past few years. Becky asked Christina a few questions to learn more about our hardworking volunteer.



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

My sister, Linden, developed MS in the late 1990s I have been involved with helping with fundraising for MS Auckland since then off and on. I recently retired and moved back into Auckland city which enables me to do a little more. Linden died in 2001. She continues to motivate me to do what I can on the MS Fundraising committee.

Q. What motivates you to volunteer for MS Auckland?

Having nursed patients in hospital medical wards it drew my attention to this condition and then when I saw the deterioration of my sisters' condition, I couldn't stand by without helping in some capacity.

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

Last year Tony Milich from Sabatini generously donated a clothing voucher which Erin bid for and won. Erin has MS. She and her husband were planning a big overseas trip to Sweden, Russia and Japan. I assisted her in claiming her prize and choosing her clothing for her big overseas trip.

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

Most definitely I think it's the Community Advisors (previously called field workers) who visit people with MS and do what they can to support them in having a good life.

Q. Best vacation ever?

I adore Europe with its vast history of centuries of architecture, the various cultures and in particular their music and philosophy. I fell in love with Spain in particular their 'joie de vivre' and visited it twice.

Q. What famous person would you invite for dinner?

Vladimir Ashkenazy - Recently we were most fortunate to attend not only his last APO concert conducting at the age of 83, but also a private interview of 50 people at Dame Jenny Gibbs home. We were able to ask him questions about his life fleeing Russia with the KGB chasing him to Iceland and the role of his Icelandic pianist wife Thorunn in the international conducting and musical circuits. They were both extremely funny and so humble. They really are very modest superstars believing that they were lucky to be born with their incredible talent.

Duncan's experience with the 'newly diagnosed group'.

Written by Duncan Grant

In July 2020 I was diagnosed with Multiple Sclerosis. Although this came with a huge shock it was also a great relief. After approximately fifteen years of minor left leg weakness and an occasional creeping sensation across my chest I finally had a cause for these symptoms. With the diagnosis, I started to make plans about how to manage the MS. I found MS NZ and joined their e-mail list; I found MS Auckland and made contact with them; I was introduced to the OMS programme; and the list goes on as I worked to learn all I could about my MS.

This is the way I work; information is power for me. Early on in my diagnosis, I met with Luminita, the community advisor provided by MS Auckland. Luminita was a great source of knowledge for me and introduced me to MS Auckland's support network. I was relieved to discover there were others out there just like me. Just as I was looking forward to meeting fellow MS warriors in the support meeting groups, the second Auckland COVID lockdown arrived.

Organiser Tatjana contacted some of us in Auckland to ask if we would like to create a new group of the "Newly Diagnosed", meeting via Zoom.

I was very nervous but thought this was an excellent idea, as we will all be in the same boat, having similar experiences.

As the meeting approached, my mind worked overtime; do I have worse MS than them? Will we all be in the same boat? Maybe they have worse MS than me? Are they on DMTs? Are they way ahead of me on accepting the changes in their lives? The list was endless in my mind.



Duncan Grant

When the day came, I was nervous, but once in the Zoom meeting I could tell we all were. After introducing ourselves we told our stories, all different but all similar and the ice was broken. Yes! I am not on my own, there are other people just like me, of a similar age with MS, looking for support just like me. Through the establishment of this group, we all discovered a place to support each other on this lifetime journey.

As I was getting closer to needing to make a drug decision, I had some more specific questions about this part of my journey. Through the group, I was able to speak with Debbie, who has MS and is a "peer support person" for MS Auckland. Debbie was a great source of additional knowledge for me on all the various DMTs, in addition to the online research I had done and other conversations I have had. I wouldn't have been comfortable in talking to someone like Debbie if this group had not been formed.

The Newly Diagnosed Group has been a great opportunity to meet people at a similar stage of their journey with MS. We've talked through medication, diet, exercise and many other factors impacting all people with MS. The group has been a lifeline for me and instead of being nervous, I now look forward to the monthly meetings, knowing I am not alone. A big thank you goes out to MS Auckland, Tatjana, Luminita, Debbie and Anu for making this new initiative possible. Roll on next month's meeting!

the club nobody wants to join, but I am happy to be part of.

Written by Mandy Bishop

When you move into a new town the best way to meet people who share your interests, and to get recommendations for the best fish and chip shop, is to join a local club. It turns out there was a club I could join, but the problem with this club was that the entry criteria was not part of my life plan.

I hadn't moved town but I was suddenly in a different place, and the club I needed to join was the 'Newly Diagnosed with MS' group.

I was diagnosed with MS in January this year but have had MS symptoms for some years prior. When I received my diagnosis, I went home not knowing what was next, adrift with an uncertain future. I contacted the MS society and they immediately leapt into action and took me in hand. One of the first things they suggested was that I meet with one of the coffee groups for support. I was not keen, for a lot of reasons; most of all I didn't want to face MS and it was a lot easier to ignore if I didn't hang out with other people with it. After all, my life was too busy for MS and I begrudged any time I had to put into it. MS wasn't going to affect me. I was just going to ignore it and carry on with my life.

As it turns out, I was wrong.

Along came a lockdown or two and a few home truths from the professionals around me and I realised I would have to pay more attention to living with MS, but then – where to start!

At around this time, Tatjana invited me to attend a zoom meeting for newly diagnosed people, an offer I found hard to refuse as all I had to do was sit in my chair and click on a link. I am so glad that I went to all the effort of clicking on that link and meeting up with a group of people who were normal, functioning, living human beings who just happened to also have MS!

We talked about our journeys and I met a teacher I could relate to who had the same perplexing 'injuries that were getting worse'. I met a young woman struggling with her pain medications who was able to find support and advice from other members. I met an accomplished woman who had lived with MS for a decade, I think, and was still strong and normal. I met a Scot with great Zoom manners and a woman who had researched everything she could. I met a young woman



Mandy with grandson Archer 1

who squared her shoulders and said 'right then', and showed us how it was done and a man who cooked his way through his MS diagnosis. We were all a bit unsure, and just feeling our way a bit. Tatjana carefully guided us, making sure everyone had a chance to speak and drew out the quiet ones in the group too.

Over the last two meetings we have talked about what pain medication people were taking, and other options. Last month was food and diet, with a bit of chat about the OMS book and program. It is great to know people who have used the resources and information on offer, to be sure it is the right path to take before making the recommended changes to my life.

The best part of the Newly Diagnosed with MS club is that it is a community of people with the same interests as me; some new friends to gossip with about MS topics and a reassurance that I am not alone on this journey.

Still no update on the best fish and chip shop in town though.

Mandy Bishop



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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.

Red Cabbage Slaw

Contributed by Ingrid Minett

You have heard the expression 'eat the rainbow'. This is because bright colourful vegetables are known for being nutrition powerhouses. The common red cabbage is one of these. It has a great dose of vitamin C, so it is an antioxidant-rich, immune booster. Compared to the green cabbage, the red cabbage is a real winner containing far more vitamins, antioxidants and cancer-fighting flavonoids. Red cabbage has also been shown to fight inflammation and arthritis. A study published in Research in Pharmaceutical Science showed that when testing the effects of cabbage on the immune response, there was a reduction in swelling.

Raw, uncooked red cabbage will provide more nutrition than cooked, so this summer consider including some red cabbage salads in your mealtimes.

This recipe below is one of my favourites. It's easy to put together and no mayonnaise means that it is light and fresh and can be enjoyed alongside any other dish. It can also be added to wraps or sandwiches, or enjoyed on its own as a snack.

I have found that this recipe generally serves 4 people for a meal. It can be kept in the fridge for 3 or 4 days, but never lasts that long at our house!

Ingredients:

½ teaspoon lime zest
4 cups shredded or thinly sliced red cabbage
¾ cup shredded or finely chopped carrot
½ cup finely chopped red or white onion
1 ½ tablespoons lime juice
½ teaspoon ground cumin
¼ teaspoon garlic powder
1 teaspoon olive oil (optional)
1 teaspoon maple syrup
½ teaspoon salt

For serving optional freshly chopped cilantro



To make:

In a large mixing bowl add the cabbage, carrots, diced onion, lime juice, lime zest, ground cumin, garlic powder, olive oil, maple syrup and salt.

With clean hands massage the mixture for about 2 minutes. This softens the cabbage and gets the flavours to meld together.

Taste and then adjust seasoning as needed. Garnish with chopped cilantro if you wish and serve and 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.

Auckland Hospital Infusion Nurses, Jane Grigor and Mary Mackenzie.

– *Your infusion therapy team*

I am embarrassed to admit that after 5 years at MS Auckland I have never properly met two very important women who are part of the MS team, Jane and Mary, the infusion nurses. We receive such lovely feedback on these two women, that I felt it was high time for me to go and properly introduce myself. I also took the opportunity to learn a little more about the important work that they do.

Jane and Mary work as part of the neuro-specific team, doing the infusions for people with MS who are on tysabri and ocrevus, and also very occasionally for people with MS who require a steroid infusion. People with other neurological conditions will also be seen by them for their infusions, but the predominate people using their services are people with MS. Jane has been with the team for 5 years and Mary for 4 years. They work three days a week each (Monday to Friday) with Wednesday as their cross-over day. When one goes on holiday, the other one covers for the full week. There are no infusions on weekends or public holidays.



The neuro-specific infusion area is unique in NZ. In other parts of the country it is not uncommon for MS patients to be together with cancer patients receiving chemotherapy. The area consists of two rooms – one is a two-person room and the other a four-person room, however when things are busy, extra chairs can be brought into the room, allowing up to 8 infusions to be going on at the same time. Tysabri infusions can take up to an hour and a half, with ocrevus lasting six hours or more.

When the decision is made for a person to start on an infusion therapy, they will be referred to Jane and Mary. They will then get a phone call from one of them to book a date and a time for their infusion. When you come in for your appointment, they will do a clinical assessment to make sure you are well enough to receive your infusion. People coming for their first time will also receive some education and Jane and Mary will make sure that consent forms are signed off and that everything has been done to start the new infusion therapy. First timers will often bring someone along with them, but generally after the first time has passed people will more often come on their own.

Some people coming for their first time will naturally be a bit anxious, but some are also very grateful, so pleased to be accepted for receiving the infusion therapy to manage their MS. Perhaps the most difficult part for some is getting the needle into their vein for the infusion. Jane and Mary are very experienced, but some veins can be a bit tricky. A good trick that I learnt from them is to drink lots of water before coming in, and to have a hot wheat bag on the vein when coming in. Both the fluids and the heat help the veins to expand, making it easier to get the needle into the smaller veins.

It's a busy little place, especially when we have short weeks, and 5 days of infusion need to be fit into 4. Tysabri was made available in New Zealand at the end of 2014, growing the infusion clinic from about 20 people to over 100 people. Now with ocrevus in the mix, it has grown even more.

It is not unusual for new friendships to be made in the infusion room. It is this camaraderie that both Jane and Mary really enjoy about their work. Jane used to be a ward nurse and says that while on a ward you generally only meet people once, but as an infusion nurse they get to see people regularly. You hear about their lives and get to know people, in the same way that perhaps a hairdresser will. They love their job and love all the people they get to meet and know.

hydrotherapy.

It has been quite a disruptive year for our Hydrotherapy this year with on again and off again classes. We are so very apologetic for the inconvenience this has caused people, but the situation was completely out of our control!

We are on again for Term 4 and hope that 2021 will be a better year for hydrotherapy.

We know how important exercise is, and many people with MS find that water-based exercise to be a rewarding way to stay physically active. There is a lot less weight on your joints when your body is submerged in water. The hydrotherapy classes can improve endurance, flexibility, strength and balance and can also improve MS-related fatigue.



The social aspect of hydrotherapy is also very important, with the groups often enjoying a cup of coffee afterwards to catch up with each other.

Please check our website - <https://www.msakl.org.nz/about-ms/what-we-do/our-services/hydrotherapy/> for updates on start-up dates for 2021.

Cost

If you are new to hydro you are able to attend two classes for free to determine if it is for you. Once you sign up you can go to as many pools as you like each week. However, it is important to let a Community Advisor know the first time you attend a pool group so that your name can be added to the list for the instructor.

Yearly fee - \$120

Quarterly fee - \$30

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

2020 Weekly Sessions

<p>Tuesday</p> <p>.....</p> <p>Lloyd Elsmore Pool Sir Lloyd Drive Pakuranga</p> <p>11:00am - 12:00 noon</p>	<p>Wednesday</p> <p>.....</p> <p>Manurewa Leisure Sykes Road Manurewa</p> <p>11:00am - 12:00 noon</p>	<p>Thursday</p> <p>.....</p> <p>Epsom Girls Silver Road Epsom</p> <p>10:30am - 11:30am</p>	<p>Friday</p> <p>.....</p> <p>Westwave Aquatics 20 Alderman Drive Henderson</p> <p>10:00am - 11:00am</p>
<p>Saturday</p> <p>.....</p> <p>Millennium Pool 17 Antares Place Rosedale</p> <p>8:10am - 9:10am</p>	<p>Saturday</p> <p>.....</p> <p>Diocesan Girls Clyde Street Epsom</p> <p>10:00am - 11:00am</p>	<p><i>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.</i></p>	

Christine Black – life with secondary progressive MS.

Christine was diagnosed with multiple sclerosis in 1985 at 32 years of age. They were living in Taranaki at the time and her diagnosis of MS was made by the neurologist at Taranaki Base Hospital. Christine's husband is also a doctor and he agreed with the diagnosis. Her symptoms included lots of patches of numbness, and then a patch of optic neuritis which seemed to clinch the diagnosis.

Life went on normally for Christine after her diagnosis.

I had no bad relapses for about 20 years. I had some minor ones, which were more of an inconvenience than anything else.

The family eventually moved back to Auckland and Christine started seeing Ernie Willoughby, and then with news that Ernie was soon retiring, Jennifer Pereira.

In 2013 she suffered a major relapse. "I couldn't walk". It was a frightening experience. Soon afterwards Christine started on the Tysabri infusions.

Until 2017 Christine felt that things were going alright. However, if she looks back, she feels that perhaps there were very gradual changes occurring over the previous 10 years.

The changes are so gradual that you hardly notice them. You make adaptations to make life easier and just keep going. One of the tests that I was given was foot tapping. You tap one foot as many times as you can for 30 seconds or a minute, and then you tap the other foot. I could see my right foot slowing down considerably, and feel my whole right side getting weaker.

Up until 2018 Christine was able to walk the 500-meter requirement to continue Tysabri. But soon afterward Christine was told her MS was progressing now and she had moved from relapsing remitting to secondary progressive MS. This is something no one likes to hear, and Christine feels that more could have been done to provide better information at this time. "Well structured bad news is better than no news at all".

Secondary progressive MS has meant a number of life changes for Christine. She switched to using a hand-controlled car, due to her right foot not working as it should and finds it much harder to work in her garden.

She also feels that she has gotten clumsier, dropping things more often. She still cooks about 4 nights a week, but says she changes how she cooks, avoiding standing over a stove for long periods of time and preparing things that can be popped in the oven instead. They also tend to do take-aways and go out for meals more often.



Christine is finding that her memory perhaps isn't what it used to be, but doesn't know if it can be put down to age or MS. She feels more routine is required now, with no more last-minute decisions for things like popping down to the shops. Life is more planned now, with scheduled rest breaks through the day.

The unpredictability of life is what Christine finds most stressful. That feeling of 'will I be able to get up out of bed this morning'. It can all be so overwhelming. Her GP recommended seeing a psychologist, with 4 free appointments provided by her practice.

Seeing a psychologist was very helpful. He helped me in dealing with feeling overwhelmed and distressed.

Christine would like to see more research into secondary progressive MS and would like to see more attention in this area. With the new disease modifying therapies available today we hope we will see progressive MS being further delayed or avoided altogether. It will be very interesting to see developments in this area over time.

Christine enjoys belonging to MS Auckland. She loves the MS support groups, does the exercises with Gilly Davy and keeps up to date with MS news. She has requested that regular information and updates on progressive MS be put in our magazine, which we have promised to do!

(Christine would be happy to talk to people who are looking at switching to using a hand-controlled car or who have recently been told they have secondary progressive MS. She can be e-mailed at cmblack@tuinet.nz).

support groups.

Have you connected with a Support Group yet?

People who attend report lots of benefits of getting together monthly with others who live with MS. Some of the benefits include feeling less lonely, having less anxiety or depression, being able to talk openly with people who have had similar experiences, improving their understanding of MS, getting practical advice from others living with MS, and generally having a more positive outlook on life.

When we were under lock down, the Support Groups were very much missed. Zoom groups were set up, which, while ideal for some people to fill the gap, were not quite the same as sitting around a table together. The zoom support group that is still operating is a new group for people who are newly diagnosed. You can read about Duncan and Mandy's experiences with the newly diagnosed group in this issue (see pages 16 and 17).



It costs nothing to be part of a group, and there is much to be gained. For first timers please contact one of our Community Advisors (see page 7 for contact details) to let them know you are interested in joining a group. They will connect you with a group that would suit your needs and make sure that they are there to welcome you on your first day. They are also open to starting up new groups if there is enough interest.

Location

Date/ Time

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)

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

Central

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

Second Saturday / Month - 11.00am
Third Wednesday / Month - 10.30am
Third Tuesday / Month - 10.30am

West Auckland & Rodney

Child Friendly Group (check for venue)
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)

Second Monday / Month - 9.30am
First Tuesday / Month - 10.30am
First Thursday / Month - 11.00am
Second Tuesday / Month - 10.30am
Third Wednesday / Month - 10.30am

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)

First Thursday / Month - 10.30am
Last Wednesday / Bimonthly - 12.00 noon
First Saturday / Month - 11.30am

Zoom Groups

Newly Diagnosed Group

once a month time and date varies contact
Tatjana for more information (tatjana@msakl.org.nz)



be the superhero you want to be.

Written by Shona Hanson

MS Auckland also supports people who have other uncommon neurological conditions which do not have their own Support Groups. Shona is one of these people. Fortunately, she found her way to MS Auckland. She shares some of her story with us below.

Be the superhero you want to be. After much thought on this I kept coming back to being the person who lifts people up both spiritually and emotionally. This has not been an easy place to be. After a period of illness and a shock diagnosis of Neuro Sarcoidosis in the early 2000's to having a challenging start to 2020 with a major medical event and subsequent decline in my illness and disability, I decided that things had to change.

I have learnt to be a fighter and not necessarily accept or take no for an answer. If this makes me seem demanding, so be it. I decided to take the rest of the year off to fight and push myself out of my comfort zone. I also spent many hours researching my condition and my entitlements to support.

Sometimes I have taken myself out of the game and had a good cry. I will give myself some time out before giving myself a stern talking to and continuing the fight by being my own advocate and finding people who are also willing to fight with me. By stepping away from the norm and looking outside the box, it has helped me to find the solutions that are right for me. It has been tiring and hard work but when you find those people who are willing to work with you it's a truly wonderful thing. The need to fight doesn't seem to stop though, so you need to be prepared for the long haul.

It is extremely important for me to be able to empower and lift other people up while making my own decisions on what I want with my care. It can feel like you are bashing your head against a brick wall at times dealing with hospitals, treatments, and bureaucracy from people and departments that are supposed to be there to help you, and believe me there have been many, many lows. Having an amazingly supportive husband, family and friends, who help lift me up on the low days is truly amazing, and I am so thankful to them, especially my husband who has stuck by me and has really only ever known me as being a "sick person". He has always been there, through some really dark times, when we have both wondered where to from here.

This year I sought out MS Auckland, even though I don't have MS, many of the symptoms I experience are similar to people living with MS. They accepted me, even though my neurological condition is outside their realm of specialty. This has meant the world to me! Just being able to talk to others and joining in with the various groups and meetings, has helped immensely and has normalised me, and my condition. Thank you to all the wonderful people I have met through MS Auckland.



Shona with husband John and Milo their bulldog

My advice to others is be up front and tell people what you want to achieve and don't be afraid to ask for help. Make things happen and encourage ideas and discussions. It isn't the easy way but the satisfaction and effort in getting there doing it your way is worth every moment! ***What kind of superhero do you want to be?***

Sandy finds freedom with her freedom chair.

Sandy has had MS for 20 years now. Life has been full of changes for her, but throughout it all she has remained a most determined and positive person. She lives by her own motto – “There’s always a way forward. You just have to find it”.

Sandy lives in an Independent Retirement Village. She moved in when she was just 52 years of age and when the minimum age was 55. Somehow, she managed to talk her way into being accepted. She has a small one-bedroom apartment with a wee balcony for her plants.



Sandy showing how easily her chair folds up.

Walking unaided is difficult now for Sandy so she relies on her walker for getting around in her apartment. However, for longer walks she is very pleased to have her Freedom Chair. Sandy purchased her chair, with the help of the Newmarket Rotary, from Paul Monk about 3 years ago, and says she has never looked back.

Scooters aren’t allowed in her Independent Retirement Village, but they allow chairs, especially small, easily handled chairs, that move easily through doorways like the Freedom Chair.

Sandy loves the fact that her chair is so light – only 23 kgs – but very strong. It folds up like a push chair and fits easily into the trunk of cars, for when she goes to visit her daughter, or goes shopping or to her support group meetings. Her daughter lives on a farm and Sandy can ride through the paddocks on her Freedom Chair without worry. She always feel safe.

Sandy has recommended the Freedom chair to other residents in her Retirement Village. A few people have opted for other, cheaper chairs, and soon afterwards wish they hadn’t. “The Freedom chair might be a bit more costly, but it is worth it”, says Sandy. “Almost anyone can use it. You don’t need fine motor skills, but you do need to be steady”.

Sandy knows that day to day things are getting more difficult for her. She receives home help 3 times a day each day and goes by her new motto “start everyday with a glass full of energy”. At the end of the day when her glass has been emptied, Sandy knows she can lie down to a good night’s sleep.

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Get in touch with Paul for your free demonstration

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The following article has been adapted from the following websites:

<https://www.cando-ms.org/> <https://www.healthline.com/health/understanding-secondary-progressive-ms>

<https://www.mssociety.org.uk/about-ms/types-of-ms/secondary-progressive-ms>

About 90% of people with MS are initially diagnosed with Relapsing Remitting MS (RRMS). At some point, some people with RRMS no longer experience periods of remission or sudden relapses. Instead, their MS symptoms continue and worsen without any break. This is known as Secondary progressive MS (SPMS).

The words “progressive MS” can set off alarm bells. No one wants to hear that their MS is, or has become, progressive. The term “progressive MS” applies to different aspects of the disease, and it helps to know how it is being used.

When symptoms worsen and abilities are affected, it can feel frustrating and frightening, particularly when a person feels he or she has been doing everything possible to manage the disease. Just when one seems to have a handle on MS and its symptoms, changes can occur, making the playing field feel totally different. Some people express fear of the future, seeing only a downhill slope. Others are disheartened and lose the oomph they need to try new ways to solve problems. This is a time when anger, grief, and anxiety may feel more intense.

It is important at this stage for everyone - people with MS, their support partners and other family members – to step back and rethink the future. There are exciting research developments in the area of progressive MS, and there are many things you can do to optimize your health and well-being with progressive disease.

Managing Your MS – Using a Team Approach

- There are disease-modifying therapies (DMTs) which may be suitable for some people with progressive MS. If you have been diagnosed with a progressive form of MS, be sure to discuss treatment options with your neurologist or the MS Nurse.
- Comprehensive MS care for a person with progressive disease also involves ongoing symptom management; rehabilitation to enhance function, comfort and safety; adaptive equipment to optimize mobility, independence and participation; and careful attention to optimizing mood and cognition.
- Your best strategy is to assemble a team of professionals you trust and with whom you can communicate comfortably whenever there are changes in function or when you experience new symptoms. Your team may include your neurologist, MS nurse, physical or occupational therapist, mental health professional

and your MS Auckland Community Advisor. These people can help you evaluate your changes and identify treatments, tools and resources to improve the situation. MS is a journey you do not need to travel alone.



Enhancing Your Health and Wellness

- You are more than your MS – and your health and wellbeing are about more than treating your MS.
- A healthy diet, regular exercise geared to your abilities and limitations, effective coping and stress management strategies and careful attention to your mood are all essential to your overall quality of life.
- If you smoke, you have one more reason to quit: the research clearly shows that people who smoke have an increased risk of disease activity and progression.
- Regular check-ups and preventive screening as recommended for your age group can help you stay healthy and well.

Research in Progressive MS

- Major clinical trials are underway, testing novel approaches to treating all forms of MS, including progressive MS.
- The International Progressive MS Alliance is focusing new resources on finding the answers that will lead to new treatments and ultimately, end progressive MS.
- Scientists are learning new information about how MS damages the nervous system and cells and factors involved in the body's ability to recover from injury. Early human trials of new therapies to repair myelin are already under way.
- Studies are providing new evidence that exercise and rehabilitation can improve many functions and even help rewire and possibly build areas of the brain, and researchers are pursuing these leads to find the best ways people can maximize quality of life.

The journey with progressive MS will be different for every individual and will need to be managed differently. Success lies in building a support network, using all the tools and resources available to you, and being creative and flexible in your problem-solving. You may need to do things differently than you did them before, but there is no reason to sit on the side-lines.

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

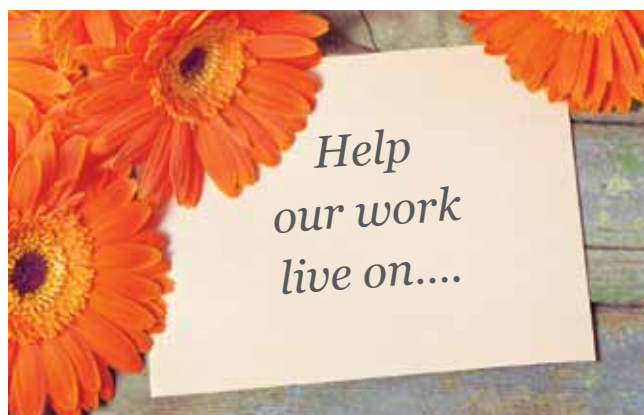
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If you would like further information on writing a Will or leaving a gift to Multiple Sclerosis Auckland, or for a confidential no-obligation chat about how your gift can make a difference, please contact Mark in the office on 09 845 5921.



For more information visit www.msakl.org.nz



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