

multiple news



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Welcome

Nau mai, haere mai e te whānau

Welcome to the 55th edition of Multiple News.

We hope this finds you safe and well despite the many and varied weather challenges we have encountered over the past months.

During 2022 we were fortunate to have the help of ASB Bank whose 'Design Thinking' team helped us to map out a typical journey of people living with multiple sclerosis. The exercise validated much of our work. We know that this magazine, Multiple News, is highly valued! Along with our monthly e-newsletter, webinars, and of course, the Community Advisor service (pg 7). Our biggest thanks to ASB, Deloitte and everyone who participated in the in-depth interviews and survey. The information that we gained has helped us ensure that we are serving this diverse community as best we can.

Along with this perspective on the MS journey, this edition glimpses into the journeys of several people in our community. Honorary Life Member Jo Smith is profiled on page 9, and we also talk to three of our wonderful support group facilitators, Christine, Hamish and Sarah, on page 12-13. If you've ever sailed, or fancy trying an ocean-bound adventure, you may feel inspired to join a Oceans of Hope challenge, which is profiled on page 16-17.

This edition also includes informative guidance on menopause (pg 8) and foot drop (next page).

Life Buoy for MS is our high profile fundraising luncheon. Its return in late 2022 following a Covid-induced hiatus was met with exuberance, generosity and warmth (see pg 10-11). I'm humbled by the dedication of more than a dozen volunteers and support of many organisations, which



make Life Buoy such a successful fundraising event for us. With increasing pressure on grant and trust funding, Life Buoy is even more critical to ensure the continuity of our programmes. Perhaps you're able to donate auction items or support this amazing event in some way. Look out for details of the next Life Buoy for MS on our website, or ask to be added to our monthly email newsletter to be kept updated.

Look out for some exciting changes in the next edition of Multiple News. In the meantime, happy reading!

Ngā mihi mahana

Nicola Bitossi
General Manager



Understanding foot drop



By Gilly Davy
Clinical lead neurological physiotherapist
Active+ Neuro Clinic

Experiencing leg weakness is a common symptom associated with MS which affects your walking. You may have heard of the term 'foot drop' which can be associated with MS.

It's a slightly misleading term as many individuals with MS do not experience 'foot drop' as a floppy foot but actually decreased ability to clear the ground when walking. This results in either catching the foot or the whole leg just feeling really heavy and difficult to move.

It is common to feel that you can walk fine for 10 minutes or so but as you keep walking your leg becomes more difficult to move and catching the ground. This is due to neuromuscular fatigue. Neuromuscular fatigue is when the muscle runs out of energy.

Unfortunately, due to where plaques are on the central nervous system, this results in certain muscles only being partially innervated, the remaining part of the muscle that is still innervated just runs out of reserves. If you take a short rest, you can often find that you can walk okay again until the fatigue kicks in as the muscle's energy reserves are depleted again.

However, it should be noted that MS is highly individual and the reason that someone may be struggling to clear the ground when walking might be due to not only weakness and neuromuscular fatigue but also potentially spasticity and loss of range of movement.

Due to the complexity of the potential impairments that could be causing the issues it is really important to have a physical assessment with a neurological physiotherapist that can assess all of this for you. Then they can provide an individualised rehabilitation program to assist.

The good news is that no matter what particular impairment is affecting someone's walking and ability to clear the ground, there are a number of options that can help to improve an individual's situation. This can include using orthotics that support your foot and ankle. Again, this is a specialised area and even if an orthotist prescribes a brace or support it is strongly recommended to complete some gait training with a neuro physiotherapist.



Gait training and orthotics can help improve issues around 'foot drop'.

To understand this issue further and to learn some key exercises to improve 'foot drop' watch the webinar on the topic. <https://www.msakl.org.nz/our-resources/webinars/what-is-foot-drop/>

Finding a neurological physio; <https://physio.org.nz/#find-a-physio> (select neurology under key word)

Community Advisor team

– What do they do?



From the work done by ASB and Deloitte (see page 14-15) we learnt that some people in our community don't have an accurate picture of the role, and the benefits of connecting with the Community Advisors.

In a nutshell, the Community Advisors are a team of professionals who provide information, guidance and support exclusively to people impacted by multiple sclerosis (MS). As MS affects everyone differently, the CA team supports the individual with multiple sclerosis, and those close to them and helps to navigate how this complex condition impacts their lives in a non-clinical context.

The Community Advisors listen and learn without judgement. They are then able to utilise their extensive knowledge, experience and unique helicopter-view to provide salient guidance, resources, referrals and connections to help support the best outcomes for now, and for what is around the corner.

The goal of Community Advisor intervention is that people living with MS are empowered, equipped, supported and informed to move forward on their MS journey with confidence. They aim to present their advice and assistance with respect and a light touch.

The Community Advisors support people impacted by MS in three areas:

Inform and guide

- Provide practical non-clinical information and guidance through NZ based resources and approved international resources and published research

Wellness

- Support people to navigate local health and community services
- Promote achievable positive lifestyle changes as appropriate for that person

Connections

- Provide referrals and recommendations into the best network of supports and connections for the person and their whānau
- Recommend support groups, peer support and other MS Auckland programmes for connection and community support as appropriate
- Recommend available financial support where appropriate

In the words of one of our members, Paul:

“MS is a part of me if I like it or not and I don't want to be at war with myself. It is a journey and I could not do it without your team”.

MS Auckland's values of trustworthiness, warmth and whanauntanga (creation of kinship through shared experience) are fundamental to the work that our Community Advisors do in the community every day. If you are impacted by MS we encourage you to engage our Community Advisors with any question you may have, or for a review of your situation. The service is free of charge and confidential. We are here to help.

Email info@msakl.org.nz or call 09 8455921



From our CAs' corner

Are you a Spoonie?

Your Community Advisors



Luminita



Catherine



Moira

Phone 09 845 5921 or email info@msakl.org.nz



Spoons are used as a metaphor and visual representation for energy rationing.

The above idea was originally coined by Christine Miserandino in her 2003 essay 'The Spoon Theory'. While out at a restaurant, to eat with a friend, Miserandino's friend began watching her as she took her medication, and suddenly asked what it was like to have lupus (an autoimmune illness).

Miserandino grabbed spoons from around the diner where they sat and gave her friend the handful of spoons she had gathered. The spoons helped Miserandino to show the way that people with chronic illness often start their days off with limited quantities of energy. The number of spoons her friend had represented how much energy she had to spend throughout the day.

As Miserandino's friend stated the different tasks she completes throughout the day, Miserandino took away a spoon for each activity. She took spoon after spoon until

her friend only had one spoon left. Her friend then stated that she was hungry, to which Miserandino replied that eating would use another spoon.

If she were to cook, a spoon would be needed for cooking. She would have to select her next move wisely to conserve her energy for the rest of the night. What would you do with the last spoon?

Essentially it is rationing/budgeting your energy levels which may have been decreased with the onset of multiple sclerosis.

Further exploration of the cutlery drawer will follow in future issues of Multiple News!

With thanks to Wikipedia: https://en.wikipedia.org/wiki/Spoon_theory

From our MS nurses



MS and menopause

If you are not a person with ovaries, please don't stop reading this. Menopause is a completely normal health event that half of the world's population will experience at some point. The support and understanding from those of you who will not experience this are not to be underestimated. Like MS, menopause symptoms are unpredictable, and the experience varies from person to person.

By definition, menopause is when menstrual periods stop for over one year, usually but not always between the ages of 45-55. Menstrual periods stop when ovaries run out of eggs to release each month. When this happens, key hormones: oestrogen, progesterone and testosterone levels drop.

This drop in hormone levels causes a range of possible symptoms: hot flushes, night sweats, mood changes, insomnia, poor mental focus, headaches, joint pain, low libido, vaginal dryness, and bladder symptoms.

Many of these are also symptoms of MS so there is a significant clinical overlap, creating potential complications in identifying the root cause of the symptom. Menopause, like MS, impacts mental health, with many people reporting mood fluctuations, anxiety and sleep disorders because of changing hormone levels.

Seek help to manage symptoms.

Speak to your GP about menopause and ask for help to manage menopausal symptoms. You don't need to tough this out on your own. There is a range of options both medical and non-medical to assist in managing menopausal symptoms. Your GP's role is to present these to you so you can make an informed decision.

Speak to your MS team about the possibility of symptom overlap. Working out if your symptoms are neurological or driven by hormone changes is the first step in managing and/or treating your symptoms.

Neurologists at ADHB are supportive of you starting HRT if your GP thinks this would help your symptoms. This echoes the sentiment of international MS specialists Dr Ruth Dobson and Dr Kate Petheram. If your GP does not support the use of HRT but is unable to provide you with a specific and personalised rationale for this, please consider asking for a second opinion. Pseudo relapses: the short-term return of old MS symptoms, brought on by increased body temperature, may increase over menopause when temperature fluctuations are experienced. This is something to discuss with your MS team who can work with you to find ways to manage this.

Fiona d'Young & Nazila Samadi
Multiple Sclerosis Specialist Nurses
Auckland Hospital, (09) 307 4949 extn 25885

Keep your bones strong

High-dose steroids used to treat MS relapses can affect bone density, so can reduced oestrogen levels during and after menopause. Ask your GP for advice on keeping your bones strong.

Consider increasing weight-bearing exercise (on your feet e.g., walking, running etc) to help bone strength and combat weight gain that some people experience during menopause. Exercise will also help with energy levels if you have MS fatigue and help towards managing sleep and mood. Ensuring your calcium and Vit D levels are at optimum levels is also recommended.

Menopause can be a challenging time for many women. With the additional impact menopause may have on your MS please reach out for help and support if you need it. We'll be asking you about this from now on in clinic and your MS community advisors can also provide support and advice in the community.

Resources: menopause in general

Applications/websites

- www.menopausedoctor.co.uk
- www.balance-menopause.com
- www.meno-me.co.nz

Watch: Davina McCall: Sex, myths and the Menopause

Read: The Menopause Manifesto by Jen Gunter

MS specific

Dr Riley Bove is a key researcher in MS and menopause. The below links are to her research papers.

- Effects of Menopause in Women With Multiple Sclerosis: An Evidence-Based Review - PubMed (nih.gov)
- Menopause and Multiple Sclerosis | Request PDF (researchgate.net)
- MS and menopause mstrust.org.uk
- MS Selfie with Dr Gavin Giovannoni <https://gavingiovannoni.substack.com/p/is-it-ms-or-is-the-menopause>
- How does menopause affect MS? Ruth Dobson- MS Trust Podcasts (www.mstrust.co.uk) available on Spotify or apple podcasts
- Dr Kate Petheram - Menopause & MS - YouTube -this is a presentation to MS health care professionals. About 30min long

Profile:

Honorary Life Member, Jo Smith

It was a pleasure to sit down with vivacious MS Auckland Honorary Life Member Jo Smith and hear her story.

What's your connection with MS, and MS Auckland?

I've had MS for 50 years now! I had symptoms for some time before I was diagnosed. I used to work in an endocrinology lab and I dropped things all the time. My husband said he knew before I did! I had had pins and needles and vision issues, too. I thought I was going mad! It was a relief to finally receive my diagnosis. There were no MRIs in those days, I recall that I had a Spinal Tap. We were living in North Carolina at the time.

I was in denial of my MS for some time. I didn't want to know about it. One day when I returned from the States, I was feeling desperate so approached MS Auckland. I connected with a Field Officer by the name of Chiria who was wonderful. At the time we had chickens and they'd poop on the front steps, which would cause me to skid around with my sticks. Despite my protests, Chiria left me with a wheelchair which I gave in to using when I went to a Kiri Te Kanawa concert – and found it so much easier! Thanks to Chiria. I've had various wheelchairs over the years.

I've been variously involved with MS Auckland over the years, including being on the Committee for several years. The highlight for me was the 'Calendar Girls' fundraiser. A calendar was produced featuring portraits of women with MS. It raised around \$6,000!

What makes up your world?

My incredible husband Warren; our three children, Joseph, Benjamin and Rachel; and now our grandchildren. We had a fun and pretty active time when the children were small. Each of them climbed Rangitoto at age two! We would go on family camps, and it didn't matter too much when I couldn't join in the walks and tramps at the time as there was often someone else who couldn't go, too.



We live in central Auckland and many years ago I was visiting Piha with a friend. I looked up the hill and fell in love with a property there, and so I bought it on the spot! Warren hadn't even seen it. Over time, we bowled the bach and built our own. We will soon be living there permanently.

Tell us something that is part of your routine

I visit the Olympic Pools in Newmarket often. I've been going for years and I love it. I'll tell you a story. Some years ago, there was a young man of around 22-23 years who would visit the pool regularly with his mother. I realised that he couldn't swim. So, I taught him to swim! I promised to bake him a chocolate cake when he could swim the full 25m length. In the end, he swam two lengths, and asked if he qualified for two cakes!

What's your piece of advice to people coming to terms with having MS?

It's not the end of the world!



After a two-year hiatus, MS Auckland's premier fundraising event, Life Buoy, was held late November last year at the Royal New Zealand Yacht Squadron's Westhaven Marina headquarters.



What a success it was! Some 180 loyal supporters purchased tickets to support the event and gathered to enjoy great company, excellent refreshments and awesome entertainment featuring MC Megan Alatini, guest speaker David 'The Brown Butterbean' Letele and auctioneer extraordinaire, Martin Cooper, managing director of Harcourts Cooper & Co.



Live auctions, silent auctions and on-table pledges and some off-the-cuff initiatives including the press ganging of Sir Graham Henry, Pita Alatini, various 'dancers' and 'singers' raised a fabulous \$94,430 for over a thousand people living with MS, and their whānau, in the Auckland community.

David Letele is an individual well placed to understand the travails of multiple sclerosis. He's had a few struggles of his own including a father in and out of





prison, near death experiences and brushes with the law. In his case these issues put him on a journey to becoming a professional athlete in rugby league and boxing and owning or starting several businesses including the high profile BBM which works with public health and social service providers. His food-bank is now the stuff of legend.

David told his rapt audience that 'choice' implies an equal starting point where in fact life is a roller coaster and we should keep reminding ourselves that anything is possible. He said he grew up *"hating the world, hating the system and hating myself"*. He said asking for help was not a sign of weakness but a sign of strength. His motivation had a couple of hundred of Auckland's hoi poloi on the feet and practicing their boxing!



A host of sponsors came forward to make the event another resounding Life Buoy success. Key supporters included Harcourts Cooper & Co, Care On Call and Pascoes The Jewellers whose fabulous white gold and diamond tennis bracelet valued at \$7,500 was a tantalising inducement to the on-table pledge draw.

The impact of Life Buoy is profound.

MS Auckland general manager, Nicola Bitossi, said in her introductory remarks, *"Every dollar donated delivers \$8.50 in measurable social impact"*. She said it was important for MS Auckland to see people with MS 'living a full life'.



Volunteer Profiles:



This issue we have not one, not two, but three of our fabulous volunteers who organise and facilitate support groups around Auckland!

Hamish Mair

What is your connection with MS, and your motivation for volunteering for MS Auckland?



My connection with the MS group started way back in the early 1970's when our son was diagnosed with MS. Cathy, the field worker who assisted us on what we needed to look after William, was so gratefully appreciated. Also, a wealth of knowledge on what benefits we could ask for from WINZ was highly beneficial.

After our son passed on in a very short period, six years later, I felt a very strong bond with the MS Auckland and after a healing period I wanted to help the people who I found had this terrible illness. It was quite by luck that after telling some people at the Manurewa pools that they had an aqua group; I discovered a very real incentive to give back some of the great passion and help that we had received ourselves

What do you wish other people knew about MS and/or MS Auckland?

I think the general public have a much greater understanding from when those days when we first were thrust into all the problems and the medical dramas that were linked to MS. I have found that we were able to engage with many members of the public what MS was and the issues faced by those impacted when we were doing our annual fundraising. Sadly, covid and the corresponding after-effects had put a serious damper on that.

If you could invite any famous person for dinner, who would it be and why?

I think my famous person that I would invite for dinner, would be either someone from MS Auckland, and or one of the Manukau MS group that I have been privileged to be a great part of. My thoughts are they are the most brave and famous people I know. MS Auckland is so passionate about the work they do, and that makes them famous too, in my eyes.

Christine Ball

What is your connection with MS, and your motivation for volunteering for MS Auckland?



My connection is my personal story which is close to 40 years of living with MS. I have Relapsing Remitting MS after a sudden and scary optic neurosis episode in my late teens. Being told at the time that I now lived with a life-long disability which was incurable, had limited treatments, was unpredictable (and be aware of any relapses) was unsettling to myself and family. A spinal tap confirmed this life changing event and with strong steroid treatments and time to recover, life returned to 'normal' again – or so it seemed. The unknown aspect of MS was huge at this time.

My motto became *'I want to live successfully with MS'* as life returned to what I had known. My eye sight was clear, I could work full time, fatigue levels decreased and on the outside everything look usual.

Over time my connection with MS Auckland has changed between not wanting to have any contact with support groups, ignoring the diagnosis and hoping that I could do it alone to now being involved in various ways. Denial is a very powerful reaction. However, when MS relapses began to occur support was welcomed.

My motto became 'I want to live successfully with MS'

My motivation for volunteering with MS Auckland is to have local friendships with others who travel the same journey. The support groups that I initially hid from are now my motivation and help to 'normalise' my MS journey. Having a regular monthly support group that I co-ordinate has been helpful in building long supportive friendships which share the common MS story, yet are lived and displayed in such varied ways.

Sharing the process of using some different MS treatment and other physical health ideas is included in our connection and been helpful to observe and notice the reality of how these can work and be tolerated. We enjoy life, understand MS distractions, adjust with life changes and life successfully!

What do you wish other people knew about MS and/or MS Auckland?

I wish that people would have a wider and positive understanding of MS; how things can change with this disability and how invisible some MS symptoms are. MS doesn't have to mean that people lose mobility, are unable to work or have limited career opportunities. MS is a complex disability that shows in many different ways and can be lived with in positive ways. Realising and understanding personal limitations which can be worked with and adapted to change is key to having a wider appreciation of MS. If there was a box called MS it needs to be coloured brightly, wildly and be flexible.

MS Auckland is a safe and supportive group to be involved with and I have a wish that many people, newly or older diagnosed, are aware of the many benefits that are offered. Support groups, peer support, newly diagnosed, fitness groups and community advisors are exciting and wonderful elements. Initiating a Saturday MS Support group while working full time has been great and nearly 20 years later we continue to laugh, enjoy friendship and care when life gets messy.

If you could invite any famous person for dinner, who would it be and why?

I would like to invite John Kirwan to dinner. Firstly, because I enjoy watching rugby, am an avid All Black supporter and remember him playing for Auckland before moving into the All Blacks. Secondly because he has a powerful life story of depression and overcoming difficult times when things become so challenging. His honesty and sharing of his journey via Depression.org with the community is a great resource and can be appreciated by many.

Sarah Toft



What is your connection with MS, and your motivation for volunteering for MS Auckland?

Some years back, when I needed more support with my diagnosis of MS, I reached out to the MS Auckland society which put me onto the field officer of the time and then the Pukekohe café group.

In terms of volunteering, it sort of just happened in a way. I'm a people person and love being around people.

I have a wish that many people newly, or older diagnosed, are aware of the many benefits that are offered.

When our group grew, I started to support our field officer, to let members know where and when we were having our support group. I enjoy doing this task as it keeps me motivated. It helped give me a sense of purpose once I'd stopped working, so I too benefit from doing all of this. Over the years, I've made some great friendships which have been enduring.

What do you wish other people knew about MS and/or MS Auckland?

I encourage people diagnosed with MS to get in touch with their local MS region and reach out for the supports that are there, and attend the social café groups.

If you could invite any famous person for dinner, who would it be and why?

I would like many famous people to come for dinner! One particular person who comes to mind is the famous singer Neil Diamond. I have enjoyed his music as long as I can remember! I'm sure he would be interesting to talk to as well as sharing his stories and music.

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The multiple sclerosis journey

Insights from data gathered by ASB and Deloitte

MS Auckland is acutely aware of the diversity of needs and challenges across our community. We want to ensure that our programmes and services reflect the needs and circumstances of all our members. We wanted to learn of any barriers to participating in our services, and any problems or ‘pain points’ that exist now or in the past that might need addressing.

We were fortunate to have the help of ASB who, together with Deloitte, guided us through a customer journey mapping exercise. Our team underwent a workshop with the Design Thinking team at ASB. After identifying potential areas to address, ASB underwent ten in-depth interviews with a range of members, targeting those who were not high users of our programmes and services. This was combined with data gathered by Deloitte via a survey to all our members living with a diagnosis of MS, which had a good response rate of 26%.

Here is a summary of their findings – a typical journey of someone diagnosed with MS

Early onset / symptoms

When symptoms (such as numbness, brain fog) first appear, they are often disregarded at first. When they don't cease, the process of investigation begins and there may be many frustrations during this period with misdiagnosis, not ‘feeling heard’, varying outcomes of treatments; while still juggling the impact on daily activities. At this time, common emotions are anxiety, stress, anger and confusion; which may be coupled by shame and embarrassment because they're ‘not themselves’ and others notice. Unless you have someone in your life with MS, you may not be aware of it, and probably not of MS Auckland, either.

“Nobody is telling me anything, I'm not getting any better”

“Just exhausted and trying to stay afloat”

Diagnosis

When a diagnosis eventuates, there's a thirst for information, via specialist(s), Google; and/or MS Auckland. Need to know who to go to for the right advice; what's happening now and in the future, and what all of this means. This is an incredibly challenging time with feelings of shock, disbelief, distress, confusion and grief. Some are in denial; and some feel relief that they now have a diagnosis and a label and plan for their symptoms.

Frustration at being ‘passed around’ and having to retell their story; feeling lost in the system. Support of the MS Nurse team, and MS Auckland, can make a big difference to feeling supported and in control. The stress can also be alleviated by the support of close friends and whānau.

“The neurologist was ‘too scientific’. Too factual. He said: “this is going to happen first, then this will happen”. Ugh.”

“I was very distressed after diagnosis, couldn't talk to people, lots of people still don't know I have it.”

“I thought you know like somebody had just given me a death sentence. Bang! Because it's a disease, there's no cure.”

“I just remember being given this really nice booklet from MS Auckland just after I was diagnosed. It was all I had.”

Initial care / treatment

Following a diagnosis of multiple sclerosis, some reach out to MS Auckland if they are aware. There is a trial of medical treatments, along with complementary approaches such as physio, counselling, dietary changes. Some people are reluctant to share their diagnosis with friends, whānau and/or their workplace. Strong needs emerge during this stage – understanding entitlements in the healthcare system; feeling ‘normal’ and getting the support needed to get on with ‘normal’ day to day life and responsibilities; consistency of healthcare provider who knows their story.

At this stage, many are exploring and trialing different treatments and supports available including funding. Support of MS Auckland is highly valued in assisting with navigation of possibilities; and also just in being there and understanding. *“The community worker provided me with practical support and advice which is exactly what I needed at that stage. She was lovely.”*

Living with MS – early stages

Once a diagnosis has been established and dealt with to some extent, there is often some forward looking. Participating in the MS Auckland newly diagnosed programme can really help. Interaction with specialist(s) is ongoing. There may be some adjustment with needing help around the home or with mobility, exploring ways to adjust lifestyle to help manage the condition. At this stage in particular, there is a need to have someone to call who is familiar with history and needs.

Some have employment issues at this stage, sometimes culminating in ceasing of employment, which leads to financial worries. Relationships can also suffer – partner, tamariki, friendships. Support that is received, from MS Auckland, loved ones and Taikura Trust, makes an enormous difference. This includes linking in to MS Auckland's monthly eNewsletter and Multiple News magazine.

At this stage, the person is often feeling isolated, lonely and worried about how the disease will progress.

If symptoms have subsided, there may be a sense of life going back to normal. There may be avoidance of, and sensitivity to, connection with other people with MS who have progressed symptoms or disability.

The impact of MS can lead to a combination of social, vocational and psychological complications. So, for those who are still relatively new to the MS experience, the adjustment to lifestyle is significant. Lack of knowledge about the disease adds to the anxieties commonly experienced by people who are newly diagnosed. MS Auckland's Newly Diagnosed programme enables people to connect with others new to MS and build a supportive network. This first year of the MS journey sets the scene for future support and management of the disease.

“When you are first diagnosed... the first year, it's really important to get support. You don't realise the emotional toll it's taking.”

Living with MS – later stages

As life continues, contact with MS Auckland may reduce if health improves. 27% of individuals 'rarely engage' with MS Auckland and a further 12% have dropped in engagement levels, at this stage. Contact often re-established with a deterioration in health. Help may be sought for assistance with mobility and/or vision issues. There is a search for current, relevant and targeted information.

Some people at this stage may still be in denial of accepting their MS, and/or wish to remain private. This results in a reluctance to attend MS Auckland's public events and/or engage with social media. Others may have difficulty accessing some in-person MS Auckland events due to mobility issues. Continuity of care is important but not always possible. Requests for donations to MS Auckland can provide confusion as to its relationship with service provision.

Where help is needed, MS Auckland is seen as very accommodating and caring; and information and wider services provided by MS Auckland are highly valued. In addition, MS Auckland's webinars, email newsletter and magazine are highly valued. Many appreciate an annual phone call to reconnect. 74% of those surveyed prefer to hear from MS Auckland via email.

Challenges at this stage include fear for what's to come / future quality of life. There can be anger and frustration at any setback; and a concern about the impact of their MS on whānau and friends. This is combined with a hope that treatments will improve.

Coping with recurrent symptoms of MS is helped by maintaining control (over one's life) and giving them a sense of hope. It's important that MS Auckland reflects on the importance in providing hope, as well as ensuring open communication with those in the later stages of MS.



ASB, Deloitte and MS Auckland team members at the workshop to help uncover the typical journey facing an individual diagnosed with MS.

Information and content (especially from global experts) that promotes new treatments, R&D as well as products and services to improve their quality of life will be critical to improving engagement with members.

“I wasn't getting support because I wasn't telling anyone. I thought I could just keep living as usual.”

“Positive stories are better – you want to have hope.”

“I like hearing about things like how to manage fatigue – because that's what I struggle with.”

Going forward for MS Auckland

We learnt that our Community Advisor service, Multiple News, monthly e-newsletter, Newly Diagnosed programme and information webinars are highly valued by our community. Areas for further focus are information and research, ensuring positivity and hope, and addressing progressive forms of MS.

MS Auckland needs to continue to build awareness of multiple sclerosis in the general community. There also needs to be clarification on the role of MS Auckland and our purpose, including that our services are free-of-charge.

In terms of the appeal of MS Auckland programmes at different stages, the study found two common situations in the first decade of diagnosis.

Two years and under since diagnosis 'want everything' – high appeal of all services, programmes and support. Appeal of programmes (except TM assessments) generally declines from that time. 5-10 years – the 'busy group' – know we are there, interaction is on their terms and in their time. There may still be privacy issues at play in this group also (getting on with life, but still want control over who knows about their diagnosis).

Warmest thanks to everyone who contributed and especially to ASB and Deloitte for their generosity, engagement and expertise. From this comprehensive information provided by our people with MS, MS Auckland will continue to develop a portfolio of programmes and services to support, guide and connect each person on a journey with multiple sclerosis.

Sailing away

Oceans of Hope gives life changing experience on the water

Oceans of Hope's aim is to help you gain self-confidence and a renewed sense of empowerment.

The camaraderie of sailing a boat with people who have similar experiences creates an environment where people can comfortably share their hopes and fears. The Oceans of Hope experience is a catalyst for creating lasting friendships and a sense of community.

People with multiple sclerosis can join the Oceans of Hope challenge, whether they are new to sailing or seasoned boaties. The crew is there to support everyone to have an amazing experience.

The next Oceans of Hope challenge in our part of the world is from Australia. Boarding is on 9 September 2023 at Manly, Queensland, Australia after 5pm at the William Gunn Jetty, Wyvernleigh Close. For more information, email oceansofhopechallenge@gmail.com.

If you are interested in joining this exciting opportunity an early registration is recommended as demand for crew positions is strong.

History of Oceans of Hope

In 2012, doctor and sailor Mikkel Anthonisen had the idea for a circumnavigation of the world using people with multiple sclerosis as an active crew. Mikkel had for many years considered how to help people with MS; not just from a medical perspective but also in their lives outside the hospital walls.

In creating Oceans of Hope, he started a new story about the possibilities as a human being in a strong community, despite illness or other limitations in life.

The UK Oceans of Hope organisation was set up by Robert Munns and Nicola Kaufman who met while taking part in the circumnavigation. Their experiences of sailing as part of this extraordinary crew left them both determined to improve the lives of others with MS.



With the guidance and support of Mikkel, they created the first Oceans of Hope UK Challenge event in Spring 2016. The flotilla of six boats was crewed by 38 people from 10 countries, completing a life changing week of sailing in Turkey.

The adventure continued in 2017 with the second Oceans of Hope Challenge in Croatia. This event brought together over 60 people together from 16 countries in a flotilla of not 6 but 10 boats!

The success of the Challenges inspired Robert, Nicola and Mikkel to establish Oceans of Hope UK as a registered charity in 2017.

Enthusiastic discussions between Ingrid Robertson of Christchurch and Robert in Croatia led to Oceans of Hope challenge opportunities becoming available in New Zealand, initially with Spirit of New Zealand and latterly, three challenges with NZ Sailing Trust and its iconic ex Round the World racing yachts Lion New Zealand and Steinlager 2. This was all magnificently organised by Ingrid.

Maria Sunde:

Oceans of Hope Challenge is a definite 'challenge' and an experience that will stay with me for the rest of my life.

I was fortunate to have the opportunity to take part in the first Oceans of



Hope Challenge in Auckland in 2019 and so welcomed the chance to do it again. It is an experience where you bond and unite with so many awesome people who are affected by the same disease as yourself. We learn from each other, share, experience discomfort, chatter and laugh through much of the day and night.

Many of the participants this time I had met from the previous challenge and it was fantastic to touch base with them again. It was great to see all the Australians who ventured back to NZ for more fun.

I had sailed way back in my 20s when I was fit and extremely active and wanted to see if I could do it again. Admittedly moving is now far more difficult but with the support of the 'fellow sailors' and the fabulous crew we sailed to some amazing places, witnessed nature at its best, viewing schools of fish, pods of dolphins etc.

The Oceans of Hope Challenge, reinforces the fact that yes, we can do anything we set our heart on. Just because we have been diagnosed with MS, does not mean we have to hold ourselves back ... there are many of us in the same 'boat' and our longing to share the same experience.

Kevin Miller:

I have had the good fortune to have four previous experiences with Oceans of Hope (OOH), my first being a harbour cruise on the 'mother ship', Oceans of Hope, during its circumnavigation voyage and more latterly on three Challenges on Peter Blake's Round the World racing maxi boats; first on Lion New Zealand in the company of Steinlager 2 and two on Steinlager 2.



Initially, the opportunity, for a previous boat owner, to sail on these iconic boats around the familiar sailing grounds of the Hauraki Gulf was the big attraction. However the real 'Challenge' I found was to experience living aboard and experiencing life on the water and enjoying the magnificent country we live in with a fabulous group of people who share one thing, a strong desire to live well with MS and not let it stand in the way of experiencing a real challenge.

The long-term memories are the those of the shared experiences, the opportunity for discussions about our lives with a common bond. The support from the group is truly memorable. Yes, it may push you outside your comfort zone but the words of achievement below, penned by an English crew mate after a particularly exciting day outside the Hen and Chicken Islands, on a passage from Great Barrier to Tutukaka, in our most recent challenge captures the sense of achievement well:



"There's no thrill in sailing when the skies are clear, and blue, there's no joy in merely doing things which one can do. But there is certain pleasure that is mighty sweet to take, when you reach a destination that you thought you'd never make".

I would like to acknowledge the team from NZ Sailing Trust, who operate these yachts. Your care and contribution is outstanding, as is your recognition of the achievements of all the Challenge participants

Duncan Grant:

In 2021 I went on the Oceans of Hope Challenge NZ. The famous round the world Steinlager 2 Maxi yacht was our mode of transport for the week.

This challenge is only for those with multiple sclerosis and it was just what I needed when I was deep in the throes of working through my MS diagnosis. We sailed the Hauraki Gulf for the week visiting a number of the islands in the Gulf with Great Barrier Island being our main stop.



We all pitched in on the boat from cooking, cleaning, grinding, sailing etc. For the first time since diagnosis I felt at home, I didn't have to explain myself about what MS was and what the symptoms were as we were all in the same boat, literally. It was one of the best experiences I have had and I would highly recommend it to all of those with MS. You meet the most amazing like-minded people. You laugh together, you cry together, you get to sail in a world-famous boat, you enjoy the serenity of the ocean and all the calmness that it brings with it and most of all you can get to put MS at the back seat of the bus for the week.

Recipe

Caribbean Pepper Pot Soup

The team at MS Auckland has 'soup club' during the winter months – we each have a turn at bringing home-made soup to share after our fortnightly team meeting. This one was a hit!



The team at MS Auckland has 'soup club' during the winter months – we each have a turn at bringing home-made soup to share after our fortnightly team meeting.

This one was a hit with the team and the cook kindly shared their recipe! The kumara thickens the soup nicely. We enjoyed it with chopped fresh chilli and coriander on the side. The recipe makes a large batch which freezes well too, creating an easy meal for later!

Serves 8

Ingredients

4 tbs oil
4 medium onions, finely chopped
4 tsp garlic, crushed
4 tsp Spanish smoked paprika
4 tsp ground cumin
2 tsp ground coriander
2 tsp salt
6 x 400gm cans crushed tomatoes
2 x 400gm cans coconut cream
4 tbs sweet chilli sauce
4 medium kumara (or potato), peeled and cubed small

To serve: handful coriander leaves, finely chopped; fresh red or green chilli, finely chopped; greek yoghurt if desired

Method

In a large, heavy saucepan over a low heat, add oil and saute onions, garlic, paprika, cumin, coriander and salt for five minutes.

Add tomatoes, coconut cream, sweet chili sauce and cubed kumara, and simmer gently until kumara is cooked (about 20 minutes). Blend if you prefer a smooth soup, otherwise leave with soft chunks of kumara.

Serve with coriander and warm bread.

Enjoy!



Support groups

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

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

The groups are based on friendship and connection with others 'in the same boat'. Although the focus is often not on MS itself, there really isn't anything quite the same as being with a group of people who quite simply 'get it'.

"The group backs each other. We encourage people to keep in contact with each other. We talk about everything and not always about MS"

"It is beneficial to get together and talk"



North Shore group celebrates Christmas

"We talk about all sorts of things, not much about MS and we try to have fun"

Most of our groups meet in-person for coffee. We also have virtual support group options for those who prefer to connect in this way.

Our list of groups is below. If you are not yet part of a group and are interested in finding out more, contact the Community Advisor team on info@msakl.org.nz or 09 8455921. They can suggest the group that fits best with your needs and/or where you live.

Our groups

South / East Auckland

Pukekohe Café Group
Botany Café Group
Manukau Café Group
Men's Group

Central

Mt Wellington Café Group
Stonefields and Onehunga Café Group

West Auckland & Rodney

Kumeu Café Group
Henderson Garden Café Group
Silverdale Café Group

North Auckland

Shore and Mayfield Lunch Group
North Shore Café Group

Newly Diagnosed

Zoom Meetings
Mt Eden Café Group
North Shore Café Group

General groups

Zoom coffee & chat (all welcome)

Date/ Time

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

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

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

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

Dates and times vary
Fourth Wednesday / Month - 7pm
Third Saturday / Month - 11.00am

Second Tuesday / Month - 10.30am

**For more information including venue/link, please contact us
info@msakl.org.nz or on 09 845 5921**

Strangest MS symptoms from head to toe



Extreme fatigue, clumsiness, weird prickly sensations, sluggish thinking, wonky vision are classic and common first symptoms of multiple sclerosis, or MS.

But the expected stops here. Damage to the central nervous system, aka your brain and spinal cord, is what causes these symptoms. That's a wide range of functions that affect many different people. So it can show up in some strange and varied ways.

Trapped in a bear hug

It's not a warm and cozy kind of hug. Called banding, this MS symptom feels like something's squeezing you firmly about the chest and won't let go. It can strike anywhere between your waist and neck, or just on one side. You might have pain or breathlessness. It happens when damage from the disease blocks or garbles the messages from your nerves. Spasms in the muscles between your ribs trigger the tightness. It often passes on its own.

Out-of-control laughing or sobbing

Pseudobulbar affect, also called PBA or emotional incontinence, prompts random outbursts of tears or laughter that have nothing to do with how you feel. Nerve damage in the part of your brain that controls emotions can cause your responses to get all mixed up. You might worry about it happening when you're in public, or in a serious setting. Antidepressants can help.

An itch you can't scratch

It's the itch that isn't. A sudden, intense tingle crops up out of the blue, anywhere on your body. But there's no skin irritation or allergy to scratch or apply rash cream to. This kind of itch doesn't stem from your skin. Dysesthetic itching is a nerve-related sensation that passes quickly. It's treatable with meds for epilepsy. Carbamazepine, gabapentin, pregabalin and phenytoin are a few.

Shocking face flashes

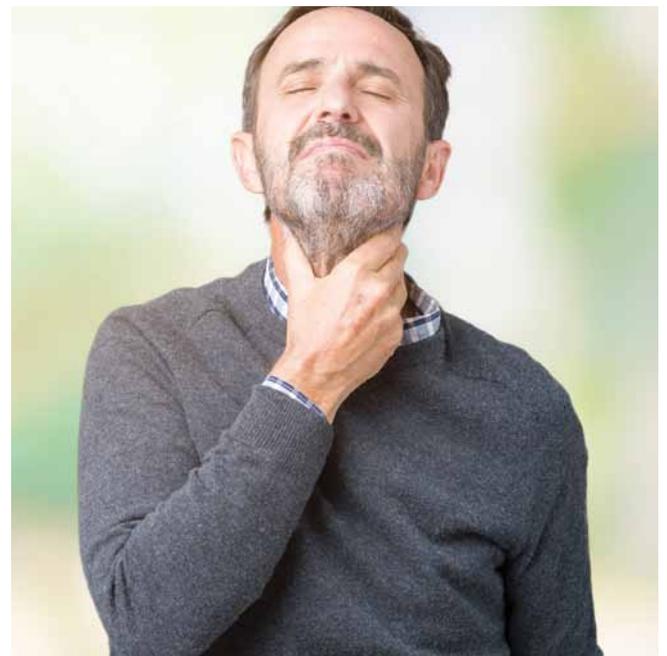
Nerve damage can trigger trigeminal neuralgia, a burning, stabbing, or shock-like pain in your cheek or jaw. It might fade fast or linger for a few minutes. Though rare, it can be a first symptom of MS. You might feel it come on as a tingle, numbness, or ache on one side of your face, like dental pain. Anticonvulsant meds such as carbamazepine, lamotrigine, or sodium valproate can help.

Fiery feet

Dysesthesia is an unpleasant "altered" sensation like burning, prickly pins-and-needles, numbness, and creepy-crawlies in any part of your body. For example, your feet might suddenly feel scalded, with no heat source, or damage, at all. Your brain gets distorted nerve signals, so it struggles to relate to something it recalls or imagines. Sometimes it comes up with some pretty crazy stuff. You can treat the weird feelings with nerve pain meds.

Hard to swallow

Swallowing isn't as simple as it seems. The nerves and muscles in your mouth and throat must work with your brain. With MS, the muscles you need to do it can weaken. Mixed-up nerve signals and sensory distortions can make it hard to chew or control the food or liquid in your mouth. Or you might feel there's something stuck in your throat when there isn't. It usually happens at a later stage of MS, but it can show up earlier, too.





Spine-tingling shock

Lhermitte's sign is really a symptom. It's a sudden 'electric' zap that shoots down your spine and legs. It happens usually when you flex your neck forward, as when you get your hair trimmed. (Another name for it is the barber chair sign.) Lesions in the cervical spine, your neck area, cause it. Lhermitte's goes away as quickly as it comes, so it typically doesn't need treatment.

Blurred vision

Damage to the optic nerve (optic neuritis), which links your eye to your brain, can trigger something called Uhthoff's phenomenon. This means your vision briefly goes blurry when your body temp rises. (Your other MS symptoms may get worse, too.) Exercise, hot baths, warm weather, even hair dryers, can all make eye-to-brain signals iffier than usual. It can help to take a cool shower, use a gel pack, and drink lots of cold water before you exercise or go out in the heat.

Optical illusions

Another optical trick MS can play is the Pulfrich phenomenon. Optic neuritis triggers this one too. It's a 3-D illusion caused by a conflict in your vision. Let's say an object is headed toward you in a straight line. Instead, you might see its path as an elliptical orbit. An oncoming car might appear to swerve toward you, or you'll miss a ball as you try to catch it. A special filter in front of one eye can help balance your vision.

Sudden spasms

Abrupt, brief spasms called paroxysms happen when electrical discharges fire in damaged areas of your brain. They might surge through your arm or leg, or the muscles you use to eat and speak. Although they can repeat several to many times a day, the bout usually ends within a few months. While scary, they're not the same as seizures. You can treat them with muscle relaxants like baclofen or orphenadrine.

Migraines

Migraines are sudden headaches that can last from several hours to days. They can sometimes be the first MS symptom. People with MS are twice as likely to have them. They can bring on nausea or make you sensitive to sound and light. This can keep you from your regular activities. People with MS seem to have family histories of migraine, so researchers are looking for a link.

Hearing problems

What's that you say? Rarely, hearing problems can be a first symptom of MS. It might have a link to swelling and scar tissue near your auditory nerve, which carries info to your brain. Plaque build-up on the nerves along this pathway can lead to it, too. These episodes usually improve, and permanent deafness is rare.

Vertigo

If you have vertigo, you may feel like you, or the area around you, is spinning. It can throw off your balance way more than just dizziness. You might also feel lightheaded or queasy from the sense of motion. It happens to about 1 in 5 people with MS. It can stem from damage in the same pathways that control your hearing and vision. Treatment can include physiotherapy, which studies how your movements affect it.

If you are suffering with any of these symptoms, please do reach out and let us know. Treatment options are growing all the time and there may be something that can help make the suffering easier for the day to day.

This article has been adapted by Belinda Butterfield, RN, MS & Parkinsons Society, West Coast, from the medically reviewed Web MD article by Melinda Ratini, DO, MS on March 07, 2021



A spotlight on the bigger picture



Multiple sclerosis affects an estimated 2.8 million people worldwide

As reported in *The Lancet*, although the past few years have seen substantial improvements in procedures for diagnosis, prognosis, and monitoring, and an expansion in the international therapeutic landscape, there are stark disparities in the care of people with the disease.

The third edition of the Multiple Sclerosis International Federation (MSIF) Atlas of MS reports that about two-thirds of patients with multiple sclerosis worldwide are living in countries that do not have national guidelines for the diagnosis and treatment of the disease.

On World Brain Day (July 22), and through further engagement, MSIF is joining forces with the World Federation of Neurology to advocate for a heightened focus on improving quality of life for people with multiple sclerosis and their care partners.

The Atlas of MS was launched in 2008 by MSIF, in collaboration with the World Health Organisation to address the absence of data on multiple sclerosis in many countries. Part one of the third edition of the Atlas reports the prevalence and incidence of multiple sclerosis in 115 countries. Part two of the Atlas, drawing on data from 107 countries, highlights the many barriers and inequalities that patients can face not only to get a diagnosis, but also to access disease modifying therapies (DMTs) and rehabilitation.

An early diagnosis of multiple sclerosis is essential to either enable prompt treatment with DMTs that can minimise relapses and reduce future disability or, where such therapies are not available, allow for lifestyle changes to help manage the disease and improve quality of life.

According to the MSIF Atlas, implementation of the 2017 McDonald diagnostic criteria in clinical practice correlates with country wealth, with around 98 percent of high-income countries compared with less than half (40 percent) of low-income countries using these criteria. The most common barrier to their use was lack of awareness or training for neurologists. Worryingly, about 83 percent of countries have barriers that further preclude early diagnosis of multiple sclerosis, such as a scarcity of qualified health-care professionals and the prohibitive cost of the diagnostic equipment and tests.

The Atlas also uncovers fundamental barriers to equitable access to treatment. Experts in about 14

percent of countries surveyed report having no licensed DMTs available. This proportion increases to 70 percent of low-income countries, including 60 percent of African countries.

Globally, the most common barrier to accessing therapies is their high cost. Other challenges are the low number of health-care professionals, poor knowledge of DMTs among clinicians, and logistical problems with the continuous supply of DMTs.

The Atlas also reports on the high unmet need for rehabilitation and symptom management, particularly in low-income countries, which are essential for a good quality of life. Therapies for fatigue and cognitive impairment are not available in about two-fifths of countries. New evidence-based recommendations on the use of MRI in diagnosis, prognosis, and disease monitoring in multiple sclerosis unify guidelines from European and North American expert groups. The recommendations address major issues concerning the use of MRI in clinical practice that have arisen in the past few years, and highlight the essential role of MRI for diagnosis as well as assessment of treatment efficacy and prediction of treatment response.

However, the recommendations are unlikely to be widely applicable in low-income countries where regular use of imaging procedures is challenging. The MSIF Atlas makes some recommendations to address the disparities in care, including calls for every country to have a national plan or dedicated management guidelines; improvements to the availability and affordability of a range of DMTs through advocacy efforts and evidence-based guidance on the use of off-label DMTs; joint efforts between organisations and networks that focus on neurological conditions to tackle shared challenges, such as the number and training of neurologists and access to cost-effective approaches to management; and stronger collaboration between health-care authorities, research institutions, patient organisations, and health-care professionals in the collection of data to establish and monitor care standards. The development of new and potentially more sensitive and specific imaging techniques than are currently widely available represents an important opportunity as new treatments emerge. However, addressing imbalances in care is essential to ensure that all people affected by multiple sclerosis are able to benefit from progress in the field.

<https://www.msif.org/>



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

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

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Remember us with a gift in your Will



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

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

Your family trust or estate can support a named project – ask us how!

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



Don't wait. MS won't.¹

TYSABRI is now available to some people with multiple sclerosis (MS) sooner.²

Speak to your doctor to see if **TYSABRI** is right for you.

TYSABRI works quickly* to decrease the inflammation in MS that causes nerve damage – helping to prevent symptoms from progressing.³⁻⁵

*TYSABRI may reduce new lesions by >85% within 1 month and reduce relapses by 87% within 3 months.^{4,5}

Use strictly as directed. Additional monitoring while on **TYSABRI** is likely to be required.³

TYSABRI[®]
(natalizumab)

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

References: 1. Giovannoni G *et al.* *Brain Health: Time Matters in Multiple Sclerosis*. Available: www.msbrainhealth.org (accessed October 2022). 2. PHARMAC. Decision to fund treatment earlier for relapsing remitting multiple sclerosis. July 2022. Available at: <https://pharmac.govt.nz/news-and-resources/consultations-and-decisions/2022-06-13-decision-to-fund-treatment-earlier-for-relapsing-remitting-multiple-sclerosis/> (accessed October 2022). 3. **TYSABRI** (natalizumab) Consumer Medicine Information. 4. Rudick R *et al.* *JAMA Neurology* 2013;70:172–82. 5. Kappos L *et al.* *J Neuro* 2013;260:1388–95. ©2022. Biogen[®] and **TYSABRI**[®] are registered trademarks of Biogen MA Inc. Biogen-186482. TAPS: BG2675. Date of preparation: December 2022. BIOG1049/EMBC.

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