



Multiple Sclerosis & Parkinson's

CANTERBURY

strong connections

NEWSLETTER February 2022

Be Prepared

Advice for when Omicron arrives

Being prepared for a stay at home with a positive COVID-19 test will happen for some of us in the next few months.

By planning in advance, you will feel a bit safer and less anxious about what may happen.

Should you become unwell, be exposed, or be waiting on a test result you should be prepared to be at home for at least 14 days – think mini lockdown!

Here are a few things to have on hand at home to help be prepared:

- Keep handy the Healthline number to call if you have any cold, flu or COVID-19 symptoms and are concerned. Call free on 0800 358 5453. If your symptoms worsen make sure to check in about whether you should take any additional measures.
- Keep your GP and chemists phone numbers handy.
- Panadol or Paracetamol and Ibuprofen – for headaches and fever. Always check the recommended dose and do not exceed.
- Throat lozenges.
- Your normal medications – if you do become ill you will still need to take these. Check with your doctor if you are unsure.
- Toiletries – soap/shampoo, tissues and toilet paper.
- Some extra groceries and easy to make meals like cans of soup or packet meals. Non-perishables last a long time and you will want something that isn't going to take lots of time or energy to make.
- A couple of bottles of sports drinks are great for replacing electrolytes if you have been unwell.
- Hand sanitizer/soap – keep up with healthy hygiene recommendations.
- Have a list of the people you contact by phone – with their numbers written down. In particular, note the phone numbers of important people that you would want contacted if you ended up in hospital.
- Can you shop online or can a friend or family member do your grocery shopping for you and leave it on your doorstep for contactless pick up?

- Can you safely isolate yourself at home? Think through some options to also protect the safety of other family members, particularly vulnerable persons. Can they go to other family members/friends, or do they need to stay in your bubble?
- Furry children – stock up if you can on pet food in case you can't get out. If you do become unwell, how will your fur friends cope without walks? If you have cats no problems but for dogs this might be an issue! If you need to go into hospital, do you have someone who can look after your pets?
- If you have carer's coming into your home – what will happen if you or they become unwell? Think of a plan before you need it!

Basically, all this amounts to an emergency kit, similar to what was encouraged after the Christchurch earthquakes. "Be prepared, not scared" is a great way to reduce anxiety! We don't know what will happen in the future – we can only be as prepared as we can.

Take care,

Deborah Ballantyne and Elspeth McKeon

MS and Parkinson's nurses

Reminder

Please get in touch if you should need some specific assistance with your MS or Parkinson's in the coming months.

Our clinical staff can advocate to other health professionals, make referrals or give you or your partner/carers some assistance to help you through.

If you leave us a message, we will get back to you.

We are still doing face to face appointments if we can, as well as telehealth and phone consultations.



Thanks Lisa

Thanks to Lisa Wood our Yoga teacher for the past 6 years. She has secured a position at the hospital and has had to cut her number of classes.

Lisa is still teaching at Te Hapua in Halswell. You can join her there for a class to help fill the gap. She would love to have you attend.



Lisa is a well-loved teacher and good at incorporating exercises that suited a range of needs with her gentle style. We would like to thank Lisa for her contribution to keeping people moving. We have suspended our yoga classes until we start up at Braintree. We have concentrated some of our gym programmes so that we have minimal exposure and they are all on one site. We are really sorry about this loss but we hope to have you flexing and stretching again soon.

Manager's Message



We had wanted to kick off the year with a series of workshops with great information to assist you to manage your condition. However, these have been put on hold and are waiting in the wings to be reinstated when it is safe to do so. Similarly, morning teas with Lesley are on hold. She will be giving the people who normally attended a call to check in.

The move to the Trust eliminated the need for an annual membership fee to the society. I was very keen to eliminate this barrier to our services for people who were not able to afford it. We now cater to all people with MS and Parkinson's and their supporters, instead of limiting it to the number of our paid members. Over time this will change the look of our service.

This year we will hit a number of milestones with our transition to the Trust, our move to BrainTree and our 60th Anniversary. These milestones allow us to mature as an organisation and continue to support you in your community.

Keep well

Karla Gunby

Executive Manager

Physio Update

Exercise classes are going well and attendance has been up in the new year. We are thrilled you are all so keen to get moving! This means classes and open gym are busy and often book up quickly. Make sure you contact us or book online so you don't miss out. We are looking at starting up online exercise group options so you don't need to miss out if you can't attend or just want to play it safe.

Exercise continues to be one of the most important things you can do to help manage your condition so we will continue to make sure you can exercise safely and regularly, whatever the Covid situation.

If you are unable to attend your regular gym classes for any reason you could try this:

Parkinson's UK Chair Based Exercise Class

<https://youtu.be/h9NQc0LYrWE>

Tara Martin

Neurological Physiotherapist

Farewell Kim

We were sad to see Kim Veenings leave MSPC at the end of the year. She had been with the organisation for 10 years and had run the exercise classes 3 or 4 mornings a week. She had a passion for helping people maintain their condition through exercise.



Kim also shared a lot of her gardening tips with us all. Kim will be missed by our members.

Tara and a new instructor Amanda Richardson are covering her classes.

How to Donate Towards Our Services

With the membership fee now removed as a barrier to our service, we are asking for a donation or a contribution towards running our services. This is tax deductible.

Since mid-2021 banks in New Zealand no longer accept cheques as deposits or issue bank cheques. But there are several ways you can support the work we do:

- Go to our website **www.ms-pd.org.nz** and fill in the donation form
- Internet Banking:
MSPC Westpac 020800 0969020 00
Please use your surname as a reference.
- Or call the office on 03 3662857 and Kirsty can support you to make a donation over the phone.

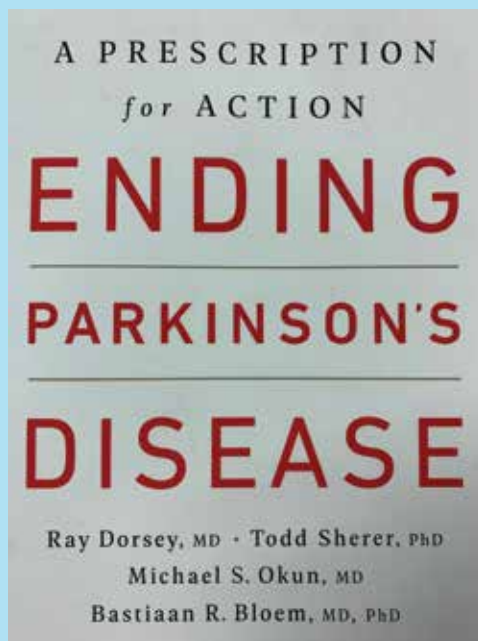
Recommended Reading

Ending Parkinson's Disease A Prescription for Action

By Ray Dorsey, MD | Todd Sherer, PhD | Michael S. Okun, MD | Bastiaan R. Bloem, MD, PhD

Ending Parkinson's Disease proposes a bold pact to prevent the disease, advocate for policies, care for patients and treat the condition with innovative theories.

The authors gather the expertise of cutting-edge researchers, clinicians, and patients to tell the full story of Parkinson's and what we can do to end it. This is an important guide for patients, families, clinicians, scientists, politicians and activists.



MSPC Training in Rest Homes and Retirement Villages

As part of our advocacy and clinical support, we train other health professionals. We regularly train nursing and care staff in residential support.

The training focuses on helping staff understand:

- the care of advanced Parkinson's, its variety of symptoms, including motor and non-motor symptoms and medical treatments
- the importance of people getting their Parkinson's medication on time
- tools to be able to help someone with advanced Parkinson's to manage their condition
- MSPC is here to help support residential staff.

To find out more phone us on 03 366 2857 or email support@ms-pd.org.nz

Christmas Party at the Papanui Club

Over 90 members attended the annual Christmas Lunch at the Papanui Club in December. It was the first week of having to show your vaccine pass and everyone was able to get that sorted. We drew the raffles and had a chocolate wheel, so people went away with a range of prizes and a great lunch.

Thanks to Kay Roper for making the Christmas Cakes, New World who helped us with the chocolate and Harewood Tunnel Wash who donated 4 gold car washes.

We were also treated to a singing performance by our Physio Tara Martin. Tara is an opera singer and sang 2 christmas carols. The power of her voice surprised us all.



Are you Interested in Participating in a New Study?

Treating constipation in Parkinson's using self-care techniques.

- Do you or your spouse have Parkinson's disease?
- Do you or they suffer from constipation?
- Would you like more information to help you manage this?
- Are you interested in trying complementary medicine?

I am a registered nurse conducting a research project to complete my Master of Health at Victoria University or Wellington.

If you are interested in participating in this research, please contact:

Bronnie Alexander on 027 2766643
or email: alexanbron@myvuw.ac.nz.

President's Message

Tēnā koutou katoa

We were hoping that the start of the new year would be a positive one and Omicron would not be out in the community. We are once again encouraging everyone to stay safe and be prepared as the days ahead unfold.

Despite Covid, this year will be an exciting one for the Society as we move to the BrainTree Wellness Centre in June. The spacious gym and large open studio along with the meeting rooms and cafe will provide us with first rate facilities and allow for a multitude of activities.

I want to thank the members who attended the Society's Special Meeting on 15 December to decide on the proposal that the Society should transition to a Charitable Trust. The meeting voted overwhelmingly that the Society should move to be 'Multiple Sclerosis and Parkinson's Canterbury Charitable Trust'. The Committee has since worked with Lane Neave to establish a Trust Deed and will be forwarding an application to the Charities Commission this month. It is hoped the process will be completed by 31 March 2022 for the new financial year and our move to the BrainTree Wellness Centre. The change to a charitable trust allows us to transfer from being a membership-based organisation to serving all people in Canterbury with MS and Parkinson's.

Take care over the next few weeks!

Ngā mihi

Anne-Marie Kite

President MS and Parkinson's Canterbury



Kiwi Access Card

Need a valid form of photo ID but don't have a driver's licence or passport? The Kiwi Access card (previously known as the 18+ card) is a government recognised form of photographic ID and evidence of age card. The Kiwi Access card is valid for 10 years and is \$55.

You can pick up an application form at a participating NZ Post or an AA Centre across New Zealand or download the application form online here:

<https://kiwiaccess.co.nz/download-application-kiwi-access-card/>



SMYLIEN Support Group

Do you have MS, are under 45 years and would like to meet others?

Our younger onset MS group meets every two months at Under the Red Verandah, Linwood for a chance to share stories and information.

Contact us on 03 366 2857



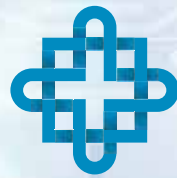
MS Feedback Group

We are looking for people to join our MS Feedback Group. It gives the organisation feedback on new initiatives, our communications and last year fed into the development of our strategic plan. We meet 3 times a year at MSPC.

If you think you could add value to the conversations and share your experiences for the benefit of others please contact Karla at manager@ms-pd.org.nz.

Volunteers Needed

We are looking for volunteers who can help distribute our fundraising appeal brochure in their local neighbourhood. If you can help, please contact Bridget - Phone 366 2857 Ext 9 or email: fundraiser@ms-pd.org.nz



New Zealand Brain Research Institute

World Class Brain Research, Right Here in Canterbury.

By **Millie Johnston**

The New Zealand Brain Research Institute (NZBRI) is an independent institute that researches neurological disorders through collaborative, high-quality research. Based in Christchurch, their work includes research into the effects and treatments for New Zealand's most common brain disorders, including Parkinson's disease, Alzheimer's and other dementias, Huntington's and multiple sclerosis. With over 40 researchers from PhD students through to professors, we're lucky to have access to such a world-class team, right on our doorstep. Here is a glimpse into a few of their current projects.

Clinical studies

The team have been trialling new commercial treatments for nearly two decades. Many people with Parkinson's, MS and epilepsy have benefited from the 11 trials which have led to successful treatments. Last year alone, there were four active clinical trials.

Our longitudinal study

The Institute conducts one of the world's largest longitudinal studies of Parkinson's disease, known as the Parkinson's Progression Programme (NPP3). Since 2007, over 300 people with Parkinson's have participated and received ongoing evaluations and assessments, including neuroimaging and neuropsychological tests. The NPP3 study has formed the foundation for many other Parkinson's-related studies, including epidemiology, caregiver burden and swallowing research.

Some of the results

The NZBRI epidemiology team has reported that there are approximately 12,000 people with Parkinson's in Aotearoa. Their research shows this number will double in the next 20 years due to the aging population. Recently, the team found that South Canterbury, Canterbury and the West Coast have the highest prevalence of Parkinson's in the country. Now, thanks to funding from the Health Research Council, NZBRI is investigating the risk factors that contribute to this prevalence by using occupational, environmental, and genetic factors.

Swallowing research

This is led by Dr Sarah Perry, who investigates how neurological disorders such as Parkinson's affects swallowing and coughing. Parkinson's can cause issues with swallowing, known as dysphagia, which can lead to choking, or severe illness, such as pneumonia from food entering the lungs. Sarah hopes that greater understanding of how swallowing is affected by Parkinson's will lead to an improved prognosis through meaningful intervention, both reducing the burden of disease and increasing quality of life, not only for people with Parkinson's but their caregivers also.

Research and multiple sclerosis

The Institute has recently returned to active research into multiple sclerosis. Although we know multiple sclerosis can reduce life expectancy, little investigation has delved into the underlying reasons. Neurologist Dr Ruth Leadbetter is leading the first New Zealand study to investigate MS mortality in Aotearoa and those underlying factors. Ruth's findings will be published later this year and will hopefully play a role in improving life expectancy in MS patients through better care and access to resources.



we need your help now more than ever

Street Appeal Cancelled

After being forced to cancel our annual street appeal in September 2021, we rescheduled a mini version for this month in an attempt to recoup some of the much-needed funding we have missed out on. Sadly, with the threat of Omicron looming we have now had to make the difficult decision to cancel this street appeal too!

Once again, this leaves us with a huge hole in our services budget. We will be moving to an online appeal again, but in the meantime, if you can help with a donation please do so at the website below.

You can also phone the office on 03 3662857 for donations using a credit or debit card.

Thank you in advance for your support. It allows us to continue the work we do.

Bridget Paterson

Fundraising and Marketing Manager



**Multiple Sclerosis
& Parkinson's**
CANTERBURY
strong connections

Please donate online at: www.ms-pd.org.nz

BrainTree Wellness Centre Update

We have experienced no delays to date and the centre remains on track for opening in June this year, which will come around very quickly.

We have a range of potential tenants expressing interest in either being based at BrainTree or utilising our amenities such as our gym, meeting rooms and studio spaces.

Our furniture and fit-out procurement is progressing well. We are going for a comfortable and homely feel for our interior design brief with lots of natural earthy colours and warmth, which compliments the large windows and abundance of natural light.



BrainTree Honey Fundraiser

We are continuing our partnership with Airborne Honey to raise funds for BrainTree. Please visit the BrainTree website where you can purchase directly from our online shop:

<https://www.canterburybraincollective.org/honey-for-brain-health>.

We are continuing to seek potential donors and sponsors of BrainTree – whether that be a direct donation or goods and services ‘in kind’. Please let us know if you are aware of anyone that may be interested in supporting us to ‘get to the finish line’.



Nicki Brown

BrainTree Centre Manager

Right: The MSPC team had a site visit to the BrainTree Wellness Centre on 31 January. Pictured from left are: Karla, Lesley, Bridget, Deb, Elspeth and Kirsty



BrainTree
A wellness centre for brain health



New Ministry for Disabled People

A new Ministry for Disabled people has been announced, which will support disabled people living in New Zealand. The Ministry of Social Development will host the ministry, but it will operate independently.

The new ministry is part of the country's wider health and disability reforms, it is based on the Enabling Good Lives vision that all disabled people and their whanau have greater choice and control over their supports and lives.

The new ministry will:

- Drive better outcomes for all disabled people
- Lead and coordinate cross-government strategic disability policy
- Work to deliver and transform disability support services
- Progress work on the broader transformation of the wider disability system.

The new ministry will be established from 1 July 2022.



Making aHSCT Available in NZ

Shared from MSNZ

The petition for making aHSCT available in NZ for MS patients is making good traction. However, we really need to push it out there and get as many signatures as possible. The petition closes on 31 May, it will then be presented to Parliament. The more signatures collected, the better the chances of getting it passed, so please, share this as far and as wide as possible.

When MS Auckland shared the petition, the signatures rose by 200 - just imagine how many extra signatures we can add to that if we all push this petition!

MSNZ has spoken with Joan, the lady that is driving this petition and is the mother of Anne who has MS. She is so grateful for all of our support. She describes the change in Anne as quite remarkable and is so pleased she 'has her daughter back' and just wants everyone else to be able to benefit from the treatment.

The original article is available on MSNZ's website:

<https://www.msnz.org.nz>

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Multiple Sclerosis & Parkinson's CANTERBURY

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