



Multiple Sclerosis & Parkinson's

CANTERBURY

strong connections

NEWSLETTER December 2021

Living well in your community

MS and Heat Management

As the warmer weather approaches here's a timely reminder about managing heat tolerance for our MS family.

When you have MS, even a small rise in body temperature can make your symptoms feel worse. Lots of things can cause this including warm weather, hot showers, a heavy meal, and exercise.

MS can affect the part of your brain that controls your body temperature causing symptoms like:

- Fatigue
- Pain
- Blurred vision
- Muscle weakness
- Balance issues
- Trouble thinking clearly

Try these tips:

- Exercise early in the cooler part of the day or at night and wear a cooling collar
- Look for activewear clothes and shoes that have mesh panels
- Wear loose fitting clothes that can breathe, like cotton, linen, and rayon
- Eat light – instead of cooking heavy meals that heat up the house, and your body, opt for more salads
- Hydrate – drink plenty of water. It helps prevent brain fog and fatigue. If your urine is pale yellow, you are drinking enough. If it's darker in colour you need more H₂O.
- Try ice and spice – ice cold non-alcoholic drinks (alcohol makes things worse), ice chips or ice blocks help you stay cool. Surprisingly, spicy food does too
- Use a fan – on a hot night be the fan hogger!
- Check out technology – there are a number of cooling collars and vests available for sale online. A cooling vest can help you safely enjoy outdoor activities. These gadgets can be expensive, so do your homework first.

For more information view this You Tube video:
<https://www.youtube.com/watch?v=DqUtHJO-yok>

Parkinson's Holiday Tips

Make sure you have a good supply of your Parkinson's medications over the holiday break (call your doctor's office for a repeat if needed).

Don't forget to take your medications with you!

Although you might be out of your normal routine it is essential to take your medication on time, every time.

If you are having issues related to your Parkinson's symptoms or medications over the holidays, please contact your GP or neurologist's office or Helen Skene/CDHB Parkinson's nurse on 03-378-6058 ext. 86058.

Remember to stay well-hydrated in the summer heat.

Deb Ballantyne and Elspeth McKeon

MS and Parkinson's nurses

Multiple Sclerosis &
Parkinson's Canterbury
wishes you all a very
**Merry Christmas
and a Safe,
Happy
New Year**



Parkinson's Exercise Accreditation Programme

We want you to have access to exercise classes in your own community so we are very happy to report our accreditation programme for external exercise groups has reached its first milestone.

On the Go Physio and Exercise as Medicine has had four classes accredited between them. This has been a joint effort with the instructors, Mark Adams and Tim Webster and support from Sport Canterbury's Rebecca Logan.

The classes are all high-level for people who are physically well, regular exercisers and who experience minimal balance and walking challenges.

We've enjoyed getting to know these instructors and their classes, which are all unique but have benefits for people with Parkinson's.

We feel confident that we can continue to grow the network of exercise opportunities for our members throughout Canterbury in 2022.

Our accredited classes are:

Amplitude run by **Exercise as Medicine**

- Tim Webster.

For more information, email: tim@eamnz.com

Parkinson's classes run by **On the Go Physio**

- Mark Adams.

For more information phone 0800 000 856

If you are interested in these classes or any of our other classes or open gym sessions, please get in touch and we can help find the best option for you.



From left: Rebecca Logan (Sport Canterbury), Mark Adams (On the Go Physio), Tim Webster (Exercise as Medicine) and front Tara Martin (MS and Parkinson's Canterbury)

MSPC Gym and Physio Appointments

Exercise is important for everyone.

Physio appointments, exercise groups and gym sessions are back in action following our lockdown!

Our gym is clean and well ventilated. We maintain small group sizes by using our booking system and our instructors and volunteers always wear a mask.

If you have any questions about this or would like some options to exercise at home, please let us know.

We can also offer Telehealth physio appointments if attending in person does not work for you. This is very effective and often a lot easier than people realise.

Please get in touch if you'd like more information.

Support from Isaac Construction

Isaac Construction has been a sponsor of MS and Parkinson's Canterbury since our first charity golf tournament in November 2018.

After a visit to our premises in 2018, CEO of Isaac Construction Jeremy Dixon was impressed by the support we were providing people and their families and became aware of how limited our financial support was.

"If they don't get support from the business community, the service they can provide our community could potentially be severely limited", said Jeremy.

"Our business is growing, and we are glad to be able to support causes like this. Isaacs staff are not only part of the Isaac community, but also part of the wider community," he said.

"MS and Parkinson's will directly or indirectly affect a number of our staff and the communities they live in. A thriving support base for people with these conditions is a necessity and the business community has a part to play in providing that support."

Thanks Isaac Construction. We couldn't do it without you!



From left: Anne-Marie Kite (MS and Parkinson's Canterbury President) with our Charity Golf 2021 Winning Team - Isaac Team Numero Uno (Kim Masina, Sam Anania, Andy Dyson, Stephen Todd)

Manager's Message

Our role with Covid

Multiple Sclerosis and Parkinson's Canterbury is mandated by the government to have our staff, contractors and volunteers vaccinated and I can confirm that we are all up to date.

Our role when there are community cases in Canterbury will be:

- To advocate on your behalf for your specialised care
- To support the DHB MS and Parkinson's nurses
- To educate those who are not familiar with working with MS and Parkinson's
- To assess and refer you on to other agencies
- To check in with you and your family

The DHB won't contact us specifically if you are a positive Covid case, so if you need us to advocate or support you, please get in touch with us. The clinical team will not be doing home or hospital visits.

MSPC is also working on a Parkinson's respite care guide, so that you will be armed with validated information to give to respite providers to help make for a good transition and an easy stay. We will let members know how they can access this.

It has been a big year for the staff and there has been a lot of changes. We have learnt fast and changed to suit your needs, so I hope we are an agile and responsive organisation for the future.

Keep well

Karla Gunby

Executive Manager



Karla Gunby
Executive Manager

How Can you Freeze on a Sunny Day?

By Tony Washington (one of our members)

*I went off to the doctors
To see what I had done
She said "you'll keep on shaking man
Coz you've got Parkinson's"*

*It's hard to get out of chairs
And turn myself in bed
All because it seems
Some chemical is missing in my head*

*How can you freeze on a sunny day?
When everything is hot?
Well, you won't find it hard to do
If it's Parkinson's you've got*

*To find a cure for Parkinson's
I'd really like the scientists to do
And make the world a better place
For me and you and you*

*I'd like to get the circuits back
That are broken in my brain
Because little tasks like tying laces
Are now a great big strain*

*I need the support of all my friends
And those who care for me
Coz being silly and making shaking mistakes
Is not someone I want to be*

*For Parkinson's tries to get the better of me
It challenges me every hour, every day
But I am positive
and that's how I am going to stay.*

Kia Kaha!

Thanks to Karen Gentle - SMYELIN Group Coordinator

I want to thank Karen Gentle, the coordinator for the SMYELIN Group for the support and care she has shown people with younger onset MS.

She has really supported the group to share tips and tricks and to encourage people to attend to meet others on the same journey.

Karla Gunby

Executive Manager

60th Anniversary Committee

We will be celebrating 60 years of MS and Parkinson's care in Canterbury in 2022.

We are planning a gala dinner at the Braintree Wellness Centre on Saturday 29 October 2022 as well as a historical project on 60 years of support and services in Canterbury.

If you have any information you could share or would like to be part of the planning committee for this event, please call Bridget on 03 366 2857.

President's Message

Tēnā koutou katoa

With the changes under the various levels of Covid we have continued to provide and adapt our services to keep you safe and we thank you for your positive response to our different ways of working.

Over the past few months, the Committee has been focused on developing the 2022-2024 strategic plan. The plan is outlined in this newsletter and addresses our vision; our future growth of numbers; the nature of our services; ongoing funding and our governance structure as we move into the BrainTree Wellness Centre.

With a number of charities moving to a trust entity and changes in the Trusts Act we are taking the opportunity to reconsider our structure. As a major stakeholder and asset owner of the BrainTree Centre we want to ensure we are 'fit for purpose'.

I want to thank the staff and members of the MS and Parkinson's feedback groups for their input into this planning process. We will keep members in touch with our progress and any recommended changes.

Let's hope we can keep Covid at bay and meet at the Christmas lunch on Monday 6th December.

Ngā mihi

Anne-Marie Kite,

President MS and Parkinson's Canterbury



Our Services under the Orange Traffic Light System

- You will need to scan the Covid Tracer when you come into the building.
- We will scan your Vaccine Pass (we will record the details so that you don't have to do this multiple times)
- Our gym will still have a booking system so that we can control numbers.
- We will work to 1m distancing.
- Face masks will be required when moving around the building. You do not need to wear your face mask when exercising in the gym.
- Our morning teas with Lesley will only be at cafes accepting the vaccine passes.
- Exercise classes, open gym, face to face appointments with the clinical staff, morning teas, workshops and meetings will go ahead with the above conditions.



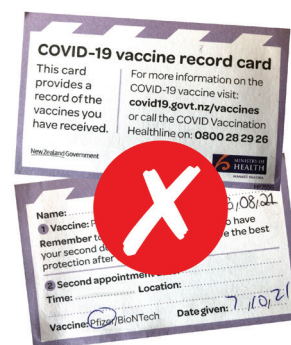
Vaccine Pass and our services

To enter the building you will need your Vaccine Pass.

We will be scanning these at the door. We will only need to scan your pass once and record the details.

We are working through the services we can offer for UNVACCINATED members. You can always access:

- Telehealth
- Phone appointments
- Peer to peer group zoom sessions
- Facebook, Instagram and our website



NOT a Vaccine Pass



CORRECT Vaccine Pass

Gym ventilation

The gym has sufficient ventilation and fresh air circulating for us to be using our air conditioning system over the summer. It was upgraded in late November.

Strategic Plan 2022-2024



**Multiple Sclerosis
& Parkinson's**
CANTERBURY
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Vision People in Canterbury with Multiple Sclerosis and Parkinson's living well in their community

Mission Enabling people with Multiple Sclerosis and Parkinson's to manage their health and wellbeing

Values	Caring:	We are empathetic and sensitive to individual situations and needs
	Enabling:	We encourage and support self-management and independence
	Responsive:	We work to reflect the changing management of conditions and needs of our community

Strategic objectives

Service development: Services and programmes are responsive to the growing needs of the MS and Parkinson's community, encouraging them and their whanau and carers to live well in the community.

Organisational sustainability: A sustainable financial plan is in place, alongside a governance structure that provides stability and protects our assets.

Accessibility and profile: The public profile of Multiple Sclerosis and Parkinson's is raised to ensure we are accessible to all ages, genders, and ethnicities.

Relationship development: We actively engage and collaborate with associated health stakeholders, neurological community service providers and funders.

Living in the Braintree Wellness Centre: We have financial security, as well as effective governance, and management to ensure the success of the Centre.

What we plan to do	Strategic Objective
Review and refresh services throughout Canterbury to reflect current best practice and models of care as well as community need Educate and support whanau, carers and those assisting with MS and Parkinson's	Service development Relationship development
Remove any barriers to providing services and support by: <ul style="list-style-type: none"> - ensuring accessibility to services - removing the annual membership fee. - recognising and catering to all genders, ages, and ethnicities - engaging with Māori, Pacifica, Asian and Immigrant communities and associated health providers 	Accessibility and profile Service development Relationship development Braintree Wellness Centre
Develop a communications and social media plan that allows us to communicate to a wider and more diverse audience	Accessibility and profile Relationship development
Review our governance structure to: <ul style="list-style-type: none"> - broaden our reach in the community - provide stability in governance and financial management - protect our assets and partnership in the Braintree Wellness Centre 	Organisational Sustainability Braintree Wellness Centre Relationship development
Establish a Funding Framework and Plan for the provision of services and support required and financial needs of the organisation	Organisational Sustainability Accessibility and profile
Embed relationships with associated health providers, contractors, and local councils so that our services are more integrated and reflect community need Build relationships with funders and stakeholders	Relationship development Accessibility and profile
Establish the framework for governance and ways of working within the Braintree Wellness Centre Collaborate with other neurological service providers with initiatives and complementary activities Elevate our support services within the Braintree Centre	Braintree Wellness Centre Organisational Sustainability Relationship development

Activities and Workshops End of Year Update

It's been a productive hive of activity since starting the Activities and Workshops Coordinator role back in April and I'm delighted to say that you are really starting to reap the rewards!

As I sit and reflect on this past year we have been delighted to offer you:

- 2 Safe Driving Workshops in partnership with Age Concern
- 3 educational workshops in partnership with Lifelinks including in person events and an online session.
- 6-weekly peer support meetings for our members with MS including in person and online sessions which have reached over 100 members
- 6-weekly peer support meetings for our early onset Parkinson's members including feedback from the UPBEAT conference held in Rotorua
- Bi-monthly groups for our young MS members at the SMYELIN Group facilitated by Karen Gentle
- Morning teas at our offices, in addition to both Rangiora and Ashburton. We have also continued to deliver Nurse and Physio clinics to both of these regions.
- Monthly meetings for our Carer's and Spouses Groups thanks to the amazing facilitation from Gaynor Morris, who has very kindly agreed to continue these throughout 2022.

Our focus in 2022 will be on continuing to reach you in the wider Canterbury community, exploring peer support for those in North Canterbury, the Hurunui and Kaikoura.

We are delighted to offer you some great speakers for a series of educational workshops starting in February, including:

- **Michael MacAskill** – Research Director at the New Zealand Brain Research Institute on Brain Health Matters (Wednesday 16th February – Venue TBC)
- **Matthew Croucher** – On the subject of Motivation and Anxiety. Matthew is a Psychiatrist working at Burwood Hospital, with a special interest in Parkinson's disease at all ages. (Wednesday 16th March – Venue TBC)
- **Fleur McDonald** – Solicitor at FM Legal – Fleur will speak about Enduring Powers of Attorney. We are just in the process of locking in a date for her which is likely to be in April.

We look forward to continuing to reach all of you with different offerings that will provide the peer support, education and outreach opportunities that can help maximise day to day life whilst living with MS and Parkinson's.

Kate Webb – Coordinator

A Message from our Exercise Class Leader – Kim Veenings

Hi everyone. What another year it has been. I'd like to thank you all for your attendance in class. Working around all the new guidelines has certainly been a challenge that I feel you have all tackled well.

I put out a challenge to my class groups in July to see if we could get from Bluff to Cape Reinga by adding our combined "exercise" kilometres. Thank you all for embracing the challenge which I am happy to say, we achieved.

Congratulations on your effort and I hope you keep it up. As we break for the end of the year, I hope you all stay active and well.



Dental Health and Parkinson's

Due to poorer motor function nearly half of all people with Parkinson's face difficulties with maintaining their daily oral hygiene routine.

Brushing your teeth, flossing and rinsing your mouth all require coordination, dexterity and control over your tongue, cheeks and lips.

The effects of motor symptoms such as tremors extend to dental hygiene, while non-motor symptoms such as apathy and depression may cause a person with Parkinson's to pay less attention to their daily dental health.

Making the most of a dentists' visit

It is important that people with Parkinson's visit their dentist every 6 to 12 months for a check-up. Here are some tips to make the most of a dentist visit:

- Book an early morning visit as the waiting times are likely to be shorter.
- If you are prone to troublesome dyskinesia (involuntary jerky movements) it will be easier if you time your visit for a period when your dyskinesia is minimal.
- If you take levodopa, take it 60 to 90 minutes before your appointment so your dentist visit coincides with the drug's peak response period.
- Make several brief visits to the dentist for any remedial work, rather than one long visit.
- Tell your dentist about all the medications you take, including over-the-counter medicines, vitamins and herbal supplements.
- You may find it difficult to hold your mouth open for long periods and to control your tongue movements and swallowing. Your dentist has special devices that can help.

(Source: Parkinson's NZ)

BrainTree Wellness Centre Update

It is a pleasure to be on board as the BrainTree Centre Manager. I have worked with a range of health conditions during my career and have come to BrainTree from the retirement village / aged care sector. I have a passion for wellbeing and a lot of experience in exercise and keeping people moving and removing the barriers that age or disability may present.



Nicki Brown
BrainTree Centre Manager

Update

I have already noted that interest is growing with respect to potential tenants and we are currently working on the furniture and fit-out stage. From my site visit I can report I was delighted with the size and space, not to mention the natural light and vistas we will have. It is a beautiful building. The roof is on, the windows and exterior cladding is being installed. The programme is well on track.

Fundraiser

Our current fundraising focus is 'honey for brain health'. We have partnered with Airborne Honey and if you purchase 4 packs of any of the range, a generous percentage will go to BrainTree. Please visit the BrainTree website where you can purchase directly from our online shop:
www.canterburybraincollective.org/honey-for-brain-health
These make great gifts. Spread the word to support BrainTree.



Roof shout at Braintree in October - Karla Gunby (Exec Manager), Ingrid Robertson (committee member) and Anne-Marie Kite (President)



BrainTree A wellness centre
for brain health

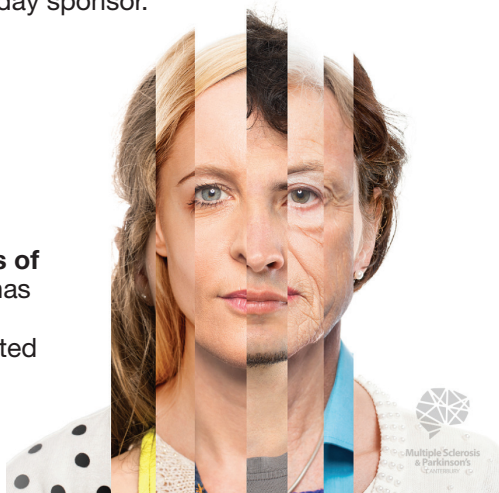
Fundraising Report 2021

It has been another challenging year for all of us, with the ongoing impact of Covid. However, you have shown us your support and enabled us to continue to offer our services to our MS and Parkinson's family in Canterbury. Thank you so much for your generosity.

Our major fundraising event of the year, our annual appeal on 3 and 4 September, had to be cancelled. We have now rescheduled a scaled down appeal on 18 and 19 February 2022 and we hope to regain some of the lost income. Could you volunteer as a site coordinator? If so, please get in touch.

We did manage to run two successful events this year, Bingo Babes in May, and our Charity Golf Day in October. Thanks to everyone who supported these two events, especially Isaac Construction, our golf day sponsor.

Our ongoing digital campaign (right), **Facts of MS and Parkinson's** has certainly increased awareness and generated some much-needed donations. Thank you.



We are incredibly grateful to have received grants from the following organisations:

- **Air Rescue Services**
- **Christchurch City Council**
- **COGS**
- **Community Trust Mid & South Canterbury**
- **Eva and Harold Wilson Charitable Trust**
- **James Maxwell Heron Charitable Trust**
- **Kiwi Gaming Foundation**
- **Lotteries General**
- **Manchester Unity**
- **NZ Community Trust**
- **Pub Charity**
- **Rata Foundation**
- **Rehabilitation Welfare Trust**
- **Roy Owen Dixey**
- **Selwyn District Council**
- **Southern Trust**
- **The Harcourts Foundation**
- **The Jones Foundation**
- **The Trust Ashburton**
- **Trusts Community Foundation**

Our newsletter production is generously supported by

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more than ink on paper.

Holiday office hours

Close on Friday 17 December – Open on Monday 10 January.
Classes and open gym will start back on Monday 10 January.



Multiple Sclerosis & Parkinson's CANTERBURY

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