



**Multiple Sclerosis
& Parkinson's**

CANTERBURY

strong connections



Winter has truly made an impressive start with frosty nights and some very wet days. The joy of living in Canterbury is that winter also bring us clear, crisp days with plenty of sunshine so make sure you make the most of those and get your Vitamin-D!

Anyone visiting us at BrainTree would have noticed the new walking track that is being created by Papanui Rotary Club in the area around our building. This is a great addition for anyone wanting to spend some time outside.

With additional classes, education sessions and speakers, we know our Wellness Centre can be very busy. Make sure you always park in the visitors carpark as the numbered parking spaces are reserved for tenants. If you have any problems finding parking, come talk to us and we will try our best to help you out.

We really enjoyed celebrating World MS day with some of you on the 30th of May



World MS Day from left: Kelly Roulston, Linda Dockrill, Lina Stroud and Leesa Loffhagen

Welcome to our newest Team Members

Tēnā koutou katoa MS and Parkinson's Canterbury whānau!

My name is Linda and I am the new Health and Wellbeing Advisor in the team.

I grew up in Timaru, where my Mum, brother and nephews still live, and moved to Christchurch to go to University in the 80's. I've also lived in the UK and in Southland but have lived here for most of my life now. I'm married to Dave Newey, who works for the Department of Conservation and we have three wonderful children - Ella (25), James (23) and Tom (20). Dave and I get so much pleasure from watching our tamariki morph into amazing adults. We also have one very naughty cat called Nico, who is constantly starving and hunts the bench tops when we aren't looking!



As a registered social worker, I have 30 years' experience working with people from all walks of life, ages and stages. I have worked in many roles over my career, however, the most relevant are my experience as a social worker at Christchurch Hospital and the seven years I spent as an Outreach Worker for the Haemophilia Foundation of NZ. My other roles have focused on children, their families and improving outcomes for them. In my personal life, I have been a La Leche League Leader (breastfeeding support) for 20 years so have a lot of experience volunteering as a peer supporter.

I was drawn to this role because I believe in viewing each person through a holistic lens, as a person with hopes and dreams, challenges and support needs. Each of us are part of a family and a community. My role here is to support you and your whānau on your journey with MS or Parkinsons. How I do this will look different for each of you. Some of you won't need much from me and others will need quite a lot, and this will ebb and flow. I hope that as we get to know each other you will feel comfortable to reach out and let me know how I can support you.

Health and wellbeing encompass all that makes up a person - our emotional, mental, spiritual and physical wellbeing. My role will involve connecting you with others, referring you or your family members to the right person or place, and providing you with the opportunity for a safe space to share your feelings and worries.

Tēnā koutou katoa MS and Parkinson's Canterbury whānau!

I look forward to meeting you!

Welcome to Amelia Davis our new Manager



It has been a very full 3 months since I started as Manager of MS & Parkinson's Canterbury - meeting the wonderful people we support and their whanau, getting to know the other tenants of BrainTree, and working with the MSPC staff and Board on the new Strategic Plan 2023 – 2026. MSPC is a small and (nearly) perfectly formed organisation, undertaking magnificent mahi - and it is a privilege to be leading the team.

The world of health and disability is not new to me as I previously worked at Hohepa Canterbury, an intellectual disability provider supporting 170 people in residential and day programmes, all based on the Steiner philosophy. Prior to this I have worked in the charity and education sectors including Community Law, Christchurch Art Festival, Christchurch City Council, and the University of Canterbury. I bring everything I have learned from these diverse settings to MSPC, and with the team, are set to deliver on the next three-year plan, including delving into digital pathways and a greater emphasis on health and wellbeing supports.

I am a Canterbury girl, having been educated at Girls' High, UC (post grad) and Lincoln University (bachelors and masters). I have mostly lived in Christchurch - ko Te Poho-o-Tamatea te matuaiwi e rū nei taku ngākau - the Port Hills are the hilly range that speaks to my heart, but I'm about to embark on a 10 acre West Melton adventure. Singing is a particular love and hobby and I have been part of Christchurch City Chorus for 14 years (come join us!). To complete my life I have one cat, two sons, three dogs and a very lovely partner.



Later this year we will be celebrating our 60th anniversary as an organization, and we are looking for any photos or memorabilia that you might have lying about as we want to create a photo board to share with the community.

If you have anything that you want to share then get in touch with Lina on 03-366 2857 or lina.stroud@ms-pd..org.nz

Health and Wellbeing Update

Health and Wellbeing encompasses all parts of a person - their physical, spiritual, mental and emotional wellbeing, as well as the wellbeing of their whānau. MSPC supports the hauora of a person through their multidisciplinary Health and Wellbeing Team.

Guided by the whakatoki - Me mahi tahi tātou mo te oranga o te katoa, we must work together for the wellbeing of all - our Team provides free assessments and supports for people with Multiple Sclerosis and/or Parkinson's, and their carers and whanau.

Our team consists of registered health professionals including a nurse, social worker and exercise physiologist and is complemented with a community engagement specialist, responsible for peer networks and social activities.

Many of you would have noticed that our health and wellbeing team have been evolving over the past few months to ensure we can support everyone more holistically.

Linda, our social worker, offers personalised supports through:

- One-to-one conversations with you and your family about your different support needs
- Connecting you with others who are going through the same experience
- Advocacy and referral to other community organisations or health supports
- Delivering research-based health and wellbeing education to the wider community, including on mental and emotional wellbeing topics

Amin, our exercise physiologist, offers personalised supports through:

- Providing functional and fitness assessments
- Developing home/gym based exercise programs tailored to the people we support – their needs, condition and aspirations
- Providing an accreditation program for exercise providers in the community to widen the reach
- Delivering research-based health and wellbeing education to the community

Jennifer, our nurse, offers personalised supports through:

- Building relationships to ensure that health complications are prevented or minimised
- Offering assessments to understand your history of diagnosis and medication, and assist you to understand the medical process, system and information you have been given
- Liaising with GPs and specialists and referral to other community-based services or allied health professionals
- Delivering research-based health and wellbeing education to the community, including on nutrition, fatigue and sleep topics.

The Community Engagement position is vacant, and we hope to have a new person in place by Spring. With sixteen peer support groups and a flourishing education and social activity program, it is a busy role! Social connection plays a pivotal role in health and wellbeing, and we are excited about welcoming a new member to our Health & Wellbeing Team.

A summary of our latest Keynote Speaker by Jess Brien

UNVEILING THE MYSTERIES OF MS: An update on MS research by Dr. Hamish Campbell

When asked what excites Dr. Hamish Campbell about the future of multiple sclerosis (MS) research, his eyes light up. "Remyelination," he explains. "That, to me, does seem a bit like magic." This was a hot topic of conversation throughout his recent presentation for MS & Parkinson's Canterbury keynote speaker series at BrainTree. Dr. Campbell believes that in the future, patients will take "a couple" of medications - one to stop the immune attack and one to help repair the myelin. However, it is important to note that this is not going to be a silver bullet and completely reverse long-term disability, and he was nervous to commit to a specific timeframe. "But I think it's going to have a big impact."

Read the full article here: <https://ms-pd.org.nz/unveiling-the-mysteries-of-ms/>

Watch on YouTube Channel: <https://m.youtube.com/@msparkinsonscanterbury8736>



Meet our newest spokesperson - Street performer, podcaster & writer

Meet our newest spokesperson - Street performer, podcaster & writer.

Jess Brien has been performing across New Zealand and internationally in a variety of festivals, circus tents, streets, and theatres with a comedy juggling show called Jess The Mess. However, it was in 2014, during her final year of drama school, that she was diagnosed with multiple sclerosis (MS), and after a health scare at the end of 2019, Jess was inspired to connect and share stories to spread awareness and hope.

This led to the creation of a weekly podcast That's So Chronic, where Jess interviews people from all around the world that are living with chronic illnesses, life changing injuries, and potentially disastrous diagnoses. Jess is also the new sparkling face at MS & Parkinson's Canterbury, where she helps with content creation, blogs and articles. She will be reporting on the 2023 MS conference in Milan this year and bringing her view of life with MS.

I'm @jesssbsrien (with four s's!) on socials everywhere, and @thatssochronic for the pod. You can find her on jessbrien.com or that's so chronic

**WE NEED
YOUR HELP**

**Our Annual Street Appeal is on the
1 - 2 September 2023**

We are looking for volunteering superstars to collect donations all over Canterbury.
If you are willing to help then please get in touch
by phone: 366 2857 or
email lina.stroud@ms-pd.org.nz

Can't keep up with all our new exercise classes?

Amin is busy trialing lots of new classes to see what our community is interested in so make sure you come down to try them out and let us know what you think.

We are planning a Yoga session to keep those limbs supple, call us to register your interest.



**Te Wiki Tūao ā-Motu
National Volunteer Week**

18-24 June 2023 | #NVW2023



National Volunteer Week

We have so many amazing volunteers helping out with different things in our organisation, it was a real treat to catch up with some of them to show our appreciation.

You are all amazing and you make the world a better place!!

Feel like you're missing out and want to volunteer with MSPC? Contact us to find out how you can help

Support Groups Update

Last week we said goodbye to Ty. She has been an important part of our team for the last year and we are very grateful for all the work she has done with setting up our support groups, speaker series and education sessions.

As part of this pilot project a report was written for the Board, clearly demonstrating both the real need people have for social connection, and the inroad Ty has made in making this happen for the people we support.

Peer support groups flourished under Ty's guidance multiplying eightfold from 2 to 16 groups. Keynote speaker and education sessions were also coordinated by Ty, and we heard about all manner of topics – from brain imaging to depression.

Not only did over 400 people attend these sessions but the speaker series have been viewed over 1300 times online.

Ka pai Ty, you are amazing and you have made a fantastic contribution to our community and your skill of whiria te tāngata – weaving the people together – will be missed.



New support groups: Parkinson's Coffee Group is looking for new participants. The group meets every 2nd Thursday of the month with volunteer; David Grant from 11am-noon at Oderings Barrington. Please give us a ring at 366-2857 to register.

A Multiple Sclerosis and Parkinson's **Ashburton walking group** has started for anyone keen who is involved in our organisation. The group meets every Wednesday at 10:30am at Argyle Park on Middle Rd. All are welcome so feel free to bring someone along and please go at your own pace. The path is all accessible.



Staying physically and mentally well can be hard during winter – so put yourself first

I've always loved the winter months – that snap of crispness in the air, the soft drizzly rain, the excuse to stay inside with my stack of books. Although it can be dispiriting getting up in the dark and no one likes being cold, I think there are lots of compensations.

But winter can be a tricky time to stay well. There are ills and chills about, it's depressingly grey and it's easy to let things like a healthy diet and outdoor exercise slip. Even more importantly, winter can be a time when your mental state dips, with the dark and cold leaving you less cheerful and less motivated. So how can you tackle the winter blues?

By eating Well, move your body, sleep tight, boost your immune system, ward off sadness, yoga, and meditation...

Read the full article In Good magazine online <https://goodmagazine.co.nz/winter-wellness-2/>



Adventures to try



Mastering Mountains wants to see people with Multiple Sclerosis and Functional Neurological Disorder experience hope, connection and positive, life-long change through self-directed outdoor adventure.

For many living with these neurological disorders, a life of adventure in the outdoors can feel far from reach. That's why Mastering Mountains assists everyday people to overcome these challenges by helping them achieve their adventure dreams and connect with community, thereby inspiring hope in others.

Mastering Mountains offers grants to people diagnosed with Multiple Sclerosis (MS) or Functional Neurological Disorder (FND) to help them overcome a specific obstacle so they can accomplish a self-directed objective in New Zealand's outdoors. Learn more here <https://www.masteringmountains.org.nz/grants>

Outward Bound Adapted Course

Over the past year, the number of adapted courses run at Outward Bound has doubled and we have welcomed students with disabilities onto 12 courses. We've had courses for rangatahi and adults with intellectual and physical disabilities and adults with early-onset Parkinsons.

Our students have shared adventures together, challenged themselves, and supported each other in their personal journeys to greater confidence, resilience and connection.

Enrolments are now open for courses from November 2023 through to May 2024. If you know someone who might benefit from an Outward Bound adapted course, please get in touch. Many of our adapted courses are fully or partially funded. Go to www.outwardbound.co.nz/adapted for more information.

Research Opportunities

Share your story

Participate in phase two of the Placing unheard voices project

Were you diagnosed with Parkinson's disease aged 50 or below?

Are you willing to share your experiences of life with Parkinson's?

✓ If you answered "yes" to both questions above, please email Tara at:

placingunheardvoices@outlook.com

✓ Your participation in this research will be confidential

✓ You will receive a \$30 voucher as thanks for your time



Placing unheard voices is a research programme exploring the lived experience and geography of young onset Parkinson's disease. Phase two of the project is about life with Parkinson's at home, at work, and in the community. I want to know what kind of places are enabling or disabling for you.

You can participate in phase two of the project even if you have not participated in phase one.

To participate in phase two of the research you will be asked to answer 15 questions. You can answer one question per day over 15 days by filling out a word document, or you can take part in an interview if you prefer. Each question will take approximately 5 minutes to answer. 75 minutes in total.

Who am I? My name is Tara, I'm a researcher at the University of Auckland and I live with Parkinson's.

Who is funding this research? The research is funded by the Marsden fund. The Marsden fund provides support for research projects deemed of the highest standard in science, engineering, maths, social sciences and the humanities in NZ.

Approved by the Auckland Health Research Ethics Committee Ref number AH24148

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

Do you or your spouse have Parkinson's disease? Do you suffer from constipation?

Would you like more information to help manage this symptom?

Are you interested in trying a Complementary therapy?

This is the last chance to take part in this study

This study will run over 6 weeks and will require participants to complete pre and post questionnaires, and a diary. Information will be provided through email or post with phone support.

I am a Registered nurse conducting this research project to complete my Master of Health Research at Victoria University of Wellington. If you are interested in participating in this research, please contact:

Bronnie Alexander on 027 2766643 or alexanbron@myvu.ac.nz

Oceans of Hope

Remember our article about Oceans of Hope in our last newsletter?

Ingrid Robertson who is on our Board of Trustees, is also an avid sailor and organises the Oceans of Hope Challenges in Oceania. Ingrid loves sailing and went to Greece in May to take part in the Athens Flotilla. You can read more about her story and watch a short video about Oceans of Hope in our blog <https://ms-pd.org.nz/oceans-of-hope-2/>



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There is lots of information on our website.
You can book your exercise classes, find the exercise timetable, find more information about our peer support groups, and any upcoming events.

If you like being social you can find us on Facebook, Instagram, Youtube, and LinkedIn Please connect with us if you can!

We are at: Braintree Wellness Centre
70 Langdons Road, Papanui Christchurch 8053
Phone: 03-366 2857
Email: support@ms-pd.org.nz
www.ms-pd.org.nz

Donations

As you all know your support is vital to ensure we can continue to provide and expand our support. There are a few ways that you can donate.

On our website: www.ms-pd.org.nz

Through your bank or online banking:
Name of account: Multiple Sclerosis and Parkinson's Canterbury Charitable Trust
Account Number: 02 1257 0062965 000
Reference: your name

By cash or EFTPOS at our office at 70 Langdons Road, or over the phone using a credit or debit card Ph 03 366 2857.



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