

NEWSLETTER JULY 2020



Credit: MSPC

Manager's Message

Robin Furley

Winter sunshine is the best isn't it? After the rain, the sun makes everything better, and even though the ground may be cold and wet, we can still bask a little in the sun.

Our last newsletter came out immediately after we came out of lockdown. It is great to know that as a country we have achieved the goal of beating the virus as best we can, while as an organisation we are now well prepared with a good health and safety plan, heaps of hand sanitiser, masks, and antibacterial wipes in the gym. We continue to hope that these won't have to be used again, at least in the near future.

Thank you to all 101 of you who contributed to our post lockdown survey. Your comments gave us a wide range of responses that have been very interesting. Here is a selection:

- How was lockdown for you?
"Lockdown was very easy for us" and "enjoyed not having to be anywhere" to "not good, lots of stress on my brain", "lonely, I was completely isolated" and "It was tough for the carer 24 hours a day for three months."

- Did we communicate with you and support you during this time? *"The weekly phone calls were very good value, a form of reinforcement" and "I was so pleased to get exercises from Anna King. Overall the support from you guys was good." "No communication" and "no contact, no support, it would have been nice just to know someone cared".*
- How are you getting on now? *"Getting on fine in general." "The MS and Parkinson's people are marvelous in their communication. We appreciate everything we receive from them whether in phone calls or emails." "I am slowly getting back to normal but having to try and have more down time to combat the fatigue."*

I would like to remind everyone that if you need help or support, you will need to contact us directly. I came across this from the June 1996 newsletter.

"Please remember that we need you to let us know if we can help you in any way. We now have 600 members and are no longer able to just sit down and phone everyone. Just as you ring your General Practitioner when you need him/her, we want you to use us in the same way. Please do let us know if you need us, we are only a phone call away."

Now, in July 2020, the same message is true, except that we have nearly 800 members. During Lockdown we did our best to contact members who are actively engaged with us – that is those members who attend any of the exercise classes as well as the morning teas run by Lesley in the community. If you feel that we could have done more to help you, please get in contact with us by phoning (03) 366 2857 or emailing manager@mspd.org.nz and we will see how we can best support you.

PRESIDENT'S MESSAGE

Tessa Kain
president@ms-pd.org.nz

As promised in the last newsletter, I am pleased to report progress on the BrainTree project.

It was wonderful to hear that so many of you were able to attend the Canterbury Brain Collective (CBC)'s presentation updating us on the building project. The response was hugely encouraging with attendees expressing enthusiasm and excitement for the building project and a positive outlook for our society's future.

The initial concept plans have been agreed and the building team continues to work with the architect, David Hill towards the final concept stage. Once that stage is completed, the consent process should be underway.

We are so fortunate to have this amazing space to look forward to, thanks to our many supporters.

Visit www.canterburybraincollective.org to join the campaign and keep up to date on progress.



I'm sad to report that we have accepted Lynne Trowbridge's resignation. In Lynne's 5 years of exemplary service, her diligence and professionalism have ensured we have had achieved the maximum benefits from our supporters, be they trusts and foundations or individual donors. On behalf of the committee, thank you Lynne.

One of Lynne's many contributions to the society has been the evolution of the Street Appeal. Her formula for this, our biggest fundraiser of the calendar, is tried and tested. The 2020 appeal will have its own challenges with fewer sites being available to collectors. This is a downward trend which we are working to counter by developing new strategies for collecting, for example, using QR codes for contactless donations.

If you're unable to collect on the street, you could always have a collection within your social circle, as part of our virtual street appeal. We average around \$100 per hour, per site, so if you were able to get even close to that total, you'd be well on your way to making a huge difference to the appeal. Many a mickle makes a muckle, as they say in Scotland!

As you read this, our AGM will have taken place and the new committee will be at work. If you have any ideas, comments, wants or needs for the next twelve months, please don't hesitate to contact us, we are here to help.

FROM THE FUNDRAISING OFFICE

Street Appeal 4th and 5th September

Our Annual Street Appeal is coming up on Friday 4th and Saturday 5th September, and we are looking for volunteers to help us collect. Our Street Appeal is still our biggest fundraising event of the year and we need your help to make it a success. We realise that some of you may feel more cautious about collecting for this year's appeal, but please be assured we will be following any health guidelines that are in place at the time.

We still have numerous sites available, including some that are new this year. We make every effort to provide everyone with a site that suits them best. However, some sites are more popular than others so act quickly to secure your desired location.

We really appreciate the help we get from members and we also know that many of you are not able to assist for a variety of reasons. Perhaps someone you know will be able to help us by volunteering this year. Maybe a family member, friend or work colleague who could volunteer just 2 hours of their time.

Please fill out one of our volunteer response forms and return to us. If you receive your newsletter through the post, you will have a form that came with it. If not, then you can get a form from the Fundraising Office, either through the post, by email or in person. If you would like more information, have an idea to share, or would like to discuss volunteering for the Appeal, please the Fundraising Office on (03) 366 2857 ext 8 or ext 9, or email events@ms-pd.org.nz.

We would love to add to our pool of site coordinators. A site coordinator:

- takes responsibility for one or more sites for 1 or 2 of the appeal days.
- they find and organise the volunteers to fill the slots for the day.

We provide any help required including helping to fill some slots if they are struggling to get enough people. If you are interested and have the time to commit, please contact us (as above) we would love to hear from you.

Golf Tournament Friday 6th November 2020

Our annual Charity Golf Tournament is approaching swiftly. We are pleased to confirm that we are hosting this popular event at Clearwater Golf Course at the Peppers Clearwater Resort once again.



The tournament offers a great chance to unwind with a bit of friendly competition. It could even be a team building event to round out the year. Not only do you get a chance to win a prize if you're one of the top three teams on the day, but we will also have a meal and drinks afterwards, with a raffle up for grabs and some great items in our mini auction.

If it's not your particular cup of tea, then perhaps you know a golf enthusiast who would love to get a team together. Or maybe you know someone who would be in a position to donate a prize, auction item or catering. All our sponsors are displayed and thanked in our promotional material before and after the event. All in all, our Annual Golf Tournament is a great day to be a part of, and one of our backbone events.

If you'd like to know more, please contact the Fundraising Office on events@ms-pd.org.nz or (03) 366 2857 ext 8 or 9.

BEQUESTS - A LASTING LEGACY

“It's not how much we give but how much love we put into giving.”

– Mother Theresa (1910 - 1997)

Leaving a bequest in your Will can make a tangible difference long after your own lifetime, helping to ensure that we continue to provide essential and up to date services to members.

A bequest is a gift made through your Will, an opportunity to make a lasting difference. It offers flexibility – you retain use of your assets and can make changes at any time to reflect your philanthropic and financial goals. A bequest can be put into a new Will or added to your existing Will. It can also be for a set amount or a percentage of your estate.

If you are considering a bequest and would like to discuss options with us, please contact the Fundraising Office on 366 2857 ext 8 (all enquiries will be treated confidentially).

We recommend that you seek legal advice from your solicitor when adding a bequest to your Will.

THANKS TO OUR SUPPORTERS

Christchurch
City Council 

COGS
Community Organisation
Grants Scheme

CERT
*Your local Gaming Trust
committed to 100% local funding.*

Lachmaben Trust

 Lottery Grants Board
Te Puna Tahua
LOTTO FUNDS FOR YOUR COMMUNITY

Jones
Foundation

 MAINLAND
FOUNDATION

**MAURICE CARTER
CHARITABLE
TRUST**

NZCT
NZ COMMUNITY TRUST

Rehabilitation
Welfare Trust

**Pub
Charity** 
Limited

 the
Southern
trust

 **Rātā
Foundation**

 **WELFARE TRUST BOARD**
To Assist The Elderly In Christchurch & Canterbury

THE AGM

MSPC held our AGM on Monday 27th July. It was great to welcome members along to hear an overview of the 2019 – 2020 financial year from Tessa Kain (President), Ann Morrison (Treasurer) and Robin Furley (Manager).

Tessa outlined that one of her key goals from July 2019 had been working with the Canterbury Brain Collective (CBC) to advance the BrainTree project; our new building in Langdons Road. Since then we have made great progress. More than 80 of our members attended a presentation about BrainTree a couple of weeks ago and came away inspired and enthusiastic about a positive future for our organisation. The land on Langdons Rd has been secured and the initial concept plans approved. These are available at our office for people to view. They're up in the gym if you would like to take a look. CBC has already raised \$4 million through grants and private donations and is now preparing for the final campaign to raise a further \$2.3 million.

We also presented our Annual Report. The Annual Report includes financial and non-financial information. Our Statement of Service Performance provides an overview of our outcomes, outputs. It explains what we do and why we do it. The Annual Report is available to any member. If you wish to take a look, it is available on our website or in the office.

Last year we had 20 new referrals for Multiple Sclerosis and 78 new referrals for Parkinson's. We held 39 Morning Teas over the year, with 496 attendances. This clearly shows how vital and well received these meetings are, with Lesley also picking up relevant information to pass back to the nurses (with the members' agreement).

We ran a survey in February, which showed that most people's experiences of our services are 'excellent or very satisfactory' – 75% approval or above in all cases.

"Whenever I have had a query the assistance has been wonderful."

"You provide an excellent service to people and are well thought of among members of the community."

"Excellent friendly staff."



A significant event of the AGM was awarding a Life Membership to committee member, Lindsay Daniel for his valued contributions to the work of the organisation. Lindsay was honoured for his work on our committee, standardising and restructuring our policies and protocols, ensuring that the committee's time is used efficiently and effectively. He has been instrumental in giving the organisation a solid basis in our governance documentation, allowing MSPC to continue to deliver quality services to our members. He has also been a strong representative for people with Parkinson's, both within MSPC and at times nationally. Congratulations, Lindsay, and thank you for your time and service.

We also wish to acknowledge two other historical Life Members, whose photos will join the others in our Life Member gallery.

Noeline McIlroy was a dedicated supporter and member since the 1960s. Noeline was known as a generous Canterbury philanthropist with a keen interest in organisations working in the disability sector. She died on her 93rd birthday in 2010.

Keith McArtney lived with MS for 48 years. He was a committee member for many years and was an inaugural member of the MS and Parkinson's Canterbury Foundation. Keith was made a Life Member in 2003 and died at 83 in 2010.

Thank you to everyone who came to the AGM and thank you to all of our volunteers and supporters who have backed us through the year.

ANXIETY AFTER LOCKDOWN

As responses to our survey came in, we began to understand how Lockdown felt for you. People have said that Lockdown was lonely due to the change in support, and isolating due to restriction of movement and the lack of ability to get out of the house. It may have had an effect on your general mental health, making you feel unsettled or anxious.

It can be helpful to recognise that most people will have been affected by Lockdown and the fear that came with Covid-19. Although it can seem strange to think of it as such, the Lockdown has been a traumatic event, and we can expect that it's after-effects will linger on, even as we get back to 'normal' routine.

People who were in Christchurch for the earthquakes of 2010-11 can expect to have feelings similar to those they had back then. Elaine Miller-Karas of the Trauma Resource Institute in the US describes trauma as "simply too much or too little for too long", and two to three months is a long time to deal with restrictions and confinements for anyone.

As reported by the World Economic Forum,

"... people who are quarantined are very likely to develop a wide range of symptoms of psychological stress and disorder, including low mood, insomnia, stress, anxiety, anger, irritability, emotional exhaustion, depression and post-traumatic stress symptoms. Low mood and irritability specifically stand out as being very common..."

The same article notes that going back to work and the 'normal' world can feel just as fraught as the Lockdown itself, with those re-entering the work force feeling the burden of restarting the economy, while also balancing fears about the virus itself and its transmission.



Credit: Canva

It is important that we acknowledge that what we have collectively been through has been traumatic. It's not dramatic to think that! For our members, it could be even more stressful. Some of us are in the 'vulnerable' category, and it is understandable that this whole experience has been more than a little troubling.

The main takeaway from all of this is to be kind. Not just to others around you and in the community, but also to yourself. If you are feeling unsettled, anxious or just feel like you need some extra help, please do not hesitate to reach out, either to MSPC, your GP, or maybe a trusted friend or family member. There is no weakness in needing some help.

Some quick tricks for easing anxious periods:

- Three deep breaths when you are feeling tense or upset can help to settle your mind and body. The body thinks it is in danger, which is why you may feel your heart racing, or as though your body is getting ready to run away. Taking three deep breaths helps to tell your mind and body that you are not in danger, and that they can settle down.
- Mindfulness is enormously helpful when you can feel your anxiety rising. A simple way to start with mindfulness is with a countdown: 5 things you can see, 4 things you can feel, 3 things you can hear, 2 things you can smell, 1 thing you can taste. This simple countdown interrupts those thought patterns that can lead into a period of anxiety and bring your focus back to the present.
- Remember to H-A-L-T. Examine what you're feeling. Are you Hungry, Angry, Lonely or Tired? This kind of introspection helps us to recognise what we are feeling and address it in a healthy way. Maybe it could also be a reminder to reach out and talk to someone about what is worrying you.

Some resources to help.

- <https://www.mentalhealth.org.nz/get-help>
- <https://www.allright.org.nz/>
- <https://mindfulnesseducation.nz/>

Sources:

Dr Elke Van Hoof, World Economic Forum,
<https://www.weforum.org/agenda/2020/04/this-is-the-psychological-side-of-the-covid-19-pandemic-that-were-ignoring/>

Bryan Robinson, Forbes,
<https://www.forbes.com/sites/bryanrobinson/2020/05/01/how-to-recover-from-psychological-aftershocks-of-lockdown-during-mental-health-awareness-month/#341979e25470>

MEDICAL APPS

A great way to make sure that you are protecting yourself in case of a medical emergency, is to make sure you have a medical ID set up on your phone. It can feel scary to think about, but having easy access to the kind of information that you can store on these apps can be incredibly useful.

They work by allowing you to update information on the app privately, but then having the ID accessible through the emergency call function of your phone, even when it's locked.

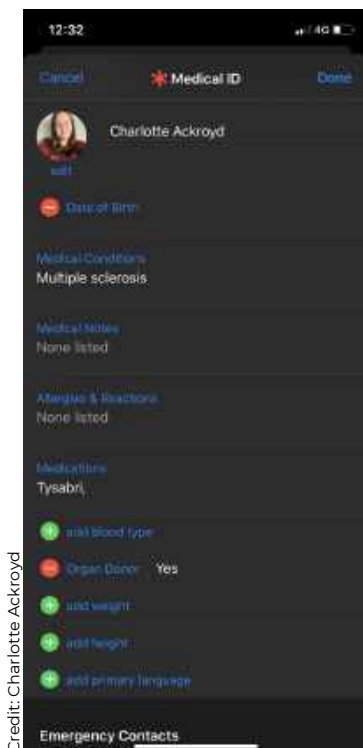
If you have an Apple or an Android phone, this is pretty easy to do. For Apple, there is a built in Medical ID part of your phone that you can update at any time. All you have to do is go to Settings > Health (it's a little way down the list!) > Medical ID.

From there, you can update your ID with whatever information you may want. There's a place to put your Date of Birth, what conditions you might have (i.e. Multiple Sclerosis or Parkinson's), any allergies you have, and what medications you take. You can also put your blood type (if you know it) and whether or not you're an Organ Donor. It also gives you a place to put your emergency contact. I have chosen to add a photo too, just in case someone would need to connect me to my phone.

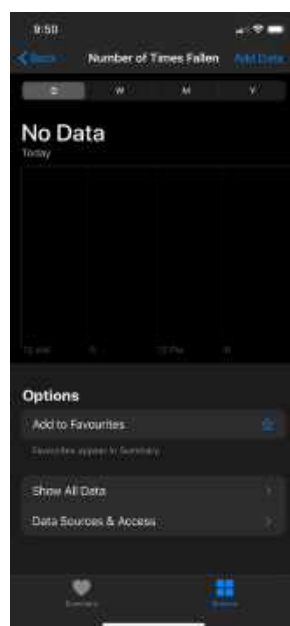
If you don't have Apple, you can still get the Medical ID app. If you have an Android phone, you can go into Google Play and download Medical ID ICE App. Just make sure you download the free one! The steps for updating that app are much the same as the Apple version, as you can add as much or as little information as you need or want.

Apple also has a very handy part of their Health app, which can record when and where you had a fall. If you go to the Health app – its icon is a pink heart on a white square – go to Browse and then to Other Data, there is an option to record Falls Data under "Number of Times Fallen". It lets you put the date and time of the fall and any other notes you want about the fall. There you can "Add to Favourites" so that it will appear on the first page of the Health app, making it easier to get to. I've tried to find a similar app for Android/Google phones, but unfortunately there doesn't seem to be an equivalent in the Google Play Store.

These apps are a quick and easy way to get information to anyone who might be helping you in an emergency, and very useful even as a way to record your medications and information if you're prone to forgetting. If you're having any issues downloading or editing these apps, you can always find help with the salespeople in mobile phone store of your network (2Degrees, Spark, Vodafone etc.), or maybe younger family members!



Credit: Charlotte Ackroyd



UNSUNG HEROES

MSPC would like to acknowledge the amazing work of those who care for our members, whether professionally or within their family/whanau. We know, from information received from our member survey in June, that the Lockdown period was exceedingly hard on those carers who look after their family members.

During Lockdown, agency carers were largely stopped. MSPC was aware of this, and we were advocating for our members who rely on agency carers not only for the essential services, but also for 'simple' things like cleaning, changing sheets and washing up. We were doing our best to get help back to our members, but we also know that some people did feel let down, and it was especially hard on those who needed 24-hour care and their family carers.

We want to remind our members that we are here for you, and also for your support networks. We have our monthly Spouses Group for the spouses and partners of those with Parkinson's. Our nurses are also here to help you. Their goal is to make sure that our members can stay in their homes for as long as possible, as safely as possible. If you feel that you need more support, our nurses can make the necessary referrals, to make sure that carers and members alike are having their needs met.



Credit: Josh Appel @Unsplash

Carers.net.nz is also a wonderful website and organisation, giving a voice to carers and offering some great resources. They offer Carer Meetups and have so many tools to help make life a little easier for you and your support network.

One of the biggest things when you're a carer, especially when you are caring for a family member, is to ensure you make time for yourself. Below is included a link to the Take 1, Take 5 Planner, to encourage carers to make time in their day for something that they enjoy or will benefit them. Carers NZ also has a great pamphlet about Respite, not just indicating the care facilities where people can go to give themselves and their carers a break, but also regarding things that can be done at home during the regular day.

There is no doubt that carers are the unsung heroes not just of our community but of the entire country.

Resources:

Carers NZ – <http://carers.net.nz>

Take 1, Take 5 Planner -
http://carers.net.nz/wp-content/uploads/2014/06/Weekly_Respite_Planner_Carers_NZ.pdf

Credit: National Cancer Institute @Unsplash



MARIE GRAHAM

Our manager, Robin, sat down with embroidery enthusiast, Marie Graham. They talked about her love of embroidery and how it affects her Parkinson's.

Marie was introduced to embroidery as a child. "I did knitting, sewing and crochet from very early years. My mother taught my sister and me to knit and sew and our grandmother taught me to crochet. We did mostly more practical dressmaking type skills. In the family I was considered a bit of an oddball because I did all this fancy work. I've always been involved in creating something, crafts of some sort."

She is a committee member of the Canterbury Embroidery Guild, which has 120 members and has six or seven sessions a week. Different aspects of embroidery are shared at the Guild, and Marie also gets ideas and inspiration from many books and magazines she has collected over the years. Some of Marie's work is very fine and she uses high magnification glasses for it. Marie's colours, needles, threads and designs come from a variety of different places.



Credit: Robin Furley

"I like doing the very fine work. There are so many different sorts and styles of embroidery. There are fashions in colour, but people have their own colours that they stick to a lot. The pieces I've done using variegated threads lift the whole design somehow."

She formerly owned a craft shop on the West Coast, where she taught beginners embroidery. She still has pieces that were started years ago and are waiting to be completed. "The danger is that I start something and then get distracted by another piece I want to do."

Marie has a sewing room in her home, where she says, "I've got far too much fabric. My excuse is, I thought I would be like my mother who is 99 and still going strong and still stitching, whereas my Parkinson's is catching up on me fast. I think embroidery helps with Parkinson's because every time I start something new, I've got to learn about it, work out the stitches, work out how I'm going to do it and how I'm going to finish it. It's all good brain work." It seems that the mental working out how to do something as well as the physical needlework is good for Parkinson's.



LOVELY HONEY



Credit: MSPC

A great way to support MSPC is to buy a jar of honey. Our honey comes from Lovely Honey, a local Christchurch business, sourced from bees in the Southern Alps. We have the honey available at our 49 Sir William Pickering Drive headquarters and with Lesley at morning teas for \$12 a jar. The honeydew honey is fantastic and can be used in a myriad of ways.

- As a sugar or syrup substitute in baking or for breakfast.
- To make honey soy marinade for stir fries.
- For honey mustard dressing or sauce.
- Mixed with balsamic vinegar and extra virgin olive oil to make a quick and easy salad dressing.
- Mixed in with oats and milk (or milk substitute) to make overnight oats. Add a scoop of natural or Greek yogurt to make it extra creamy!
- As a glaze for vegetables. Great with root veg or Brussels sprouts.

We're also lucky enough to have some new products available. We have two new honey flavours, creamed honey and Kamahi honey. We also have a new product, a yummy blackcurrant cordial. All three of the new products are the same price, \$12 each. Well worth a try if you're looking for something new! If you would like one of these new products, let us know and we will order them for you.

If that's what your appetite, here is a great recipe with quick prep to use your honey in.

One-Pot Honey and Lemon Chicken

Ingredients

- 3 lemons
- 50g butter or margarine
- 3 tbsp Lovely Honey
- Leaves from 4 rosemary sprigs or 2 tsp dried rosemary
- 1 garlic clove, finely chopped or from paste
- 8 chicken pieces, such as thighs and drumsticks with skin
- 750g potatoes, peeled and cut into small chunks



Credit: BBC Good Food

1. Preheat oven to 200c/180c Fan.
2. Squeeze the juice from 2 of the lemons into a small pan and heat with the butter, honey, rosemary, garlic and salt and pepper to your taste. Heat until the butter is melted and it's easy to mix together. Don't overheat or boil.
3. Put the chicken spaced evenly in a large roasting tin; piling the chicken up will mean it doesn't cook evenly.
4. Add the potatoes around the chicken, then coat evenly and generously with the lemon honey sauce.
5. Cut the third lemon up into wedges and tuck it in around the chicken, if you want a really lemony flavour.
6. Roast for 50 minutes – 1 hour, or until the chicken is cooked (depending on your oven) and the potatoes are crisp and golden.
7. Serve with your favourite side dish – winter veg, a nice green salad or even couscous.

NOTICES

Liftware

MSPC have two sets of Liftware to give away to someone who needs it. They were generously donated by a member's family once they were no longer needed in order to benefit someone else. Liftware is a type of cutlery designed to level out and stabilise itself. It was made to aid those with hand tremors or limited mobility. If you think it could help you, contact Charlotte (03)366 2857 ext. 9 or frassistant@ms-pd.org.nz. As we only have two sets, it will be first come, first served.

Junk Mail and Facebook Notifications

We are aware that many of our emails are not getting through to our members. Please check your Junk Mail and set us as a safe contact so that our messages go to your main Inbox. In a similar vein, we are aware that the posts we make on Facebook aren't reaching our followers. If you don't follow us yet, please do! If you do, please go to our page and hover over the 'Following' tab. It will give you the option to turn notifications on. This will mean you will get a reminder every time we post to Facebook, ensuring you don't miss a thing!

Entertainment Book

Get your new Entertainment Membership today to support MS & Parkinsons Society Canterbury and receive this year's exclusive offers. Entertainment Memberships can start anytime and contain thousands of offers for dining, travel and fun family activities! Get some great discounts and offers, while also supporting local business as they get back on their feet. Purchase today: www.entertainmentbook.co.nz/orderbooks/13x4351

Scholarships and Awards

There are several scholarships and awards available to people with Multiple Sclerosis for a variety of purposes. All guidelines and application forms available on the MSNZ website under "Scholarships, Grants and Awards".

- Dorothy L Newman Scholarship - contributes towards course costs for retraining after a diagnosis of MS. Open 1st September – 31st October.
- Mastering Mountains Grants – contributes towards therapeutic outdoor activities (run by Mastering Mountains in conjunction with MSNZ). Open 1st September – 31st October.
- Esme Tombleson Awards – "MS Person of the Year" and "Caregiver of the Year". Deadline 30th September.

Lovely Honey

We are pleased to say that our stocks of Lovely Honey are filled again!

We have Honeydew Honey and Blackcurrant Honey available for \$12 a jar. It's available from the office at our 49 Sir William Pickering Drive headquarters or from Lesley at her Morning Teas.

We also have new products available to pre-order.

Clinics with Anna Fraser

Our Parkinson's Nurse, Anna Fraser, is still having clinic appointments on a Wednesday. There are three times, 10am, 12pm or 2pm and they're all held at our headquarters at 49 Sir William Pickering Drive.

There are times when it can be more convenient to have an appointment in a quiet, private setting, rather than a home visit. Just make an appointment with our office on (03) 366 2857 ext. 6.



Working out in the Open Gym, June 2020



Parkinson's Power: The first class back after Lockdown, May 2020



The crowd at the Braintree presentation, July 2020



The AGM, July 2020

Our Contact Details

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