InTouch Newsletter

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Bob McDonald steps down from leading the Bega Valley Support Group

Growing up in the Mallee country of South Australia as one of eight children gave Bob McDonald, now 77, early lessons in hard work and resilience.

Bob, who has recently stepped down after 12 and a half years as President of the Bega Valley Parkinson's Support Group, recalled how he left school at 15 after overhearing his parents discussing financial worries.

"I went out the next day and got myself a job at the bank," says Bob. "You should have seen their faces when I told them. I had a lot of good years working for the Bank of Adelaide."

Bob also had a very keen interest in sport and was a talented footballer who played for the South Australian Football League for two decades. Golf, tennis, and marathon running were added to his sporting interests when he moved to interstate and then to the South Coast for his banking career.

"I've run seven marathons in Sydney, Adelaide and Canberra, but when I was training for the Melbourne marathon, I noticed my right leg was getting very tired and after 15 to 20 kilometres I was tripping over," he recalls.

"And then when I was doing a presentation at the golf club, I noticed that my right hand was shaking, and my handwriting wasn't legible. I went to my GP and had an MRI done and that was when I got my diagnosis.

"I decided then that I wasn't going to let it beat me. I was very fit and determined to keep exercising and doing whatever I could. If I couldn't run, I could do long walks. It was 26 years ago and here I am.

"But back then I didn't know anyone else with it. By 2008 I was starting to feel a little bit isolated in dealing with it, but there were no support groups around this area. So, I decided to do something about it."

Bob contacted Parkinson's NSW for some assistance and together with two others, Sue Nelson and Naomi Lewis, the Bega Valley Parkinson's Support Group was founded.

"We had about 18 people at our first meeting and I was elected President," says Bob. "As the group developed, we had a range of speakers and we had educational sessions including a specialist neurologist who had Parkinson's himself giving a talk.

"We also arranged a lot of activities including lunch events as sometimes people living with Parkinson's don't get out very much. There can be 40 people laughing and

having fun at some lunches and some have been amazed because they didn't think they could go out and enjoy themselves.

"It's great to see everyone with a smile on their face. People come out of their shell."

But it's not just people living with Parkinson's who benefit from the Parkinson's support groups run by volunteers like Bob McDonald. "It's also important for carers to be able to get out and talk with others who have similar experiences."

The Bega Valley Support group now has around 50 participants and will continue under a joint Presidency.

"I've met a lot of people and made good friends over the years," says Bob. "It was also a learning experience for me. I've learned so much as well."

Community Heroes program continues to generate publicity

The Parkinson's Community Heroes program launched in April (Parkinson's Awareness Month) continues to pay off in publicity and raised community awareness for the 18 Support Groups which participated.

The program allowed Support Groups to name heroes who had assisted them in their local communities.

Nominations included local politicians, clubs providing meeting venues, Allied Health professionals and leaders of art, exercise, and other activities and organisations beneficial for people living with Parkinson's.

Study shows COVID-19 vaccines are safe for people living with Parkinson's

A study authored by a group of Parkinson's experts – including neurologist Professor Bastiaan 'Bas' Bloem who has a global reputation – says COVID-19 vaccination with approved vaccines should be recommended for people living with Parkinson's (unless there is a specific contraindication).

Based on the interpretation of the scientific literature by the study's authors:

- Compared to the general population, the risk of COVID-19 infection causing serious, life-threatening disease seems higher for people living with Parkinson's – at least among those with more advanced disease.

- The approved mRNA-based vaccines and viral vector vaccines under development are not known or expected to interact with the neurodegenerative process in Parkinson's.
- The types or incidence of side effects of these vaccines in people living with Parkinson's seem no different than in the general population.
- The vaccines also seem safe for older adults. However, caution is needed with very frail and terminally ill elderly people living with Parkinson's in long-term care facilities.
- COVID-19 vaccination is not known to interfere with the current therapies of Parkinson's.

The authors strongly encourage visiting the website of the International Parkinson and Movement Disorder Society where recommendations will be updated as new data are published. Find recommendations for patients here.

Source:
COVID-19 Vaccination for Persons with Parkinson's Disease: Light at the End of the Tunnel? by Bastiaan R. Bloem, MD, PhD, Claudia Trenkwalder, MD, Alvaro Sanchez-Ferro, MD, Lorraine V. Kalia, MD, PhD, Roy Alcalay, MD, Han-Lin Chiang, MD, Un Jung Kang, MD, Christopher Goetz, MD, Patrik Brundin, MD, PhD, and Stella M. Papa, MD. Published online in the *Journal of Parkinson's Disease*, ahead of the publication of Volume 11, Issue 1 (February 2021) by IOS Press.

Exercises to improve gait

Parkinson's causes changes in walking. This occurs due to the nervous system not being able to send the messages correctly to the muscles – not the muscles themselves.

Therefore, to improve your walking you must give your body stimulus to activate the nerve pathways. This can be done by doing complex activities and exercises such as those mentioned below.

These will be a great add-on to your regular exercise which will work excellently in conjunction with your other therapies such as physiotherapy, speech therapy, nutrition, and pharmaceutical routines. However, be mindful that your body will only change according to the amount you challenge it.

Improving muscle strength or muscle flexibility will not change a movement pattern. The brain signal also needs be changed.

To improve someone's balance we must take them out of balance. Being out of balance (unstable) comes with risks.

It's not easy or quick and is mentally as well as physically challenging. These activities are some movements that the brain needs to reprogram new patterns, switching on more nerves that will improve how the body moves.

The Squat

Builds functional strength in the legs and no matter what level you are at, there is a way you can perform this exercise.

You can hold onto a walking frame or poles. Commence from a seated position using you frame or sticks to assist with the squat up movement and to lower yourself down with control.

The Lunge

Similarly, to the squat, the lunge will improve leg strength. However, the legs being placed in forward and backward positions simulate the walking action more closely – and challenges and improves balance.

The lunge uses diagonal movement i.e., left leg, right arm, stimulating diagonal nerve activity.

Line drill

This exercise is used to assess an athlete's flexibility and stability. However, as it challenges and improves balance and stability, it's a great exercise for improving gait.

Toe touch drill

This exercise works static balance on one leg and the ability to transfer weight through different directions which is important for gait. It also strengthens weak glute muscles.

Progress Walking Difficulty

Increase the intensity of your walking i.e., longer or faster strides or both. This will use more nerves through the body and recruit more muscles.

To increase intensity and variety into stimulating your nervous system, try using small hurdles of various heights to initiate lifting the leg over things, as per the picture.

Sensa Mat

Walking on a Sensa mat fires more sensory nerves within your feet which has been shown to improve motor nerve function within your feet and up through the rest of the leg.

The Sensa mat also improves your foot stability and can be used as a tool to increase difficulty of any exercise for progression.

When working on balance, stability, agility, or any exercise in which you may feel unsteady, have someone with you to assist.

Use something to help your stability, such as sticks, a walking frame, parallel bars, stable chair, or wall whenever is necessary.

Sources

- *6 Ways To Improve Your Ability To Walk Co*rrectly by Nick Jack
- *Twist Conditioning Sports Strength* and *Twist Conditioning Sports Movement* by Peter Twist
- *Functional Training For Sports* by Mike Boyle
- *Movement* by Gray Cook
- *Corrective Exercise Solutions* by Evan Osar
- *Back Pain Mechanic*, *Low Back Disorders* and *Ultimate Back Fitness & Performance* by Dr Stuart McGill

Parkinson's Specialist Nurses in action

Parkinson's Specialist Nurses are highly trained and experienced nurses based in communities of need. They are dedicated to supporting local people living with Parkinson's.

These Nurses are funded 50/50 by Parkinson's NSW and the Local Health District in which they are based. This series of articles invites clients to talk about the value of Nurses to their local Parkinson's community.

Brian and Barbara Grant – Supported by Nina Digiglio

Brian Grant was 82 when he was diagnosed with Parkinson's in August 2020, but the previous 12 months had been difficult for him with his health.

"He'd had a lot of problems with falls and things, but nobody ever suggested it might be Parkinson's until well after that," said his wife, Barbara. "It was a shock when it was finally diagnosed. It's not hereditary and we didn't know anyone who'd had it. We knew nothing about it.

"It wasn't until Brian had a bad fall and injured his ribs and ended up in hospital that the nurse caring for Brian got in touch with the Parkinson's Specialist Nurse. We met her when she came to see us at home."

"I'd seen the specialist and my doctor but neither of them really went into what it was in any detail," recalls Brian. "Until Nina came to see us I didn't really understand my Parkinson's."

Parkinson's Specialist Nurse Nina Digiglio visited the Grants in their home in Bangalee, a suburb of Nowra in the Shoalhaven area of New South Wales.

"She was here for two hours with Brian and she sat and started from the beginning," said Barbara.

"She explained exactly what Parkinson's is about and talked through all the symptoms. She got Brian to walk and did lots of tests (for Parkinson's) on him and as she did it she explained what it meant and how it comes about. She was really, really wonderful."

"She was really lovely," Brian agrees. "She sat and talked and answered my questions and was so very helpful."

Barbara, who is a member of the local CWA branch, also invited Nina to speak at one of their meetings.

"She was very informative, and it helps people to understand about Parkinson's," said Barbara. "She rang me recently and just asked how things were going. She's absolutely marvellous. It should be essential that anyone diagnosed with Parkinson's can have a Specialist Nurse come to their home to explain it."

Antioxidants may lower risk of Parkinson's

By Diana Campelo Delgado, PhD

A diet rich in antioxidants like vitamin C and E may lower a person's risk of developing Parkinson's, a large long-term study suggests.

Titled *Dietary antioxidants and the risk of Parkinson Disease – The Swedish National March Cohort* the study was published in the journal *Neurology*.

Vitamins C and E are antioxidants that can be found in fruits and vegetables such as oranges and broccoli (vitamin C), or almonds, avocado, and spinach (vitamin E).

These vitamins are important for general health and are known to prevent cell damage and inflammation.

Now researchers in Sweden have evaluated the diet of a large population of people — the Swedish National March Cohort — and specifically assessed their consumption of vitamins C and E.

The study included 43,865 men and women, ages 18 to 94, who did not have Parkinson's. The participants were followed through records collected from the country's National Health Registries from 1997 until 2016, over an average of nearly 18 years.

At the beginning of the study, participants were invited to answer questionnaires regarding their diet during the previous year.

Researchers then analysed their consumption of dietary antioxidants, notably vitamin C and E. Variables were adjusted for energy intake and data was analysed using appropriate statistical models.

Over the course of the study – which had a mean follow-up of 17.6 years – 465 participants (1 percent) developed Parkinson's disease.

Importantly, the groups with the highest levels of dietary vitamin C and E each had a 32 percent decreased risk of developing Parkinson's disease than those with the lowest levels of these antioxidants.

Interestingly, no association with Parkinson's risk was found with dietary beta-carotene, found in kale, pumpkin, squash, and carrots.

Although the results of the study are indicative of the importance of diet in the risk or development of Parkinson's, the researchers noted several limitations to their study.

First, the fact that diet was examined through questionnaires — and only at the beginning of the study — may be less accurate than direct observation. Also, the analysis did not account for possible changes over time.

Nonetheless, although further studies are necessary to determine the exact amount of vitamins C and E that may be helpful at reducing the risk for Parkinson's, "…our findings suggest that dietary vitamin E and C intake might be inversely associated with the risk of Parkinson disease," the researchers wrote.

First published in Parkinson's News Today

Are you watching our *Wellness Wednesday's* videos?

Wellness Wednesday's videos are hosted by Parkinson's NSW Exercise Physiologist Alyson Blanks.

Topics include short and easy exercises you can do anywhere, nutritional advice, tips on mindfulness and other health matters.

You can join in on Facebook every Wednesday at 1pm by clicking this link:

https://www.facebook.com/parkinsonsnsw

Or you can view the growing collection of short videos at your leisure on YouTube here:

https://youtube.com/playlist?list=PLNNFUfiPBotL3pJw0XD3zgLEtkc_juZIG

Topics covered so far include:

- Balance exercises
- Daily stretching exercises
- Neuroplasticity
- Getting started and maintaining an exercise routine
- Movement for Motor Symptoms and posture checking
- Stretches to target stiffness
- The importance of Speech Therapy

For all online meeting (Zoom) details please go to: https://www.parkinsonsnsw.org.au/online-meetings-for-support-groups