



The Parkinsonian

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WORLD PARKINSON'S CONGRESS

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I would like to express my gratitude to Parkinson's NZ and the Board for giving me a once in a life time opportunity to attend the 2nd World Parkinson's Congress in Glasgow which over 3000 people attended. I went to the Congress hungry to find out what I can do today to help those living with Parkinson's, talk to others like myself who work closely with those who have Parkinson's, and to improve on the quality of care that I give our members. I attended several of the scientific sessions and, to be honest, was totally blinded with facts, figures and scientific talk. So I decided to stick to where I felt more comfortable; sessions that were targeted for the allied health professionals and those that live with Parkinson's.

The Congress was all about bringing the Parkinson's community together. I found a real willingness for patients, clinicians and researchers to interact amongst one another. It was great to see researchers etc at some of the practical workshops. One researcher said to me that they often get stuck in the laboratory and forget to put a human face on the disease.

Dr Barbara Habermann (USA) has been conducting research with people with Parkinson's and their family members for 15 years. I attended several sessions on "Caring about the Caregiver". She spoke of common emotional responses that Parkinson's care partners may experience. "The carer needs to be aware of any physical and emotional changes". Studies show that 45 to 60 percent of care partners suffer from depression. Therefore the carer must learn to ask for help and look for resources. A study of older adults who were care partners for their spouses (with a variety of chronic illnesses) showed that 63% had a lower life expectancy than their counterparts who were not caring for their spouse.

Dr Marsh (USA) spoke about depression and cognitive dysfunction that are both common problems in individuals with Parkinson's. These have negative effects on quality of life, disability, and caregiver burden. While there are established treatments for depression, and some evidence of treatment approaches for cognitive dysfunction, both are under-recognised by clinicians and individuals with Parkinson's and, thus, often under-treated. Since symptoms of depressive and cognitive disturbances overlap and each condition aggravates the other, a better understanding of these relationships, and how they manifest, will help to define treatment strategies and focus research on underlying causes.

Professor Bastiaan Bloem (Netherlands) discussed that medical management of Parkinson's is mainly focused

on drug treatment. Unfortunately, adequate delivery of health care is threatened by the insufficient expertise among therapists, and the generally low patient volumes for each individual therapist. "Parkinson's Net" is a new initiative in the Netherlands that now have trained "Parkinson's teams".

CONTINUED NEXT PAGE



I was given a scholarship by Parkinson's New Zealand to attend the congress as a poster abstract I'd submitted was chosen to be presented at the conference.

My poster was about Parkinson's Otago's Mobile Clinic which aims to improve access to, and quality of care for those living in rural Otago. The poster identified how the multidisciplinary clinic, consisting of; a neuro-physiotherapist, speech therapist, occupational therapist, social worker and field officer was set up to ensure an adequate assessment of a person's needs occurred on an annual basis at a local area that is also supported by Field Officer home visits. Each assessment is between 60 and 90 minutes. Individual assessments are completed along with the multidisciplinary consultation. Follow up appointments and recommendations are made if required.

A WORD FROM THE CHIEF EXECUTIVE

KIA ORA E HOA MA

The thoughts and best wishes of all of us at Parkinson's New Zealand are with the people of Christchurch. For those that have died moe mai ra, rest in peace.

I can only imagine the shock, grief and difficulties being experienced by those of you who live there.

Fortunately the staff and committee of our Canterbury division are physically safe and well. At the time of going to print we have not heard of any casualties amongst our members.

I think that much of the country has been in a state of shock in a sense. A result of this seems to be that people are treating each other with a kindness not often seen these days. I have held my family and friends closer these last few weeks. I have found my day to day

contacts with people – on the bus, on the street and even driving have been more courteous. Neighbours I've never spoken with before and even strangers are initiating conversations. These more often than not start with – “Do you have any family or friends in Christchurch?” – and almost everybody does. I am moved by this but saddened that it has taken a tragedy of this magnitude to remind us of our reliance on and responsibilities for one and other.

The other topic that is being brought up multiple times a day is – “do you have an emergency kit?” For people living with Parkinson's there are some extra considerations and the information on page 3 is helpful.

ME TE WHAKAARO NUI

Deirdre Deirdre O'Sullivan

WORLD PARKINSON'S CONGRESS REPORT CONTINUED FROM PAGE 1

Prof Bloem explained that Parkinson's Net gives patients what they want most; which is to put themselves back in charge of their own disease, and to be able to select a well-trained expert/team of their own choice. Patients are desperate to receive the best possible care, and the Parkinson Net approach ensures the presence of high-level expertise that is visible to both patients and the referring physicians. The quality of care should ultimately serve to maintain a good quality of life and preserve independence. Prof Bloem stated “we need to listen more and allow them to play a crucial role in managing their own condition.”

In one of his other sessions, Prof Bloem spoke about why he feels patients are crucial in managing response fluctuations with Parkinson's and looked to how technology will have an increased role in the future. He said: “I think in 10 years time, patients will be wearing sensors – perhaps on a wristwatch, this will record whether the patient is on or off and help predict excessive movements or dyskinesias.

Tom Isaacs (UK) was diagnosed with Parkinson's aged 27 and is the co founder of the Cure Parkinson's Trust (UK). He shared his list of 25 points/ways of living with Parkinson's. He spoke of the positive and challenging aspects of Parkinson's with powerful openness. “My glass is always half full”, he joked, “mostly because I spill the rest”. Despite Tom struggling to stand still on the stage due to his dyskinesia it was obvious that his cup was more often than not full to overflowing!

I also attended two separate workshops on “*Laughter Therapy*” and “*Music and Parkinson's*”. The laughter therapy session was a lot of fun and encouraged people to come together in a group and laugh. Laughter releases endorphins, which improves the mood and helps relieve pain. I found it fascinating that some of the people really struggled to walk into the Music and Parkinson's workshop, yet once the music started they began to move freely. The facilitator encouraged people to use not only their mind and body but also their imagination. Because these sessions were interactive it is hard to explain what we did but I think it clarified the importance of people

exploring alternative therapies in conjunction with their drug therapy.

Congress Video Competition - this competition was designed to raise awareness about Parkinson's and help people understand what it's like to live with the condition. Tony Cox (UK) “Spring Tide” and Pamela Quinn (US) “Welcome to our World” both took first place in the Parkinson Congress video competition. These two very inspirational and moving videos along with other submissions are well worth viewing at the following website <http://www.worldpdcongress.org/about/videos.cfm>.

The overwhelming feature that I will bring away from this conference is that Parkinson's NZ offers a world class service. The conference was a fantastic event and one which I won't forget. I met some amazing and inspirational people. I have returned to New Zealand with more knowledge than when I left and I hope to be able to share this with others in my role as Field Officer.

My poster presentation was well received. I spoke with one Neurologist from the USA who was very envious of our free Field Officer Service. He said that unless you have health insurance/money you do not have easy access to health services such as physiotherapy, Occupational Therapy, Neurologists and certain medications etc. He sees 30% of his patients free of charge but was unable to offer them some of the more expensive and possibly more appropriate medications. He is currently trying to set up a clinic, similar to our mobile clinics.

I have since found this comment left on the World Parkinson's Congress face book page from Betsy (USA) “*Today several nurses from Australia, New Zealand, and England dropped by to see our poster about our newly diagnosed support group. I learned that people with Parkinson's who live in these countries receive much more TLC than they would if they lived in the U.S. For example, the nurses I talked to get to know their patients and visit them in their homes. In fact, they visit them frequently! And they help them make necessary changes as the disease progresses. WOW!*”

EMERGENCY PREPARATIONS FOR PEOPLE WITH PARKINSON'S

The recent Christchurch earthquake is a reminder that disaster can strike at anytime and without warning. For people with Parkinson's there are a few extra things to think about when preparing for a civil defence emergency.

🔥 Staying safe during a disaster

EARTHQUAKE - If you have mobility problems you may find it difficult to get into a safe place. If you can't get safely under a table, move near an inside wall of the building, away from windows and tall items that may fall on you. Cover your head and neck as best you can. If you are in a wheel chair, lock your wheels. If you are in bed when an earthquake strikes, use your pillow to protect your head and neck. Pull sheets and blankets over yourself.

VOLCANIC ERUPTION - If you live in an active volcanic zone, learn about your community's warning systems and emergency plans. Stay inside during an eruption. If you must go outside, wear protective clothing, cover your head and breathe through a mask or cloth.

FLOOD OR CYCLONE - If you haven't been advised by officials to leave your home, stay inside and at the highest level you can. Listen to your radio.

TSUNAMI - If you live in a Tsunami risk zone, find out what warning systems are in place. If you live near the beach or river when a strong earthquake occurs, move inland at least one kilometre or go up a hill to at least 35 metres above sea level immediately. Listen to your radio.

🔥 Preparing for a disaster

Talk to family, friends and neighbours and organise a personal support network of a minimum of three people. They should be people who are regularly in the same area as you. These people can alert you to civil defence warnings and help if you need to be evacuated. Make sure they know the layout of your home, where to turn off power, water and gas, and where your getaway kit is located.

You will need to agree on how you will contact each other during an emergency. Don't count on telephones working. Choose a signal for help that you all understand. This could be shouting, knocking on the wall or using a whistle. Visual signals could include hanging a sheet outside your window to alert them you are still inside.

Decide on a meet up location so should you have to evacuate, you can find your family and friends. Organise a place you will leave and look for notes should you become separated. Make sure you have a list of mobile phone numbers of your family and friends. Ideally have a mobile phone with the

numbers stored in it. Even if you find it difficult to use the phone yourself, you can ask someone to help you phone or text loved ones to let them know you where you are. Include Parkinson's New Zealand's number (0800 473 4636) in case you are having problems accessing medication. Make sure you keep the phone charged.

🔥 Getaway kit

Your get away kit should include the essentials you will need if you have to evacuate. You should put the items together in a bag or backpack that you can easily carry.

- Comfortable shoes as you may need to walk to safety.
- Medication - ensure you have 7 days medication in your getaway kit. Keep a copy of your 'Get it on time' card with the times and dosage of your medications, and your doctor's contact details on it.
- Food and water.
- Personal items - warm clothing, glasses, toothpaste and toothbrush, soap and towel.
- Cash - keep a small amount of cash in your kit in case you need to buy something.
- Family documents - birth and marriage certificates, passport and drivers licenses, insurance policy, mortgage information.
- Torch, radio and batteries.

🔥 During disaster recovery

In the aftermath of a disaster you may be living in your home with some or all services disrupted, or may have been moved to an emergency shelter. If you require assistance from Civil Defence, make sure you let them know if you have special requirements. For example, you may need to let relief workers know if you can't wait in line for long periods of time for food and water or disaster relief assistance.

For more information - General Civil Defence information can be found at the back of the Yellow Pages, or at www.getthrough.co.nz.



🔥 Leukemia drug could treat Parkinson's

Scientists at Johns Hopkins University have discovered that the over-activation of a single protein may shut down the brain-protecting effects of a molecule which can lead to the most common form of Parkinson's. This discovery means that Imatinib (known in NZ as Glivec), a drug commonly used to treat leukemia, may be used to slow the progression of Parkinson's.

Parkin is a protein that protects brain cells by 'tagging' certain toxic elements that are then destroyed naturally. Results of a new study show that an over activation of a protein called c-Abl can shut down the activity of parkin which contributes to a build up of toxic proteins. These toxic proteins kill brain cells, enabling the progression of Parkinson's.

Researchers say that now they understand the mechanism that shuts down parkin, they can explore new therapies to slow down or stop the progression of Parkinson's. In studies already conducted, cells were incubated where c-Abl was active and parkin's ability to tag the toxic proteins was significantly decreased. The team then incubated these cells with Glivec, a well known c-Abl inhibitor and found that parkin's normal protective function was restored.

The researchers concluded that the progression of Parkinson's could be slowed using Glivec. Although Glivec is already approved to treat some forms of cancer, further testing will be required before it is approved for the treatment of Parkinson's.

Source: Scienceblog.com

🔥 Parkinson's cycle test

In a study published recently in The Lancet, Dutch neurologist Bastiaan Bloem suggests that a simple test to see if a person has "regular" Parkinson's or atypical Parkinson's is to ask if they can still ride a bike. In a study of 111 Parkinson's patients who cycled regularly before being diagnosed, the 34 participants who said they

couldn't cycle anymore had been diagnosed with atypical Parkinson's. Of the 45 study participants who had "regular" Parkinson's, only two reported trouble cycling. The researchers concluded that the loss of the ability to ride a bicycle after the onset of Parkinson's might serve as an indication they have atypical Parkinson's.

In their early stages, Parkinson's and atypical Parkinson's look quite similar. The difference, according to the US based National Parkinson Foundation, is that people with atypical Parkinson's can have a different mix of symptoms.

Cycling takes coordination and balance. It is harder to cycle with the subtle problems caused by atypical Parkinson's. The biking test is especially well suited to people who have been active cyclists before being diagnosed with Parkinson's. The advantage of the bike test is that it is less invasive and cheaper than other diagnostic tests.

Source: Medscape.com

🔥 Fatigue and excessive daytime sleepiness

New research published in the European Journal of Neurology suggests that 72% of people with Parkinson's suffer from fatigue or excessive daytime sleepiness, almost half suffering from both. Researchers at the University Hospital of Zurich in Switzerland studied 88 people with Parkinson's and looked at how common fatigue and excessive daytime sleepiness are. They also looked at whether these symptoms overlap, and if they are linked to other Parkinson's symptoms or medications.

- 72% of people with Parkinson's experience fatigue, excessive daytime sleepiness or both
- Fatigue was found in 59%, excessive daytime sleepiness in 48% and both complaints in 35% of the study group
- Fatigued people had more severe movement problems and were more likely to suffer from insomnia and depression
- Insomnia was more common in people with excessive daytime sleepiness

- Medication seemed to play a greater part in excessive daytime sleepiness than fatigue – taking dopamine agonists plus levodopa appeared to make excessive daytime sleepiness problems worse for some people in the study

Parkinson's UK are currently funding research into combating sleep problems for people with Parkinson's which will hopefully lead to an improved understanding and better treatments.

Source: Parkinson's UK

🔥 Anxiety linked to Parkinson's balance problems

A recent study, conducted by researchers in Canada and the Netherlands, confirms that anxiety and fear have a direct influence on how people feel about balancing and falling in certain situations, regardless of whether they have Parkinson's or not.

Fear of falling and anxiety are two commonly reported non-motor symptoms in Parkinson's. The anxiety associated with a fear of falling can prevent many people with Parkinson's from enjoying the benefits of regular exercise outdoors.

Researchers studied a group of 30 people, 14 with Parkinson's, 16 without. The study subjects were positioned standing in three different situations with increasing perceived risk:

- Standing quietly at ground level
- Standing at the edge of a surface with an elevation of 80cm
- Standing at the edge of a surface with an elevation of 160cm

Researchers recorded how stable each individual felt and how anxious or fearful they became. The researchers found a link between a person's perceived risk of falling and their actual risk of doing so. They also discovered the link between anxiety and/or fear and balance was the same for both groups. This research will now be used to develop ways for people with Parkinson's to manage their fear or anxiety of falling.

Source: Parkinson's UK

🔥 Scientists find five new genes linked to Parkinson's

Up until around 15 years ago scientists believed Parkinson's did not involve inherited genes. It was thought that the loss of nerve cells in certain parts of the brain was the result of toxins in the environment and other lifestyle factors. However, studying families who had appeared to have a pattern of inheritance of Parkinson's revealed a variety of genes play a part in developing the condition. Researchers have discovered that although only around 5% of people with Parkinson's have inherited the genes that directly cause their condition there are other genes whose presence increase the risk of Parkinson's.

Scientists have recently identified five new genes linked to Parkinson's in a genetic analysis where they reviewed nearly 8 million possible genetic mutations. This brings the number of risky genes identified in developing Parkinson's to 11. The more of these genes a person has the greater the chances are they will develop Parkinson's. The discovery of these genes might represent progress toward a treatment or cure.

PINK1 GENE

In 2004 researchers discovered that inheriting a faulty form of the PINK1 gene was responsible for causing a rare form of Parkinson's. New research has uncovered why people who inherit the faulty versions of the PINK1 gene are more likely to develop the condition.

The PINK1 gene produces a protein that is important for keeping the nerve cells' mitochondria healthy and working well. Mitochondria is the cells' energy producing 'battery'. In the inherited faulty version of the PINK1 gene, protein builds up inside the cell and damages the mitochondria. Without healthy mitochondria, the nerve cells cannot function properly and will eventually die, causing an insufficient

dopamine to be produced. Understanding how the PINK1 function leads to nerve cell death will allow new and better treatments for Parkinson's to be developed.

Source: Parkinsons UK & Huffingtonpost.com

🔥 DBS may stabilise Parkinson's symptoms

A study published in the November issue of the International Journal of Neuroscience has shown that in patients with Parkinson's who are effectively treated with deep brain stimulation, the natural progression of the disease's motor symptoms appears to stabilise over time.

Researchers at the Mount Sinai School of Medicine in New York City investigated the long-term progression of Parkinson's motor symptoms in 50 patients treated with subthalamic nucleus deep brain stimulation (STN-DBS). Patients were evaluated before DBS surgery and at yearly intervals using the Unified Parkinson's Disease Rating Scale: 21 patients at year one, 17 at year two, 14 at year three, 16 at year four, and nine at year five. Four clinical states were assessed: off medication and DBS off, off medication and DBS on, on medication and DBS off, on medication and DBS on.

The researchers found that motor scores measured without medication and with DBS off were virtually unchanged compared to the preoperative scores of patients up to five years after surgery. This result was seen in patients with both shorter (<11 years) and longer duration of Parkinson's prior to surgery. There was also no consistent deterioration from untreated baseline in any of the motor subscores, which included tremor, rigidity, bradykinesia, and axial symptoms.

The researchers concluded that untreated Parkinson's motor scores did not worsen over time in patients undergoing STN-DBS, suggesting that there is no progression of motor severity. These results

could be explained either by a natural stabilization of Parkinson's motor symptoms after many years or neuroprotective properties of STN-DBS.

Source: physorg.com

🔥 Dogs for disabilities

The Kotuku Foundation: Assistance Animals Aotearoa aims to train and place disability assistance dogs in New Zealand. They currently have one trained Neurological disability dog working and are looking for people who feel they would benefit from having a dog trained to assist them. Assistance dogs for people with Parkinson's have been trained and used in the US since 1997.

Parkinson's walker dogs can assist people with Parkinson's in a number of ways. Dogs can help unfreeze people who suffer from freezing of gait. A verbal cue is given to the dog who will tap the person's foot with a paw, restoring physical movement. Research carried out in the US has shown that the occurrence of falls as a result of freezing reduced by over 75% when using a walker dog.

Walker dogs are also trained to counterbalance stumbling. If a patient stumbles to the right for instance, the dog is trained to shift its entire weight to the left, to keep the person upright. In the event of a fall, the dog is trained to brace perpendicular to the person, assisting them to get up.

Furthermore, not only do walker dogs help protect against falls and resulting injuries, but allow Parkinson's sufferers to maintain and maximise their independence and mobility as well as providing emotional support and companionship. In addition, the dog's presence signifies to the public that the handler has a disability rather than being intoxicated.

Anyone interested in finding out more about having a disability dog trained for them should contact the Kotuku Foundation on (021) 2984741.

Source: Kotuku Foundation

Please do not interpret anything in this magazine as medical advice. Always check with your Doctor. The appearance of any article or other material in this publication does not imply the agreement of Parkinson's New Zealand with the opinions expressed therein.

DENTAL HEALTH & PARKINSON'S

Why is it important to look after my teeth and mouth?

Three physical symptoms of Parkinson's can present challenges both for daily dental hygiene and regular visits to the dentist. A healthy mouth is critical to chewing, tasting, swallowing and speaking. For people who have difficulty swallowing, good dental hygiene is important to help prevent chest infections.

Poor motor function means nearly half of all people with Parkinson's have difficulty with their daily oral hygiene routine. Tooth brushing, flossing and mouth rinsing requires coordination, digital dexterity and tongue-cheek-lip control. Tremor and other movement disorders associated with Parkinson's can cause difficulty for dental hygiene routines.

There are also behavioural changes in people with Parkinson's that may negatively impact on dental care. These include apathy, depression and forgetfulness, all of which may lead a person with Parkinson's to pay less attention to their daily dental health. Some medications to control Parkinson's may cause dry mouth which increases the risk of tooth decay and infections. Tooth grinding at night is also common in Parkinson's patients and can be the cause of abnormal wear and tear on teeth.

What can I do to improve my dental hygiene?

The key to good dental health is good preventive dental care. Here are a few tips for maintaining good oral hygiene at home:

- Reduce the amount of sugar you eat and cut down on the number of times a day that you eat sugar or sugary foods.
- Ensure your teeth or dentures are cleaned daily.
- Address dental problems in their early stages.
- Visit your dentist and hygienist every 6–12 months so problems can be identified and treated to prevent them from worsening.
- If you are able to use it safely, use a non-alcohol mouthwash to keep your mouth clean. Some people with Parkinson's are at risk of choking when using mouthwash.

Tips for people with natural teeth

- Ensure you brush your teeth at least once a day (preferably twice a day), making sure you clean all sides of your teeth.
- If you find brushing your teeth tiring, you could clean one part of your teeth in the morning and the other part of your mouth in the evening.

- An electric toothbrush provides the repetitive motion required to clean teeth effectively and may make cleaning your teeth easier.
- Cleaning between teeth with floss or special brushes is important. There are special holders for floss which can make it easier to use.
- Your dentist may be able to prescribe you with a fluoride gel to help prevent tooth decay. They may also be able to provide strategies for dealing with a dry mouth.
- If your carer helps you clean your teeth, they may find it easier to stand behind you (like a dentist does) to effectively brush and floss your teeth.

Tips for people with dentures

Some of the symptoms of Parkinson's, for example loss of muscle tone, difficulty controlling facial muscles, dry mouth or problems swallowing, can make wearing dentures difficult. It is important your dentures fit you correctly as badly fitting dentures can cause problems with speech and damage your gums which may lead to infection and problems eating. To keep your mouth healthy if you wear dentures:

- Ensure your dentures fit you correctly. Badly fitting dentures can cause problems with speech and cause damage to your gums, leading to infection.
- Clean your dentures daily with denture paste, a soaking solution or a nailbrush with soap and water.
- Never use toothpaste on your dentures as it is too abrasive and will damage them.
- Clean dentures over a sink filled with water – this will avoid breaking them if they are dropped into the sink.
- If you have difficulty brushing the dentures, fix a nail brush to a surface so you only need to use one hand to brush your dentures.

How can I make visits to the dentist easier?

It is important that people with Parkinson's visit their dentist every 6 to 12 months for a check up. Some symptoms of Parkinson's can be aggravated by anxiety so it is important to make your visit to the dentist as low stress as possible.

Some tips when visiting your dentist are:

- Book an early morning visit as the waiting times are likely to be shorter.
- If you are prone to troublesome dyskinesia it will be easier if you time your visit to a period when your dyskinesia is minimal. This might be early morning.

- If you take levodopa, take it 60 – 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 you require, 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 of time and to control your tongue movements and swallowing. Your dentist has special devices that can help.

- A rubber bite block may be placed between your teeth to keep your mouth open and reduce stress on your muscles.
- A tongue retractor may be used to keep your tongue in one place.

As with all of your health care providers, you should build a rapport with your dentist and ensure they understand your condition. If you would like further information about Parkinson's to pass on to your dentist, please contact Parkinson's New Zealand on 0800 473 4636.



GET GOING FOR PARKINSON'S



Steve Horwell raised nearly \$2,000 competing in the Coast to Coast race in February. He completed the event in 18 hours 55 minutes. Steve is pictured here with his 'Where's Wally' support crew. L to R Angela Newport, Dorothy Horwell, Steve Horwell, Rachel Horwell and Ian Horwell.

Get Going is a way you, your friends or family can raise money to help us provide our vital services. You don't have to run a marathon to support us - although we don't mind if you do! There are many more sedate activities you can organise that are fun and will raise money. Here are just a few ideas.

HIGH TEA

Get out your good china, invite a group of friends around and put on the Ritz with a High Tea. With dainty sandwiches and little cakes you can catch up with old friends and charge them for the pleasure of your company and your cooking.

BRIDGE DRIVE

Bridge Clubs often run a Charity Drive a few times a year. Ask if Parkinson's can be the recipient of one of these Bridge Drives. If your club doesn't already organise a Drive, organise one either at the club or in your home and charge an entrance fee.

GARDEN PARTY

Got a beautiful garden you love to show off? A garden party can be as big or as small as your garden will allow. Charge an entrance fee, ask someone musical to provide entertainment and provide morning or afternoon tea for your guests - scones with cream and jam make an inexpensive yet popular treat. You could even sell homemade preserves or crafts to raise extra funds. For more information on organising an event, please email us at info@parkinsons.org.nz or call 0800 473 4636.

BRAIN WEEK

Brain Awareness Week is a global campaign to increase public awareness about the progress and benefits of brain research. Brain Awareness Week also aims to increase community awareness of the potential for improving the long term health of the brain through lifestyle changes and risk-reduction strategies.

During Brain Awareness Week there will be Brain Days held in Whangarei, Auckland, Wellington and Dunedin. Regional public lectures will be held in 14 centres. Events are free and no registration is required.

For more information go to the Brain Awareness Week website www.brainweek.org.nz.

REGIONAL PUBLIC LECTURES			
City/town	Date	Speakers	Lecture title/topic
Queenstown	Monday 14 March	Dr Andrew Clarkson	Understanding how the brain can be repaired after stroke
East Auckland	Tuesday 15 March	Dr Barry Snow	Parkinson's disease
Gisborne	Tuesday 15 March	Dr Maurice Curtis	New brain cells for the damaged brain
New Plymouth	Tuesday 15 March	Dr Jon Simcock	Brain disorders: progress and prospects
West Auckland	Wednesday 16 March	Dr Edward Mee	The history of surgery on the brain
Napier	Wednesday 16 March	Dr Maurice Curtis	New brain cells for the damaged brain
Wanganui	Wednesday 16 March	Dr Jon Simcock	Brain disorders: progress and prospects
Palmerston North	Thursday 17 March	Dr Jon Simcock	Brain disorders: progress and prospects
North Shore	Thursday 17 March	Dr Claire McCann	Aphasia, the brain and language
Hamilton	Thursday 17 March	Dr Lynette Tippett	Alzheimer's disease: memory, markers and managing
Pukekohe	Thursday 17 March	Dr Kiri Brickell	A review of dementia – what, who and how
Invercargill	Thursday 17 March	Dr John Reynolds	Teaching the brain to overcome neurological disease
Tauranga	Friday 18 March	Professor Jamie Sleight	Anaesthesia: a tool to unlock the mechanisms of consciousness
BRAIN DAYS			
City/town	Date	Speakers	Lecture title/topic
Whangarei	Wednesday 16 March	Dr Phil Wood	Alzheimer's and dementia
		Professor Louise Nicholson	Neuroinflammation in the brain: is cell coupling a contributor?
		Dr Nicole McGrath	Neurology in Northland
		Dr Bronwen Connor	Stem cells and the brain: discovery, myths and reality
<i>Plus various support group speakers</i>			
Auckland <i>(A full day's programme with lectures, workshops, activities and displays)</i>	Saturday 19 March	Dr Karen Waldie	The growing brain: what goes on in your child's head
		Professor Alan Barber	Stroke: what it is and what is being done about it
		Dr Winston Byblow	Fit body, fit brain: how physical activity can maintain brain power
		Dr Ian Kirk	Being human: the science of memory, consciousness and personality
		Dr Suzanne Purdy	The language of music: research on speech and song
		Dr Edward Mee	Brain exploration: A history of neurosurgery
Wellington	Saturday 19 March	Dr Melanie McConnell	What can studying brain tumours teach us about motor neurone disease?
		Dr Crawford Duncan	Something forgetful happened to me on the way to the... (dementia)
		Dr Stuart Mossman	Transient global amnesia
		Dr Cathy Stinear	Predicting and priming recovery after stroke
Dunedin	Saturday 19 March	Dr Liana Machado	Maintaining control over visual orienting: age-related changes and potential remedies
		Dr Graeme Hammond-Tooke	Stimulating the brain with electricity: from electric rays to magnetic coils
		Dr Andrew Clarkson	Understanding how the brain can be repaired after stroke
		Dr Louise Parr-Brownlie	Shedding light on Parkinson's disease

UPBEAT is a special interest group for people with early onset Parkinson's (aged under 60 at time of diagnosis), their families/whanau and friends. Many of our divisions have UPBEAT groups and Parkinson's New Zealand provides a newsletter, Outward Bound course and annual weekend conference. For information on joining UPBEAT please look on our website or speak to your field officer.

In November, Sandy and I attended our seventh UPBEAT weekend conference in Palmerston North, along with about 55 others from around the country. Even having attended so many UPBEAT weekends in the past 10 years, I can still say that I learnt new things and of course both met up with old friends and hopefully made new ones.



Dr Pietro Cariga, Neurologist, gave a good introductory overview of Parkinson's disease, medications and treatments. He gave quite a focus to the effects that some drugs can have in causing compulsive behaviours and the need to be aware of the degree to which this can occur. Doctors are not always good at explaining this to patients.

Similarly with the second topic on the Friday that looked at sexuality – another issue that some in the medical profession can have difficulty with or perhaps chose to ignore. I liked Dr Kirsteh Holst's summary: "we (doctors) may not be good about talking about sexuality, but there are things we can do to improve the situation if we know there are problems". This issue, like many others, is a two-way street and is best faced by talking about it.

Eleni Nikolau, Psychiatrist from Waikato Hospital, gave an exceptional presentation on Saturday. She has a great ability to speak with empathy and compassion. She spoke on emotional issues in relation to Parkinson's – clarifying such things as depression, apathy and anxiety. There was much of interest in her talk but one thing that stuck in my mind was her description of individuals: the person you were before Parkinson's is still the same person after developing Parkinson's (notwithstanding that things have changed).

I think we can sometimes forget that as time goes on.

A lot of other good things happened on the weekend and these comments barely scratch the surface. If you can be at the next weekend that is organised I am confident you will learn a great deal and really enjoy the experience.

AGM NOTICE

Parkinson's New Zealand will be holding their Annual General Meeting and workshops on Friday 8 April and Saturday 9 April at the St John's Conference Centre in Wellington.



🔥 Tauranga

Parkinson's Tauranga were entertained at their Christmas lunch with the first ever performance by The Brainwave Singers which includes some of the division's own members. The Brainwave Singers had only had four practise sessions but already members are seeing improvements in their breathing and speech. Although being able to sing is not a requirement to join this group, the performance at the Christmas lunch was enjoyed by all.

🔥 Taranaki – Steam Boat Trip

Members of the Southern Taranaki division enjoyed a day trip to ride on the Paddle Steamer in February. First stop for the group was a delicious lunch at the home of a former member who had moved south to Whanganui. The trip on the Paddle Steamer along the banks of the wonderful Whanganui river was enjoyed by the group. There was a stop for refreshments at the Berry Farm on the way home and it was an enjoyable day for all.



Taranaki Steam Boat Trip

🔥 Manawatu

Andrew Robertson, a driving instructor for over 25 years, spoke at a recent support group meeting in Manawatu. Members were advised that the comfort of the driver's seat was very important and that in most cars you can adjust the seat height and angle and also the seatbelt height. The most comfortable distance between the driver and steering wheel is the width of an A4 envelope. Age Concern have a seniors driving programme to assist older people to continue driving.

🔥 Hawkes Bay

Hawke's Bay members were entertained at their Christmas lunch by a Kapa Haka group and school choir performance. Division members joined in clapping and foot tapping to keep in time with the music. Members of the division also held a collection of food to donate to the Napier Food Bank. Two boxes were filled with 'goodies' to help make Christmas easier for those in need.

🔥 Central Otago

To remind members of the importance of exercise, the Central Otago division exercise group recently conducted a test. Each member of the class was timed rising from a sitting position, walking across the room, round a marker and back to the seat. They then spent 10 minutes on an exercycle or treadmill and repeated the timed walk. All the people without Parkinson's (the group is open to friends and caregivers too) had slowed down, showing the effects of the exercise. However the people with Parkinson's had showed an improvement in their gait and time.

“I've stopped falling!” Finally! Walking aids for Parkinson's

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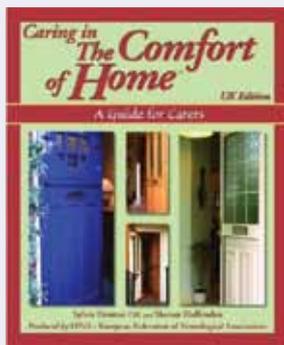
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BOOK REVIEW *By Kevin Miles*

CARING IN THE COMFORT OF HOME, A GUIDE FOR CARERS (UK Edition)

Sylvia Denton CBE and Sharon Haffenden

Produced by Efna-European Federation of Neurological Associations

My wife was diagnosed with Parkinson's Disease 17 years ago. For the first 11 years I was her partner who tried to support her as the disease progressed, her needing to stop work, difficulties with medications and side effects. I really didn't think of myself as a carer as such. I did many things I wanted to do and we did much together. We travelled, relocated an old house on to 6 hectares of land, had a large barn built, developed gardens, attempted horticulture enterprises, ran stock etc.

When Sandy had a stroke 6 years ago things changed dramatically for both of us.

I think for many couples it is the advent of a more traumatic event which may suddenly see the role of carer go from a slowly progressive situation to a more full-on occupation.

I have had to learn or discover on my own much that is written about in this book. From my experience I would consider a New Zealand version to be of value. Notwithstanding, there is still much that can be gained from reading this book.

The book is divided into 9 chapters.

In Chapter one, 'The First Steps as a Carer', there is an interesting passage in a section about Choosing to become a Carer. "Sometimes you may feel you have no choice about whether you become a carer and, understandably, you may feel a mix of complex emotions. For others, caring may be a conscious choice. Whatever your situation, becoming a carer can raise all kinds of thoughts and dilemmas...

"If you do have the opportunity to talk it through, make choices and to set some boundaries, it will

probably benefit both you and the person you care for in the long term".

As a carer it is valuable if you can arrange your own support system. From experience, that is not always easy!!

Chapter Two: 'Making the Most of Help Available'. It is important that you become aware of everything that is able to be accessed. I have found it essential to document everything and keeping a regular diary invaluable. An interesting point in the Chapter suggests that in the UK a carer has the right to an assessment of their needs. Although that has happened to some degree to me in the provision of carer relief days, it is not done here as a rigorous process.

The other Chapters include information on costs (not directly relevant to NZ), caring day by day, avoiding burnout, diet and nutrition, injury prevention (very important for both of you), emergencies and first aid.

I will finish with one other interesting quote. "Many people begin caring as if it were a sprint. They think they can and must do everything themselves. (Guilty!) You may be able to do that for a few weeks or even months, but the average carer spends more than four years in the role, and no one can sprint for that long! Instead, pace yourself from the start. Learn to say no, if that is what you want to say".

Caring in the Comfort of Home is available on loan from Parkinson's New Zealand's Library. To borrow this, or any other of the books in the Library, please email info@parkinsons.org.nz or telephone 0800 473 4636.



Parkinson's New Zealand

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