International Parkinson’s Meetings, Sydney

The 9th Asian Pacific Parkinson Association (APPA) Meeting was held in Sydney, 15 & 16 June 2013. The event was based at the Sydney Convention Centre in Darling Harbour, during a very mild winter weekend with both the Dalai Lama and the British and Irish Lions Rugby Team also in town, making for a vibrant atmosphere.

The APPA Meeting was a full and informative two days. With many Parkinson’s experts in town for the MDS Congress, it was a unique opportunity to hear from a truly international line-up of speakers. Speakers came from Germany, Italy, the Netherlands, the UK, Canada, USA and Singapore as well as Australia and New Zealand. To help capitalise on this opportunity Parkinson’s New Zealand reported from the event via social media for those who couldn’t attend.

SATURDAY

The first day’s presentations were mostly centred on promising areas of research and the development of future treatments. Professor Tim Anderson from Christchurch described the theme in his talk on ‘Emerging therapeutic developments’ as ‘Watch this space’.

There was a strong focus on the mechanism of Parkinson’s – what causes Parkinson’s, how it develops and progresses at a cellular level. It is felt that a better understanding of the underlying pathology of Parkinson’s will provide biomarkers (ways to identify Parkinson’s before it becomes symptomatic) and ultimately new treatments. The idea being that once we know how Parkinson’s ‘works’, we will be better able to find ways to stop it.

There was a lot of discussion on the genetics of Parkinson’s. This was covered by Thomas Gasser, Professor of Neurology at the University of Tübingen, Germany, who spoke on ‘Genetics
and Parkinson’s specifically, but also by Dr Thomas Kimber, a neurologist at the Royal Adelaide Hospital, who gave an ‘Update on the causes of Parkinson’s’ and a number of other speakers.

SUNDAY

Day two looked at non-motor symptoms of Parkinson’s and their treatment. It was quite different in tone and scope from day one, being much more focused on the current state of play. Topics covered included sleep disturbances, impulse control disorders, cognitive issues, speech and swallowing, anxiety and depressions, and exercise.

While day one was about Parkinson’s at the molecular level, day two was about the brain. What is happening in the brain, particularly the complex interaction between different parts of it, during sleep, cognition and impulsivity, and how they are affected by Parkinson’s. The speakers presented an overview of the non-motor symptoms they were addressing and then discussed the latest thinking on the subject. Many also reviewed non-medication strategies for dealing with them and what people with Parkinson’s can do to gain a measure of control and relief from their symptoms.

HIGHLIGHTS

The last speaker on day two was Professor Lynn Rochester from the University of Newcastle. She updated attendees on recent research on exercise and Parkinson’s. This included some of her work on using ‘virtual reality’ games where you complete tasks as well as move around. They are testing the theory that exercising your mind and your body at the same time might be better than doing them separately. She also discussed using exercise to prevent falls. After her presentation we asked Lynn to elaborate on this. A video of her advice can be found on our website or YouTube channel (www.youtube.com/user/ParkinsonsNewZealand).

Another speaker who emphasised the importance of exercise was Professor Bastiaan Bloem from Radboud University Nijmegen Medical Centre, the Netherlands. His presentation was a highlight for attendee Anna Gabb from Auckland.

“A little light relief was provided by Bastiaan Bloem, the Dutch neurologist who had the patient who could ride a bike but not walk very well (see favourites on Parkinson’s NZ’s YouTube channel). He also showed a clip of a Czech man with Parkinson’s who biked down steps, climbed a vertical ladder up the side of a building on to the roof and could walk on stilts. Don’t try this at home! Get active instead to slow the progression of Parkinson’s, use the stairs, not the lift. If all else fails get yourself a coach to motivate you, avoid falls by getting rid of the clutter and obstacles in the home, get dancing and fill your life with music and song.”

MDS CONGRESS

Later at the MDS Congress Lynn Rochester and Bastiaan Bloem (with Ruth Hagestuen, Director, NYU Parkinson’s and Movement Disorders Center) ran a session on “What we have learned from the different integrated care models of Parkinson’s and other movement disorders”. At this session evidence from the UK and Netherlands showed that a multidisciplinary team approach to care, with a patient and family focus, improves the person’s quality of life. Participatory medicine (where patients take an active role in their care) was also found to be important. An overview of services in different countries showed that New Zealand was one of the most successful countries in providing good quality patient-centred care.

Stephanie and Diane also attended sessions on “Nursing and allied health care for Parkinson’s” and “The role of the Movement Disorders nurse: a global perspective”. Both came away feeling that the best practice and roles described were very similar to that of a Parkinson’s New Zealand Field Officer. Diane said “it is reassuring that the research being presented supported our role and the benefit to our clients.” For Stephanie “the take home message from that was that New Zealand nurses are doings things right.”
I hope you enjoy reading about the recent Asia Pacific Parkinson’s Association patient meeting and Movement Disorders Society congress held in Sydney in June. The patient days were a whirlwind of information and I was pleased to see that a number of our members attended. This was the first meeting of this kind that Parkinson’s New Zealand has updated members via social media (Facebook and Twitter) during the patient days. It was good to get much positive feedback from members who were happy to get this information.

The World Parkinson Congress runs from 1 – 4 October in Montreal, Canada. This is the largest meeting of its kind and I’m delighted that two of our Auckland members have had submissions accepted. Andy McDowell has had his short film Smaller shortlisted for the video competition (you can view this video on our website) and Andrew Johnson has had his poster presentation ‘Parkinson’s, it’s all in your head’ accepted for display. In addition, Dyllis Parker has received a scholarship to attend. I’m really proud of the participation we will have on this global stage. I have been on the Communications Committee for the congress for the past three years so it is good all the work of Parkinson’s organisations around the world is finally coming to fruition. I urge members who use social media to follow us to receive updates during the congress. We will also be adding short video interviews with speakers to our website.

We held the 2013 Field Officers Conference in late August.
NEW ZEALAND PARKINSON’S RESEARCH – NEW FUNDING ANNOUNCED

The results of the Neurological Foundation’s July 2013 grant round included funding for two Parkinson’s research projects.

Professor Winston Byblow from the Auckland Centre for Brain Research received a grant for his research project “Falling off the curve: the link between impulsivity and dopamine”. About 20% of people with Parkinson’s being treated with dopamine agonists develop impulse control disorders. The aim of the research is to develop tools to identify who may be at risk of developing this side-effect.

The project will evaluate tests to measure impulse control. Professor Byblow’s team proposes that when such measures are combined with information about a person’s dopamine gene profile, this knowledge could determine if someone is or isn’t a good candidate for dopamine agonist treatment. This would lead to better individualised treatment of Parkinson’s.

Associate Professor John Reynolds at the University of Otago has also received a grant to continue his work on dyskinesia in Parkinson’s. Using a model of dyskinesias and state-of-the-art methods, the research will look at which cells in the brain are affected by dyskinesias, and how changes within these cells can affect their function in the brain. This will also help to identify new pathways that could be targeted for novel dyskinesia therapies.

neurological.org.nz

INSULIN LINKED TO PARKINSON’S AND OTHER BRAIN DISEASES

Researchers at the University of Auckland Centre for Brain Research have just had a paper published in ‘The Journal of Neurochemistry’ reporting results that may hold important clues into why there is less plasticity in brains affected by Parkinson’s and Alzheimer’s, and links to insulin resistance and diabetes.

The results came out of a major five-year project to understand how stem cells start and stop migrating in the brain that has also helped to unlock the secrets of how stem cells migrate during development and in adulthood.

In the brain immature cells move from where they are created to their final position and role as neurons. There they connect to other adult brain cells and become part of the brain’s circuitry. However the brain is a fairly rigid matrix which is not easy to move through. In order to reduce friction and facilitate their movement through the extracellular matrix the immature cells have a special slippery coating. Once in place this must be removed to allow the cells to form their connections.

The slippery coating is formed by a molecule called polysialic acid-neural cell adhesion molecule (PSA-NCAM) on the cell surface. While this process has been known and studied for at least 20 years, what controls it, particularly how the ‘coating’ is removed has been unknown. This has been a focus of the Auckland group’s research. They have now demonstrated what happens to the slippery molecules once the cell no longer needs them. The cell internalises the molecules and recycles them ready for future use. The cells do this after receiving two specific cues.

One of these cues is from collagen, which makes up part of the rigid structure outside of the cell, and the other is from a gaseous molecule called nitric oxide, which works on the outer membrane.

What they have also found, and what is reported in their latest study, is that in cell culture when there is an increased amount of insulin and IGF-1 (insulin-like growth factor 1 which has some similar functions to insulin) present, the cells cannot internalise the slippery molecules and instead they remain on the cell surface. Insulin blocks the removal of polysialic acid and therefore the cell cannot connect properly and form synapses with other nearby cells.

Senior study author, Dr Maurice Curtis explains

“This is interesting because it is well known that in Parkinson’s and Alzheimer’s the brain is less sensitive to insulin. This may hold major clues to why there is less plasticity in brains affected by Parkinson’s and Alzheimer’s in adults as well as helping to unlock the secrets of how stem cells migrate during development of the brain.”

They have now begun testing new novel drug compounds that target how polysialic acid is removed from the cell in the hope of improving neuron connectivity.

sciencealert.com.au/news

PEPPERS FOR PARKINSON’S

The findings from recent research suggesting that edible sources of nicotine may provide a protective effect against Parkinson’s were widely reported in May.

The interest in nicotine containing foods is because previous research has shown that smokers have a lower risk of Parkinson’s. This has suggested that nicotine may have a protective effect on brain cell function. But, since no one would suggest people take up smoking, there is an interest in other sources of nicotine. For example there is a large clinical trial currently being conducted in the US and Germany (NIC-PD) on transdermal nicotine patches (the sort people use to when trying to quit smoking) for Parkinson’s. This is expected to be completed in January 2015.

Nicotine is also found in plants other than tobacco from the Solanaceae or nightshade family. Many of these are commonly eaten vegetables including capsicums (peppers), potatoes, tomatoes and eggplant. Capsicums have the highest concentration. The study published in ‘Annals of Neurology’ indicated that eating foods that contain even a small amount of nicotine, particularly capsicum, may reduce the risk of developing Parkinson’s.

In the study researchers analysed lifetime dietary habits of people with Parkinson’s and healthy controls. They found a slight association between diet factors and Parkinson’s incidence. Eating nicotine-containing foods seemed to give a protective effect against Parkinson’s. This was most obvious in people who didn’t smoke and ate the foods richest in nicotine. They also needed to have consumed them regularly (2-4 times a week). The association was not found with other vegetables so the effect appears to be related to nicotine rather than ‘healthy eating’. 
The authors caution that their study shows an association between dietary nicotine and Parkinson’s, which is not the same as a causal effect, and that further studies are needed.

sciencemediacentre.co.nz

GENE PATENTS AND PERSONAL MEDICINE

In June the US Supreme Court ruled on a long running patent case AMP v Myriad Genetics. The case hinged on whether the patents on two human genes associated with breast and ovarian cancer are invalid. The patent had allowed biotechnology company Myriad Genetics a monopoly on genetic testing for BRCA, genes that play an important role in determining risk of breast cancer for a subset of women with a strong family history of the disease.

The Supreme Court’s unanimous decision focused on the patentability of isolated gene sequences. Their not-unexpected ruling was that naturally occurring genes are not eligible for patent protection. The decision invalidates hundreds, if not thousands, of patent claims on naturally occurring genes. Many of these are due to expire in a few years and these type of broad patent claims have been on the decline for over a decade. The massive sequencing efforts by public and private organisations over the years have made it more difficult to meet patentability requirements.

The Court however ruled that it is still possible to patent non-naturally occurring sequences. This includes the ‘cDNA’ versions of natural genes. Natural genes contain introns and non-coding sequences, cDNA have these edited out. This suggests that it is still possible to obtain patent claims on a novel use of a naturally occurring molecule, be it a gene or a protein.

The impact of the decision is therefore most likely to affect companies that have a product that relies almost exclusively on the naturally occurring sequence, such as a diagnostic test. However Myriad is expected to continue to hold a monopoly in BRCA testing for the near future thanks to patents relating to other parts of the process as well as its market dominance.

So while the decision that natural genes can’t be owned is welcome, its impact on the biotechnology industry may be limited. What does this mean for Parkinson’s?

James Beck, Director of Research Programmes at the US Parkinson’s Disease Foundation commented

There are several companies that have been trying to develop gene therapies for treating Parkinson’s. While the patents these companies may hold on the naturally occurring sequence is likely not enforceable anymore, the shortened version of the gene still has a valid patent and that is what counts—It is this shortened form that is actually used in the experimental therapy.

While the Court’s ruling that naturally occurring genes are not patentable is certainly historic, I think the initial effects are relatively limited, especially for Parkinson’s.

genomicslawreport.com
bionews.org.uk
Parkinson’s Disease Foundation Blog

REPORTS FROM THE MOVEMENT DISORDER SOCIETY’S 17TH INTERNATIONAL CONGRESS OF PARKINSON’S DISEASE AND MOVEMENT DISORDERS, SYDNEY, 16-20 JUNE 2013

A number of posters and abstracts were presented at the Congress. Such reports are usually the early results from ongoing research projects and the data and conclusions in them should be considered preliminary. However they often show some interesting findings and highlight research to keep an eye on.

TRENDS IN ANTI-PARKINSONIAN MEDICATION USE IN NEW ZEALAND: 1995-2011

New Zealand Brain Research Institute Research Fellow Dr Toni Pitcher presented some initial results for her group’s research into the use of the Parkinson’s medications in New Zealand.

They are using the national prescription database. This includes all prescriptions of publically funded medications that are filled at community pharmacies. For the 17-year period from 1995-2011 they have observed some distinct trends.

A large increase in the volume of levodopa, amantadine and COMT inhibitors was seen. The authors suggest that it is likely that this reflects an increase in the utilisation of these medications in the treatment of Parkinson’s and related disorders.

Declines were seen in the amount of anticholinergics and selegiline. While dopamine agonists as a group have declined, within the group there has been a large increase in the use of ropinirole since it was funded in 2005. These changes are thought to reflect changes in clinical practice as newer and safer drugs are made available.

The findings are part of a wider epidemiological study using prescription data for Parkinson’s drugs to provide an up-to-date estimate of the prevalence of Parkinson’s in New Zealand.

mdsabstracts.com
PATIENTS’ PERSPECTIVE ON TREATMENT OF CONSTIPATION IN PARKINSON’S

An Australian PhD student presented some results from her research on the management of constipation in people with Parkinson’s.

The study recruited people with Parkinson’s between the ages of 50 and 84 and asked them to describe experiences of dealing with constipation issues. They completed a series of quantitative surveys about their current life satisfaction and their current level of disability and their ability to perform activities of daily living. They talked about their views on treatment of their constipation.

Most of the participants had experienced constipation. Nearly 80% reported the problem to their doctor. Of these 95% stated they were either very unsatisfied or unsatisfied with the information and care they received.

The author noted that “This is exceedingly important to the patients. They feel that they are being mismanaged or actually ignored.” Participants suggested “that the medical support they received was limited by stereotypical views of them as an older patient. They are treated like old people, not like neurological patients.”

medpagetoday.com
mdsabstracts.com

PARKINSON’S AND H. PYLORI

Helicobacter pylori generally known as H. pylori, is a gut bacteria found only in humans. Although very common (half to two-thirds of people may have it), in some people it can cause gastrointestinal diseases including peptic ulcers. In people with Parkinson’s it can interfere with the absorption of medication, particularly levodopa.

This has been known since 2006 and studies have shown that eradication of the bacteria can improve the onset of action of levodopa, the “on” duration of the medications, and symptoms.

A new study on H. pylori and Parkinson’s was presented in Sydney. A Malaysian group reported their finding. From a group of 76 Parkinson’s patients in their clinic, 27 were found to be positive on a breath test that is sensitive for H. pylori infection. After treatment for the infection (a combination of antibiotics and proton pump inhibitors) the onset of action for levodopa improved for these patients. The “on” time also improved as did Parkinson’s disease rating scales and questionnaires measuring quality of life.

The author suggests that the results show that people with an erratic response to oral levodopa should be screened and treated for H. pylori.

www.parkinson.org
www.medpagetoday.com

MEDICATION ALONE MAY BE INSUFFICIENT IN TREATING DEPRESSION IN PARKINSON’S

New findings from the US National Parkinson Foundation (NPF) Parkinson’s Outcomes Project were presented. In a study entitled “Approach to Treatment of Depression in Parkinson’s Disease,” the researchers examined which approaches to depression care correlated with the lowest prevalence of depression among patients seen at NPF’s Centers of Excellence. Patients were treated with; antidepressant medications, counselling by a social worker, treatment by a mental health professional, or a combination.

The study showed that depression was most effectively treated at centres that refer their depressed patients to a mental health professional or social worker. The lead author of the study commented

“This particular study highlights the importance of team care. We found the best care is achieved when neurologists coordinate with other health professionals to aggressively fight Parkinson’s. In fact, a ‘depression team,’ consisting of a social worker and a psychiatrist coordinating with the neurologist, yielded the best results.”

The study looked at 2,423 patients across ten centres, found 1,121 depressed patients (46%), but at the best centre only 30% showed signs of depression. Centres prescribed antidepressant medications to between 29% and 63% of their depressed patients. High-prescribing centres achieved no significant reduction in depression versus low-prescribing centres. Other treatments, however, did correlate with better outcomes.

The work is part of the Parkinson’s Outcomes Project, a longitudinal look at which treatments produce the best health outcomes. Started in 2009, the study represents data from more than 6,000 people with Parkinson’s in four countries.

parkinson.org

PARKINSON’S PROGRESSION MARKERS INITIATIVE (PPMI)

The PPMI is an observational clinical study taking place at sites in the United States, Europe, and Australia. It aims to collect clinical and imaging data and biologic samples from various cohorts that can be used by scientists to establish markers of disease progression in Parkinson’s.

Study participants will be required to complete motor assessments, DaTSCAN and MRI imaging, serum, plasma and urine collection, CSF collection, olfaction testing, DNA testing and neuropsychiatric/cognitive testing. They will be followed for three to five years.

The study completed enrolment of its newly diagnosed and healthy control cohorts in April 2013. They are also following a group of people who have Parkinson’s but their brain scans show normal dopaminergic function, known as the SWEDD (Scans Without Evidence of Dopaminergic Deficit) cohort.

PPMI is now looking for participants for a prodromal cohort. This cohort will follow people who do not have Parkinson’s but do have one of the conditions that are often early signs of it, specifically people with REM sleep behaviour disorder and people with a loss of their sense of smell. Also people with a genetic mutation linked to Parkinson’s (in the LRRK2 gene).

Four posters from the PPMI were presented at the Congress. These focused on establishing the baselines for the potential markers being followed, and some early observations.

ppmi-info.org
How do Muscles work?
Skeletal muscles in the body are the muscles that are affected by cramp and dystonia. These muscles are the mechanism that allows our body to move. The movement is created when pairs of muscles work together, one muscle in the pair will contract while the other stretches causing the desired movement. To reverse the movement the muscle that had contracted stretches while the stretched muscle contracts. Many of our body’s movements are created by groups of muscles, not just one pair, stretching and contracting together to perform the movement we require.

Muscle Cramps
A muscle cramp is a sudden and severe pain that occurs when a muscle tightens causing it to shorten. Usually, the pain associated with muscle cramp is short lived (lasts for several minutes then eases slowly) and, if repetitive, this only lasts for a few days until the muscle recovers from the cause of the cramp.

What causes muscle cramp?
Cramp has a number of causes, some of the main causes are

• Lack of movement – this can be caused by a symptom of Parkinson’s akinesia, or through a lack of movement in general. Because of the lack of movement the muscles become less elastic or flexible causing cramp.
• Rest cramps – this cramp is very common especially in older adults. Rest cramps often occur during the night and can be painful and disturb sleep. The cause of rest cramps are unknown. Often this cramp is initiated by making a movement which shortens the muscle. Rest cramps in the calf muscles are common and may occur when pointing your toe while lying in bed.
• Prolonged exercise- after you have undertaken a sustained activity that your body may not be used to (for example taking up a new exercise or a big day gardening) you may suffer from cramp over the next day or two as your muscles recover from the activity.
• Dehydration or a lack of electrolytes – muscles are considered ‘electric’ tissues in the body. In order to move, muscles require sufficient amounts of certain ions. Many of these ions are carried in water. Where there are insufficient ions the muscles can’t contract properly and this can cause cramp.

What Parts of the Body are Affected?
Cramp can occur in almost any muscle in the body but is more likely to occur in the muscles of the arms and legs.

What Treatments are There?
Cramp can be treated by stretching and massaging the affected muscle. Applying heat or cold packs or a topical heating rub may also help to relax the muscle. Your doctor may be able to prescribe medications to relax the muscles which may also help.

There is limited evidence that physiotherapy can help with cramp, however some people do find it useful. A physiotherapist can give you exercises to improve your posture and help prevent the muscles becoming weaker or shorter. They can also give stretching exercises which may help prevent stiffness and soreness.

Ensuring you drink plenty of water and being more active may also help with muscle cramps.
Skeletal muscles in the body are the muscles that are affected by cramp and dystonia. These muscles are the mechanism that allows our body to move. The movement is created when pairs of muscles work together, one muscle in the pair will contract while the other stretches causing the desired movement.

Dystonia

WHAT IS DYSTONIA?
Dystonia is a movement disorder characterised by sustained muscle contractions and spasms. These contractions may force the body into repetitive, patterned, often twisting movements and abnormal postures. The term dystonia may be used to describe this type of movement but it may also be used to describe the medical condition.

Dystonia may affect a single body area or multiple muscle groups. Dystonia can be a condition on its own (primary dystonia), for example excessive blinking or blepharospasm and writers cramp. It can also be connected to other movement disorders as is the case with Parkinson’s (secondary dystonia).

WHAT CAUSES DYSTONIA?
Dystonia has many different causes. Damage to the central nervous system or genetics may cause dystonia. The dystonic movements that occur in Parkinson’s are often due to low levels of dopamine in the brain.

HOW DOES DYSTONIA AFFECT PEOPLE WITH PARKINSON’S?
Sometimes people with Parkinson’s experience foot dystonia which causes twisting and cramping of the feet. This may make the toes curl into a claw like position, the big toe may extend and the foot may turn in. This often happens in the early morning prior to the first dose of medication and is known as early morning or “off” dystonia. It is often painful and the person may have difficulty getting out of bed. Often this type of dystonia improves with levodopa.

WHAT TREATMENTS ARE THERE?
Medication – There are a number of medications including muscle relaxants that may be used to treat dystonia. For people with Parkinson’s a change to the dose or timing of levodopa medication may help. Your doctor or neurologist will advise you on this. It might be helpful if you or your carer keeps a diary to show how your dystonia relates to your Parkinson’s medications. Talk to your doctor before changing any of your medications.

Some types of dystonia, for example blepharospasm and writer’s cramp can be treated with botulinum toxin (Botox) however this is not often used to treat the dystonia that occurs in Parkinson’s. This medicine is injected into muscles and reduces the over activity of these muscles by blocking the release of acetylcholine, a neurotransmitter. Botox treatment can last for several months before the treatment needs to be repeated.

THANK YOU
Respite Care Funding

Caring for another person is challenging. That is why taking a break every so often is important for both the physical and mental health of carers. There are two sorts of funding provided by the Ministry of Health to help carers take breaks: Carer Support and Respite Services.

**CARER SUPPORT**

Carer Support is a subsidy towards the daily cost of your breaks. You can choose if this is used to pay an alternative carer to come to your home or for relief care in a formal setting, for example a rest home.

**WHO IS ELIGIBLE?**

Unpaid full-time (more than four hours per day) carers of people with a disability are eligible for Carer Support. You don’t have to live with the person you support, as long as you are their main carer and responsible for their on-going care. You will not be eligible for Carer Support if the person you care for is in residential care or paying for full-time care. Carer Support is also not available for short-term convalescent needs.

**HOW DO I ACCESS THE SERVICE?**

To qualify for the subsidy, and determine how much you are eligible for, both you and the person you care for will need to be assessed. This will usually be done by a Needs Assessment Service Coordination organisation (NASC).

You will need a referral for a needs assessment to your local NASC. This is a documented request for needs assessment and/or service coordination. This can be provided by your doctor or Parkinson’s Field Officer. You can also refer yourself, contact your local NASC for a referral form.

Once you have been assessed and determined to be eligible, the assessor will allocate you Carer Support days. Generally this is reviewed annually. However you can ask for a review earlier if you feel you need more days.

**WHAT DO I GET?**

You are assigned a certain number of days per year through the assessment process. These need to be used within this time frame and can’t be carried forward. How much time you are allocated is determined by your need (as assessed).

The subsidy is designed to be flexible, so that you can make your own decisions about how you take your breaks and use the subsidy to pay for them. However this also means you have to make your own arrangements.

You can pay either informal carers (friends or some family) or formal carers (homecare agency) to provide respite in your own home. You can also use the subsidy for respite in a care facility, either residential or day care. If you want to use an informal support carer note that some family members are specifically excluded from receiving the subsidy. This includes the parents and partners of the person being cared for as well as other family members living in the household. Access to formal carers may be limited by the services available in your local area. Your NASC will provide you with information on local service providers.

**HOW DOES IT WORK?**

You can claim either full days (eight to 24 hours), or half days (four to eight hours). Four hours is the minimum unit claimable, but you can combine shorter periods to make up a half day. You will be advised of the payment rate by the assessor.

The payment is not automatic. You will have to complete and return a claim form after services are provided. Carer Support generally provides only a partial contribution towards the cost of relief care. You will usually need to ‘top-up’ payments to meet the full cost.

**RESPITE SERVICES**

Respite Services, also known as formal out-of-home care, are community-based services, such as rest homes, contracted by the Ministry to provide this service. As with Carer Support, access to Respite Services requires assessment by a NASC. They will check your eligibility and then work with you to identify what your needs are and what services would best meet them.

The amount of funded respite support available to you is based on your needs and availability of services. Respite can be planned and accessed on a regular basis, but is also available in times of emergency or unforeseen event.

Note that the funding arrangements and criteria for Carers Support and Respite Services are different for people under 65 and those over 65. Each District Health Board contracts one or more NASC organisations, so there are regional variations in the forms and processes. Your Parkinson’s Field Officer can help you navigate the system.

**FOR MORE INFORMATION**

More information can be found on the Ministry of Health’s website [www.health.govt.nz/disability](http://www.health.govt.nz/disability) under the ‘Your Health’ menu on the right. Or call 0800 373 664. They also produce a pamphlet ‘How to Claim Care Support’.

**NEEDS ASSESSMENT SERVICE COORDINATION (NASC) ORGANISATIONS**

Contact details can be found online at [www.health.govt.nz/disability](http://www.health.govt.nz/disability) under ‘contact’. Your doctor or field officer can refer you to your local NASC. The Ministry also provides a guide ‘Needs Assessment and Support Services for Older People: what you need to know’.
REAL LIFE STORIES

Deep Brain Stimulation

In the last edition of The Parkinsonian we produced a factsheet on Deep Brain Stimulation. As a follow up here are three people’s experiences of undergoing this procedure.

RICHARD

Richard was diagnosed with Parkinson’s in 2002 aged 50. He had his DBS operations in mid 2011. In an interview with the local newspaper some months later he described the surgery as “better than winning Lotto”. For Richard, the assessment to see if he was eligible for DBS was really tough, but not as tough as the gap between the first and second operations. “After the first operation you come out nice and steady, then you have to wait six weeks for the second operation. I was really hammering on their door to get the second stage done as I’d reverted back to where I was feeling lousy after the initial period of feeling really good.”

Richard says DBS has made a huge difference to him. “I can go out socially now. Before the operation I’d have to go home at about 8.30 as my medication would no longer be working. Now I go to a pub quiz night and as far as I know the people there have no idea I’ve had this operation. That is how good it is.”

Since the DBS operation Richard has only had to have his DBS adjusted twice. For the first 18 months he stopped taking all medication, although he is back on madopar now to control his dystonia. There has also been some deterioration in his walking. “I’ve not got the Parkinson’s shuffle, but my walking isn’t as free as it was.”

“My advice to anyone eligible for the operation is to go for it!”

PAM

Pam was diagnosed with Parkinson’s in 1978 at the age of 39. It was 8 years before poor movement and slight tremors meant she required light medication. With time, increased periods of ‘freezing’ required her to take more medication and ultimately Pam vacillated between intense movement (sometimes for up to 6 hours) and complete non-movement.

In 2001 Pam went to Sydney and was the second New Zealander to have the DBS operation. Her husband Bill described seeing her after the operation “I was astounded when I walked into Intensive Care and saw this lovely lady, half asleep, lying serenely and completely calm. If there had ever been a time when I believed in God I think it was then. I remember touching Pam’s face and it felt as smooth as a babys’ bottom. It was amazing—ALL the Parkinsonian symptoms had disappeared”. Pam and Bill flew back to New Zealand a few days after the second operation.

Pam returned to her part-time teaching job after a few weeks off and retired 8 years later. Pam enjoyed a virtually Parkinson-free life for the next ten years. However the Parkinson’s has continued to progress and although she doesn’t have the dyskinesia she had before the operation, she is weaker and now walks with the aid of a frame. Bill says that for Pam the operation was a life saver and although her Parkinson’s has progressed life is easier for Pam because of the DBS.

GORDON

Gordon underwent DBS at the end of 2010. He had been diagnosed with Parkinson’s 11 years earlier when he was 50. As he had a history of depression he had the DBS probes inserted into the Globus Pallidus interna which carries less risk of exacerbating depression.

The change in Gordon’s condition after the DBS was switched on wasn’t dramatic. “I didn’t have a bad tremor before the operation, my problem was mainly mobility issues, and being able to use my hands, it was like they didn’t belong to me.”

A few weeks after Gordon had the second operation to fit the Implanated Pulse Generator (IPG) he got an infection. “I was feeling depressed so I did nothing about it. When my wife came home after a trip away she got me to the doctor. I was lucky that the infection was only at the IPG site and didn’t go into my brain, but I still had to have the DBS completely removed.”

“It was difficult to decide to have the DBS done again as I was concerned about getting another infection. But my son was getting married and I wanted my dyskinesia under control.”

“DBS was certainly worth having. Although it has made my speech worse, my mobility and the control I have over my hands is much better. My family are happy I had the procedure. I’ve not had a reduction in my medication however if I’m late taking my pills or miss a dose it doesn’t affect me like it would have before.”

Auckland member Andrew Johnson’s blog yougandshaky.com details his assessment for DBS and his experience of undergoing the operation. Andrew also posted a video on You Tube showing the difference DBS makes to him as he switches the impulse generator off. This video has since gone ‘viral’ having had 1.2 million views. There is a link to the video on Andrew’s blog.

“I can go out socially now. Before the operation I’d have to go home at about 8.30 as my medication would no longer be working.”
You can help make a real difference in the lives of people living with Parkinson’s by including Parkinson’s New Zealand in your Will.

It’s a common misconception that only wealthy people leave money to charity when they die. The reality is that most bequests are made by ordinary, hardworking people who want to make a positive difference to their community after they’re gone. Legacy gifts provide much needed funding of the important service we provide.

It is easy to include Parkinson’s New Zealand in your will at the same time as providing for your loved ones. And you can leave as much or as little as you want.

For more information about leaving a gift to Parkinson’s New Zealand, please call 0800 473 4636 and we will send you out our leaflet. You can also look under ‘fundraising’ on our website parkinsons.org.nz. If you have already left us a gift in your Will, please do let us know. We would like to thank you for this gift in your lifetime.

If you or someone you know would like to raise funds for Parkinson’s New Zealand, please contact us on 04 472 2796 or 0800 473 4636 or getgoing@parkinsons.org.nz.

The possibility of events you could undertake are endless and we are always here to help you with your fundraising efforts.

**EXERCISE**

**HAMSTRING STRETCH**

(1) Sit on the edge of a chair with one leg out straight in front of you.

(2) Pull your toes towards you and lean forward from your hip, keeping your chin up, until you feel a stretch down the back of your leg.

(3) Hold for 5 slow breaths in and out then swap legs.

“I’ve stopped falling!”

Finally! Walking aids for Parkinson’s

Stability
The U-Step was created to increase your independence. Its ultra stable foundation braces you in every direction. It’s not like pushing a walker. Instead the U-Step surrounds you and moves with you.

Safety
The innovative braking system is easy to use and puts you in complete control. The U-Step will not roll unless you are ready to walk. When you lightly squeeze a hand brake, the unit will roll with you. Once you release the hand brake the unit will stop.

Laser Light helps prevent freezing
If you suffer from freezing episodes, U-Step has a solution. Introducing LaserLight an exclusive optional feature of the U-Step. Simply press the red button on the handlebar and a bright red laser line is projected on the floor for you to step over. It is amazing! Our laser offers an entirely safe, obstacle-free visual cue that helps you break the freezing episode and walk normally.

Also available from U-Step - the Lasercane - a cane that projects a bright red laser line on the floor for you to step over to help break freezing episodes. Ideal for those who do not need a walker as yet but require the obstacle-free visual cue to get you moving freely again.

Order your U-Step now! Web www.ustep.co.nz Call 0800 382 884
Mobility Manawatu, 222 Ruhine St, Palmerston North

Finally! Walking aids for Parkinson’s

Stability
The U-Step was created to increase your independence. Its ultra stable foundation braces you in every direction. It’s not like pushing a walker. Instead the U-Step surrounds you and moves with you.

Safety
The innovative braking system is easy to use and puts you in complete control. The U-Step will not roll unless you are ready to walk. When you lightly squeeze a hand brake, the unit will roll with you. Once you release the hand brake the unit will stop.

Laser Light helps prevent freezing
If you suffer from freezing episodes, U-Step has a solution. Introducing LaserLight an exclusive optional feature of the U-Step. Simply press the red button on the handlebar and a bright red laser line is projected on the floor for you to step over. It is amazing! Our laser offers an entirely safe, obstacle-free visual cue that helps you break the freezing episode and walk normally.

Also available from U-Step - the Lasercane - a cane that projects a bright red laser line on the floor for you to step over to help break freezing episodes. Ideal for those who do not need a walker as yet but require the obstacle-free visual cue to get you moving freely again.

Order your U-Step now! Web www.ustep.co.nz Call 0800 382 884
Mobility Manawatu, 222 Ruhine St, Palmerston North
The Wellington division has an active Nordic walking group. Every Monday morning sees a small committed band of Nordic walkers meeting to exercise for one hour. Led by an “infinitely patient” trainer, the members of the group find the regular gathering both enjoyable and encouraging.

TARANAKI
In June over 20 UPBEAT members gathered at Ian and Dorothy Horwell’s deer farm for a potluck afternoon tea. This was a great opportunity for younger members to meet others, mingle and share concerns and support. Although it was winter the weather was kind and some of the deer wandered up to the house to greet the visitors. It was a most enjoyable, relaxed afternoon. In July it was time for the division’s Annual Games/Quiz Day in Stratford. Teams of members competed in a variety of activities ranging from badminton shots, indoor bowls, block tower building and culminating in a quiz. The focus is on a fun day but some competitiveness was evident!

MID-WINTER SEASON
The mid-winter Christmas lunch is a major fixture on the social calendar for many of the divisions around the country. This year was no exception with fun-filled events happening up and down the country in June and July.

The Wairarapa division held their lunch at Solway Park. The field officer organised a choir who donned colourful wigs and sang carols, which everybody loved. Members from all parts of the Kapiti-Horowhenua division met at Melt Café in Waikanae for their mid-winter fest. They enjoyed the great entertainment provided by local musician Ryan Edwards. Waikato held their lunch at Cosmopolitan Club in Cambridge. It was a great opportunity for members to meet the new Parkinson’s New Zealand Clinical Leader Stephanie Clare who was visiting the division.

CONFERENCE REPORTS
Waikato committee member Tracey Gilmour and her husband Rob were among the members who travelled to Sydney for the Asian Pacific Parkinson Association Meeting in June. She shared some of what she learned from it with the Hamilton Support Group in August. After her return from the MDS Congress, Wellington field officer Diane spoke to support groups in Wellington, Northern Wellington and the Hutt Valley. There was considerable interest in hearing from Diane with nearly 60 members attending.

AUCKLAND
In June Auckland held a carers’ workshop. In the past they have held an annual carers’ lunch to bring together carers from across the city. This year it was decided to run an education session focused on the needs of carers. So as well as lunch, carers heard presentations from three speakers. Psychologist Emma Holmes and neurophysiotherapist Julie Rope spoke about mental and physical self-care. Co-founder of Carers New Zealand Laurie Hilsgen led an open discussion on caring for each other in the presence of Parkinson’s. Attendees found the workshop very valuable and the branch plans to repeat it next year.

WELLINGTON
The Wellington division has an active Nordic walking group. Every Monday morning sees a small committed band of Nordic walkers meeting to exercise for one hour. Led by an “infinitely patient” trainer, the members of the group find the regular gathering both enjoyable and encouraging. They are learning to lengthen their walking stride, holding their heads high thereby improving their stature and generally being more sure and balanced in their walking. They feel that they have made progress, which is helping to ward off the worst effects of Parkinson’s on their normal walking. Another exercise group meets on Friday mornings and this too is popular and fun.