



The Parkinsonian

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OUTWARD BOUND 2012



The cutter Matahorua

At the beginning of April, nine UPBEAT members, three of their partners, and two Parkinson's New Zealand staff members battled their way through the 6-day Outward Bound course at Anakiwa. None of them will ever be the same again.

Almost as soon as Helen Pool was diagnosed with Parkinson's in 2010 she decided it wasn't going to define her life.

So a couple of months later, when during a weekend at TOPEC (Taranaki Outdoors Pursuit Education Centre) organised by the Taranaki Parkinson's Division, field officer Sue Alleman suggested Helen think about going to Outward Bound, it seemed like a good idea.

One of the highlights of the course, Helen says, was an overnight stay at a remote bush-lined bay in the Sounds.

"We were given time for reflection – to think about our values and what is important to us. We were given some paper and a pencil and I sat on the shore staring out at the sea and thought 'this is what life should be about'."

"I was challenged every day and, looking back, feel proud of my achievements and have the confidence to try new things and not let fear of failing rob me of new experiences."

DOROTHY WALLACE – HAMILTON

I wrote down the following which I intend to try and follow:

- KEEP POSITIVE AND ENJOY LIFE
- LIVE IN THE MOMENT
- HAVE NO REGRETS
- DON'T DWELL ON THE FUTURE

"I think the main thing I learnt from Outward Bound is to believe in myself, and not to be afraid to try new things; that I'm stronger than I think, and that I can do anything I put my mind to. Even if things don't turn out how I expect them to, at least I've given it a go and won't be left wondering 'what if.'"

One of the things Outward Bound has changed is Helen's attitude to telling people about her condition.



Helen Pool

Article continued next page

UPBEAT/OUTWARD BOUND



Rowing the Matahorua



Walking group



Tony and Ruth Spelman

After being first diagnosed with Parkinson's, she told very few people – only family, a very close friend, and her boss.

"I was obviously still coming to terms with the diagnosis myself and I didn't want people to look at me and think 'poor Helen'. I felt that as there were no obvious symptoms, they didn't need to know.

"But since I've returned from Outward Bound and with what I've learnt about myself, I've felt the time has been right to tell a few more people. I've told two very close friends (who I tramped the Tongariro Crossing with in March 2011 and who had no idea) and two work colleagues. The situations just presented themselves, the time seemed right, and I felt comfortable about telling them.

"I have a lot to thank Outward Bound for."

"...it was amazing how each person was encouraged and supported in their activities by the team members and the instructors."

IRENE TAYLOR-LEVIN

Ruth and Tony Spelman from Auckland continue to share and enjoy the benefits of doing the UPBEAT Outward Bound course together.

One of the three couples to do the UPBEAT course this year, the Spelmans say the course helped them both as a couple and as individuals to adjust to Tony's recent diagnosis and to engage positively with other people about his condition.

Like more than a few other participants before him, Tony found the high-ropes course, which involves traversing a wire slung 8 metres off the ground, an exhilarating and epiphany-inducing experience. Tony's initial reaction was that it was simply "too high and too dangerous", but by "focusing on the moment and taking one step at a time" he made it across. The experience gave him the strength to face the future with a more positive attitude, he says.

His identity is not defined by his condition, Tony's decided.

"My challenge has been to accept that Parkinson's does not have to change my ability to take on new challenges or limit what I do physically."

RUTH WISEMAN -NEW PLYMOUTH

Rather, it's just a condition that accompanies him on his life journey and its fearful aspects are just another issue, amongst others, that can be handled positively.

Ruth took the opportunity on the course to stand back and let the people with Parkinson's get on with things themselves, and to remember that people with Parkinson's can do anything, they just do it more slowly.

"Usually in a group situation I'm more comfortable in the role of a leader and have a tendency to leap in a bit quickly, but this time I stood back and really enjoyed having no responsibility and just sort of being there."

One benefit of this, Ruth says, was noticing the changes Tony had undergone since his diagnosis that normally she wouldn't have seen.

Doing Outward Bound as a couple has provided a positive point of engagement for people to approach the subject of Tony's Parkinson's, Ruth says.

"Most people don't know anything about Parkinson's and you need to give them a way in." Outward Bound is that conversational entry point.

The course had one unexpected benefit, Ruth says. When they did the course, Tony had just started taking medication for his Parkinson's; but because he had a "very free" approach to time-keeping, he hadn't quite got the hang of taking his medication at regular intervals.

"Being among a group of people who were taking medication throughout the day in a very matter-of-fact way helped him get into a routine with his medication."

Parkinson's New Zealand would like to say a big thank you to Douglas Pharmaceuticals whose ongoing support makes the UPBEAT Outward Bound course possible.

A WORD FROM THE CHIEF EXECUTIVE

TENA KOUTOU KATOA

It's been a busy couple of months for our organisation, with reports from around the divisions suggesting demand for our services is increasing. Unfortunately we continue to face an on-going funding challenge. It isn't getting any easier! While that's true, there are still plenty of good things happening out there.

In this issue we share the inspirational story of Shelley Musk. Shelley ran the Paris Marathon at the beginning of the year for Parkinson's New Zealand. I strongly urge that if you know of anybody about to undertake a challenge who could raise funds for us, please put them in touch with our *Get Going for Parkinson's* Programme.

The stories from this year's UPBEAT Outward Bound course are also inspirational and confirm what a sound investment supporting this course is. I would like to take this opportunity to personally thank Douglas Pharmaceuticals for their wonderful on-going support that makes this course possible.

People make our organisation. We have recently said goodbye to several long-serving personnel, including Margaret Conaghan, who served Parkinson's in the Wairarapa for 44 years.

At the AGM Andrew Dunn stepped down as Chair of Parkinson's New Zealand. Thank you Andrew for all your years of work and support. I'm looking forward to working with Andrew's successor, Margaret Adamson.

Parkinson's New Zealand is currently looking for people with skills to join our board. Further details are on page 8. If you, or somebody you know, could contribute in this way, please get in touch.



Deirdre O'Sullivan



AGM 2012

Parkinson's New Zealand held its AGM/workshops in Wellington, 27-28 April.

The AGM itself was preceded by several workshops. The first was presented by Lynn Johnson on employment legislation and best practice. Lynn made it very clear just how complicated and potentially fraught the whole employment field had become.

PARKINSON'S NEW ZEALAND AGM – WELLINGTON

Parkinson's New Zealand (PSNZ) Clinical Lead Leanne Morgan updated members on her efforts to build connections with other services and specialists and set in motion a process of continuous service improvement. Part of this process involves establishing a national database.

The other workshops gave attendees the opportunity to throw ideas around about how the challenges the organisation face now may be met in the future.

The AGM dinner at the Plum café in Cuba Street proved to be a good venue to unwind. We were pleased that our patron David Levene was able to join us.

The AGM itself went smoothly and ran for an hour. Margaret Adamson became Chair of the Board of PSNZ, replacing Outgoing Chairperson Andrew Dunn. Fiona Mathieson was elected Vice-Chair. Nick Dangerfield was voted Treasurer.



Dr Barry Snow – neurologist

🔥 Living Cell Technology announces NZ trial

Living Cell Technologies (LCT) is a biotechnology company incorporated in Australia with operations in New Zealand. It develops therapies based on live cell implants, its most advanced therapy being for Type 1 diabetes. It has also been working on neurological conditions including Parkinson's. Recently it announced plans for a clinical trial of its cell therapy treatment in Parkinson's patients to be conducted in New Zealand. The Phase 1 trial will investigate the safety and clinical effect of the company's NTCELL treatment in people with Parkinson's. LCT is preparing an application to New Zealand's medicines safety authority Medsafe to conduct the trial. Auckland neurologist Dr Barry Snow has agreed to be the Principal Investigator. Pending authorisation, LCT expects to begin the trials early in 2013.

The potential treatment involves transplanting choroid plexus cells from disease-free pigs into the brain. Choroid plexus cells are naturally occurring "support" cells for the brain and when transplanted can help protect and repair damaged nerve tissue. These cells will be enclosed in LCT's special encapsulation technology to prevent the immune system from rejecting them as foreign.

The human trial follows on from successful pre-clinical studies in monkeys in China. LCT produced a Parkinson's-like condition in monkeys using drugs and then implanted NTCELL into affected brain areas. It says that within two weeks improvements in both motor abnormalities and neurological function were observed in the NTCELL treated subjects compared to controls. These improvements persisted for at least six months beyond the NTCELL implant with no evidence of inflammation or other adverse event. The company hopes these results will translate into human studies.

🔥 Handedness and Parkinson's

One of the most characteristic aspects of Parkinson's is its asymmetry (motor symptoms are more pronounced on one side of the body). As with so much about the condition, the reason for this is not known but there are a number of theories. One of which is that it relates to handedness. There have been a number of studies on the correlation between hand dominance and dominant Parkinson's side but the results have been inconclusive. The Movement Disorders journal recently reported and commented on a meta-analysis of 10 large studies in which information on both handedness and the side of onset of Parkinson's were recorded. From over 4000 patients they found that about 60% of the right-handed patients had right-dominant Parkinson's and 40% left. While for left-handers, the ratio was reversed: 60% left dominant, 40% right. The difference was statistically significant however it is not 'robustly exclusive'. There are still a large number of people where hand dominance and Parkinson's dominance do not coincide.

🔥 Artistic productivity and creative thinking in Parkinson's

Creative drive and enhanced artistic-like production may emerge in patients with Parkinson's during dopamine therapy.

When some people with Parkinson's start taking dopamine, they experience a burst in creativity and spend much of their day pursuing artistic endeavours such as drawing, painting, sculpture, or writing. This newly acquired artistic focus can interfere with their social life and daily duties. As a result it can resemble impulse control disorders (ICDs) and punding – a compulsive fascination with repetitive mechanical tasks (see ICD factsheet on pages 6-7).

A small Italian study sought to determine whether the enhanced artistic production in people with Parkinson's was from increased impulsivity, possibly associated with ICDs, or from a triggering of innate artistic skills.

They considered artistic-like productivity to be enhanced if patients reported working on any form of art more than two hours per day after the introduction of dopamine treatment. Using established ratings systems for creative thinking and impulsiveness they found no correlation between the two. The authors think that the study suggests that newly acquired artistic production in people with Parkinson's is not associated with impulsivity or impulse control disorders. Artistic-like production might represent the emerging of innate skills (although not necessarily talent) in a subset of predisposed people with Parkinson's.

🔥 Neurologix files for bankruptcy

Neurologix Inc, the US gene therapy biotechnology company co-founded by New Zealand Parkinson's researcher Dr Matt During filed for bankruptcy in March. On filing the company listed assets of US\$1.2 million and debts of US\$12.9 million. As well as its financial issues it was reported to have some managerial troubles at the top. The company was developing a number of gene therapy technology products. The most advanced was NLX-P101, a treatment for Parkinson's, which went through a successful Phase 2 clinical trial last year.

🔥 Tracking Parkinson's

To mark their Awareness Week in April, Parkinson's UK announced plans for "Tracking Parkinson's", the world's largest ever in-depth study of people with Parkinson's. This ambitious five-year project, fully funded by Parkinson's UK, aims to speed up the search for a cure by finding 'biomarkers'.

Parkinson's UK are focusing on biomarkers because they believe that finding biomarkers is crucial to finding a cure for Parkinson's. Biomarkers are small changes in the body that can be measured to show how severe a person's Parkinson's is. Without a reliable biomarker it is difficult to diagnose Parkinson's accurately or measure how it progresses - which is a massive barrier to testing new treatments. Having a biomarker for Parkinson's would also help to diagnose Parkinson's earlier, when people are most likely to benefit from the new treatments scientists are working on.

The study is happening in a network of more than 40 study centres across the UK and will involve thousands of people with Parkinson's across the country. They are currently recruiting people who have been diagnosed with Parkinson's in the past three years or were diagnosed before the age of 50. They also want to include a smaller number of brothers and sisters of people with Parkinson's (who are enrolled in the study) to participate.

🔥 Revisiting 19th century treatments

Jean-Martin Charcot, the 19th century French neurologist who had a major role in defining Parkinson's as a distinct disorder, developed a "vibration chair" that showed improvements in his patients. Charcot got the idea for developing the chair, which copied the continuous jerking of a carriage or train, after his patients informed him that their uncomfortable or painful symptoms seemed to disappear during long carriage rides or train journeys, and that the relief lingered for some time

after the journey. However Charcot died before being able to conduct a more comprehensive evaluation of his therapy.

A team of neurological researchers in the US has replicated Charcot's work. Attempting to mimic Charcot's vibration treatment with modern equipment they wanted to confirm or refute the historical observation.

The researchers randomly assigned 23 patients to one month of 30 minute long daily therapy sessions in either a vibrating chair or the same chair without vibration, with both groups listening to a relaxation CD of nature sounds during their session. Both groups showed an improvement in both motor and non-motor symptoms.

The researcher commented that while their results confirm Charcot's observation of improvement in Parkinson's with chronic vibration treatment, the effect is not specific to vibration. Instead, the data suggest that relaxation in a lounge chair or simply the participation in a research protocol can be equally beneficial.

🔥 Levodopa intestinal gel clinical trial results

Pharmaceutical company Abbott has presented positive results from their Phase 3 clinical trial evaluating levodopa-carbidopa intestinal gel (LCIG) for the treatment of advanced Parkinson's. The study showed that patients treated with LCIG for 12 weeks reported improvements (that were both clinically meaningful and statistically significant) in "off" time compared to levodopa-carbidopa immediate release (IR) tablets, without increasing dyskinesia.

LCIG contains the same active medication as the tablets but in gel form and is administered directly into the small intestine via a surgically-implanted tube connected to a portable pump. This provides a continuous delivery of medication during the 16 hours-a-day of pump use.

The study was a randomised double-blind, double-dummy trial involving patients with advanced Parkinson's (average duration over 10 years).

This means all the group had a pump implanted with half the group receiving LCIG infusion plus placebo capsules while the other half received levodopa-carbidopa tablets plus placebo gel infusion.

The key findings were that after 12 weeks, mean "off" time decreased by 4.0 hours per day with LCIG. Mean "on" time also improved by 4.1 hours compared to the tablets.

Almost all participants reported some side effects from the treatment, particularly related to placement of the intestinal tube.

LCIG, which is also known as Duodopa, is currently being evaluated in patients with advanced-stage Parkinson's in additional Phase 3 clinical trials in the USA. A number of New Zealand patients have been participating in these trials including the pivotal double blind placebo controlled trial. It is approved in 40 countries outside the US.

SOURCES: Parkinson's UK, Living Cell Technologies; Bloomberg; Movement Disorders Journal; Parkinson Disease Foundation (US); medicalnewstoday.com; Parkinson's Disease News

MICHAEL J FOX VISITING AUSTRALIA IN AUGUST

Actor and Parkinson's activist Michael J Fox will be making his first visit to Australia in August. He will be speaking at two public events at the Melbourne Convention Exhibition Centre.

On the 14 August he will be interviewed onstage as part of a show "Michael J. Fox - A Funny Thing Happened on the Way to the Future". A proportion of all ticket sales will be donated to the Michael J. Fox Foundation and Parkinson's Victoria. He will also be a speaker at the Australian Chambers Business Congress on 17 August.

For more information see visionaryseries.com.au and businesscongress.com.au

“A possible side effect of some Parkinson’s drugs is the development of impulse control disorders. It is important to seek help as soon as you suspect that you, or someone you are caring for, may be affected this way.”



IMPULSE CONTROL DISORDERS

This fact sheet first appeared in the UPBEAT newsletter. It is reproduced here by popular request.

A possible side effect of some Parkinson’s drugs is the development of impulse control disorders.

It is still unclear how many people may be affected by these problems but it is now believed to be around 20%. For many of these people the changes in their behaviour can be minor but the problem behaviours that can develop may sometimes have a big impact on the person affected and on those around them.

It is important to seek help as soon as you suspect that you, or someone you are caring for, may be affected by one of the types of impulse control disorder outlined below.

Impulsive and compulsive behaviour

Normal behaviours are often motivated by the prospect of pleasure or gratification or to avoid anxiety and distress. As we mature we learn to modify this by using our brain-power and self-control. Impulsive behaviour is when a person acts out of impulse not thought: doing things they probably wouldn’t have done if they had stopped and considered the consequences.

There is no real pattern to the spur of the moment decisions the person may make because their behaviour varies with the setting, but the impulsivity is a common factor.

In contrast, compulsive behaviours are repeated time and time again by people with this problem, often to help reduce the anxiety or worry that results if they do not satisfy the urge to carry out the behaviour. This is obsessive and the person will feel they can’t stop themselves.

Why can people with Parkinson’s be affected?

It is thought that impulse control disorders are caused by abnormalities in the “reward circuit” of the brain which is controlled by dopamine. In Parkinson’s, some medications replace the loss of dopamine resulting from changes in the brain’s substantia nigra which regulates a person’s ability to move. It appears that, in some cases, medication which is intended to replace the dopamine in the substantia nigra also affects the “reward circuit” of the brain, resulting in impulse control disorders. The illness itself may also predispose to these problems for some people, but it appears that it is always medication affecting dopamine that triggers them.

Who is likely to be affected?

Research has yet to clearly identify who is more likely to be affected by impulse control disorders as a result of Parkinson’s medications. There is some evidence that people are more likely to be affected if their Parkinson’s is more advanced as they are taking higher doses of Parkinson’s medications. Impulse control disorders are more prevalent in men than women, and in people with early onset Parkinson’s. Frequently a person will have more than one impulse control disorder and they also have a higher risk of hallucinations or delusions, depression or anxiety.

What are the more common Impulse Control Disorders in people with Parkinson’s?

Gambling

The person may become progressively unable to resist the urge to gamble. They will usually indulge in many

types of gambling (eg lotteries, internet gambling, casinos and raffles). The gambling will continue despite pleas from family or friends to stop, massive financial losses and the break down of relationships. The person may even steal or deceive others to satisfy this urge.

This can happen when there was a past history of gambling problems, or none at all.

Hypersexuality

Hypersexual behaviours range from intrusive but private sexual thoughts or urges, to more obvious inappropriate, unwanted or offensive behaviours. The scale of this change in behaviour varies from person to person and can be really distressing for the person and those around them.

There may be increased demands for sexual activity within an established relationship or, in a departure from previous behaviours, the person may begin to use pornography, prostitutes or engage in internet-based sexual activity. They may also develop sexual fantasies that are unusual for them or other new behaviours such as exhibitionism, cross-dressing or a desire for aggressive sex.

Obsessive Shopping

People may develop an irresistible urge to buy more than they need or can afford. This obsession with buying things can lead to financial problems.

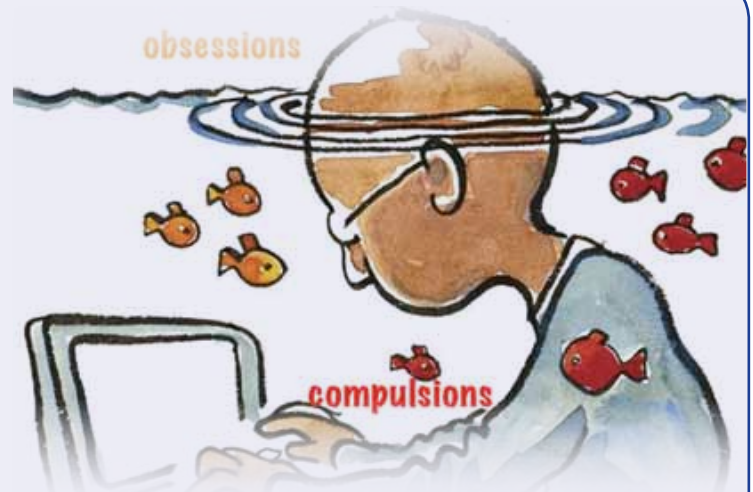
Binge Eating

People who develop this problem can't control their appetite and will eat large amounts of food in a short period of time. They may be embarrassed about the amount of food they are eating so eat alone or on secret. The eating may lead to feelings of guilt and the person may gain a lot of weight.

Misuse of anti-Parkinson's medications

A person may excessively use anti-Parkinson's medications and exhibit drug seeking behaviours as if they were becoming addicted to the drug. They may insist on increases in dopaminergic medications to treat "unbearable" motor symptoms and will have a distorted view of "on-off" motor states.

It is not uncommon for people with this type of impulse control problem to have had a history of mood disorder before the onset of Parkinson's and they may report an intense "high" during the "on" state and become irritable, anxious or even suicidal in the "off" state. Sometimes it is use of other drugs, especially alcohol, that becomes a problem 'out of the blue' relating to the use of Parkinson's medication.



Punding

A person may develop compulsive behaviour such as a fascination with taking apart technical equipment which they may not be able to put together again, collecting a particular object, or hoarding. They may obsessively sort or organise objects, often changing the criteria for sorting the object – they may first sort an object by colour, then by size, then by age etc. They may talk in long monologues about these activities without actually telling you anything.

What should I do if I'm experiencing impulsive or compulsive behaviour?

People often find it traumatic to realise this is happening to them, or they may not be aware they have a problem which may be noticed by family or friends. Since all of these behaviours can be normal to some degree it is important not to leap to conclusions. When they are related to an impulse control disorder these behaviours are not a reflection on the individual and it is important they seek help.

Speak to your GP, Neurologist or Field Officer if you think you or someone you care for is affected by impulsive or compulsive behaviours. Health professionals are trained to discuss matters like these, which may be considered embarrassing, without being judgemental. You may also wish to take someone along to your appointment to support you and as an extra set of ears for anything you might be told.

If you think you are affected by impulse control disorders it is important you don't change your medications without first talking to your doctor. Your doctor may adjust the level of medication you are on or change the medication as some patients tolerate one form of dopamine agonist but not another. They can also look into what other treatments may be used to control these symptoms.



Every April, up to 40,000 runners jostle their way through the streets of Paris in the Paris International Marathon. In amongst them this year was Shelley Musk from Papakura.

Shelley ran the 42km race in memory of her parents – Shelley’s mother, Joyce, died in January 2011 and her father, Harry, who had Parkinson’s, died two weeks before the event. Shelley raised more than \$2,200 for Parkinson’s New Zealand through sponsorship.

“My Dad had Parkinson’s for over 20 years. It was very hard to watch him become so affected, but I always drew strength from his courage and determination, and his ability to maintain a sense of humour in the face of such an enormous personal challenge. I was humbled by his acceptance of his Parkinson’s yet always felt inspired by his determination not to give in to how the condition was compromising his quality of life.”

“I chose the Paris marathon as both my Mum and Dad were of French descent and I always had a strong sense of home when I visited Paris with them or with my daughter Kate. Dad was a Normandy veteran and helped liberate the city, which I was immensely proud of; and my parents went there on their honeymoon. So it is a city which I have a great emotional attachment to.”

Shelley completed over 780kms of training for the marathon. She was sometimes accompanied by her daughter, Kate, who rode alongside on her bike.

Fitting her training around her roles as a mother and the CEO of the Qantas Jetconnect airline was a test of her planning and project management skills, Shelley says. Having good people around helped.

“My coach Tony and my work colleagues at Jetconnect continued to encourage me when the going got really tough, particularly over the last five weeks of Dad’s life, which was when I had to train the longest distances.”

The course started in front of the Triumphal Arch and continued down the broad Champs Elysées, passed

through two Parisian woods and wound past the Eiffel Tower and Notre Dame Cathedral. The winner this year, clocked a time of 2:05.11. Shelly shaved 15 minutes off the time she ran the New York marathon in 2009. (Shelley raised over \$6,600 for Parkinson’s New Zealand during that event.)

Something like 250,000 onlookers lined the course.

“The French were fantastic supporters and would call out to us our names (they were printed on our shirts) or “Go the All Blacks!”

And, just in case any of the runners felt a little jaded towards the end of the course, the organisers served up red wine and cheese at the 35km mark.

“There were two particularly emotional moments for me along the way. At 21 kms I saw an older lady who reminded me of my Mum who was holding a small sign saying ‘I love my daughter Emilie’; I choked back the tears as Mum was meant to be with me. The other moment was at the end. The relief of finishing and knowing my friends and family were there was overwhelming and all the emotion of having lost my Mum and Dad so close together came flooding back.

“What’s next? I’ve set myself a goal of doing five marathons before I’m 50 and I’m rapidly running out of the time! (Shelley defines a goal as “a dream with a time limit.”) So I plan to run the Auckland marathon this year, then Boston in 2013 and London in 2014. Hopefully the knees and body will stand the physical challenge!”

PARKINSON'S NEW ZEALAND IS LOOKING TO CO-OPT A NEW BOARD MEMBER. WE ARE PARTICULARLY INTERESTED IN PEOPLE WITH ACCOUNTING SKILLS.

For more information please contact;
info@parkinsons.org.nz

CARERS' CORNER



By nature, Kiwis are pretty stoical. We pride ourselves on being able to "get on with it" and not having to ask for help. But sometimes you have to. Seeking help isn't an admission of failure or weakness; sometimes it's the most courageous thing you can do. Fortunately, carers have plenty of places to turn to when they need help and support.

Friends and family and neighbours are a good place to start. That's what they are for. But unless they are living through the same thing, with the best will in the world, their empathy and understanding can only go so far. And this is what makes carers' support groups so valuable.

At a carers' support meeting you will be surrounded by people who are having the similar experience. You will have a bond of understanding up front. You will speak the same language; you will be able to speak directly and not be misunderstood. This was very evident at the UPBEAT Weekend held in Auckland earlier this year; where, in the first of the carers' sessions a solid rapport was established within minutes as people realised others faced similar challenges to them. Support meetings are a great opportunity to lighten your load with camaraderie, humour, and understanding. They will give you not only a good release but also a lighter perspective on things and the chance to hear how other people have resolved similar challenges.

Even if you're not comfortable in groups, make yourself go along anyway and with a bit of luck you'll click with someone there and you can organise an informal mutual support group of two. Anecdotal evidence suggests there are more than a few such groups around the country where carers meet weekly over a glass of wine or a meal and chat.

Your field officer can tell you how to go about contacting a group. Field officers typically have a wealth of experience that makes them easy to talk to; you won't have to say much for them to pick up your signals. They are there to look after you just as much as the person you care for. They will listen.

They may refer you to any of a number of more formal support mechanisms, including your GP, a counselling service, which they respect and personally recommend, or to the Needs Assessment and Service Coordination (NASC) agency.

NASC is the first step for a person to get Government-funded disability support services. Services may include help with personal support, meals, household management, carer support, day programmes, and respite support provided by rest homes and private hospitals. They are also a good source of information about other support agencies.

Another good source of information and support is the internet. A good place to start is by downloading a copy of A Guide for Carers, published by the Ministry of Social Development. This has a lot of practical information about getting help.

The Carers NZ site has a wealth of information as well: carers.net.nz

A search of the internet will also quickly reveal there are a lot of people out there having the same or a similar experience. Some of them are writing about it in blogs. Have a look and you'll quickly realise that you aren't alone.

Caring for somebody with Parkinson's isn't easy but there's no need to make it any tougher by battling on alone. Reach out to others. You may be surprised how good it feels.

THANK YOU

IRIS & ERIC NANKIVELL
CHARITABLE TRUST



FIRE SAFETY



One of the early symptoms of Parkinson's is a poor or non-existent sense of smell. Combined with other problems such as mobility or cognitive issues, hyposmia (decreased sense of smell) or anosmia (a complete lack of a sense of smell) can be deadly in a fire.

Last year the New Zealand Fire Service attended over 3,700 house fires; in over 80% of them, smoke alarms were either not installed or not working. Smoke alarms save lives, property, and heartbreak. Everybody should be protected by them, particularly people with Parkinson's.

The New Zealand Fire Service stresses that smoke alarms are the first line of defence in home safety. Modern, relatively inexpensive, alarms will detect smoke before it can be seen.

The Fire Service strongly encourages homeowners to contact their local fire station for free advice about choosing and installing smoke alarms. On request, local fire service personnel will fit the correct number of smoke detectors into a house, mounting them in the most effective positions, and will often do so free of charge.

There are simply no good reasons not to install detectors. While it's important to regularly test alarms, this can be done with the end of a broom handle (some smoke alarms can be checked by shining a flashlight at them.); and the advent of Lithium batteries with 10-year working lives has made the risky annual trip up a ladder to replace batteries a thing of the past.

While installing smoke detectors is the first line of defence against fire, establishing and practicing an escape plan for each room is also important. In theory, every room in the house should have at least two exits; but in practice, what is practical for an able-bodied person may be an impossibility for someone with Parkinson's.

But just coming up with a plan is a useful exercise in itself and may reveal potential traps. For example, do all doors actually open? Are they kept locked? If so, are the keys handy? Keys should be kept in deadlocks at all times when the occupants are at home.

Everybody should keep a torch beside their bed so they can escape even if it is dark. If there is a fire, call 111 immediately and get out and stay out. Have an outside

meeting place, such as the letterbox or a designated tree where the household can gather and conduct a head count.

Many people with Parkinson's have speech difficulties. Their voice may be inaudible or unintelligible, but in an emergency, this is not a problem. When an operator answers an emergency call on a landline, that line is automatically locked and remains locked until released by the operator. If an operator understands enough to direct a caller to a particular emergency service but the service cannot understand the caller's address details, the operator will trace the call. While they are convenient, cell phones cannot be quickly traced. All calls will be followed up.

Parkinson's impacts on memory. Kitchens are the seat of many domestic fires, and many house fires that start in the kitchen occur because food is left unattended on the stove or in the oven. A person with Parkinson's (or anybody else for that matter) should train themselves never to leave the kitchen – even for a short time – when food is frying or grilling. Don't leave the house if food is simmering, baking, or roasting. If you must leave the kitchen while cooking, take a spoon or potholder with you as a reminder to return to the kitchen.

Everyone must take steps to protect themselves from fire, but this is especially important for those with Parkinson's as their condition may compromise their natural defences.

"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. Its 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

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Our laser offers an entirely safe, obstacle-free visual cue that helps you break the freezing episode and walk normally

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NEWS FROM AROUND THE COUNTRY



Northland members Don Swift and Merle Armiger cut the anniversary cake with Patron June Grove

🔥 Northland 20th Jubilee

Northland celebrated their 20th Jubilee in conjunction with their AGM on 13 April. The event was a great reunion for the division's "pioneers" and an inspiration for those involved now. Dawn Billington and Jill Ramsey, founders of the Whangarei and Dargaville Support Groups respectively, attended and spoke.

🔥 Auckland & Waikato World Parkinson's Day

To mark World Parkinson's Day (11 April) the Auckland division hosted a public lecture by neurologist Dr Kiri Brickell. Parkinson's Waikato also marked the occasion and celebrated their relocation to their new Frankton office with an Open Day.



Hawke's Bay Patron Rhod Murray, Deirdre O'Sullivan, President Jeanette Barker & husband Peter

🔥 Hawke's Bay celebrate 30 years

In April Hawke's Bay members and guests gathered at The Mission Estate Winery to celebrate 30 years of caring for people with Parkinson's and their families.

During the lunch Field Officer Morag Murray presented an outline of the division's milestones. A display of photographs and memorabilia brought back many memories and generated much laughter.



Margaret Conaghan

🔥 Wairarapa – Margaret Conaghan retires

After 44 years of service to Parkinson's in the Wairarapa, Margaret Conaghan has retired. Margaret was a founding member of what later became the Wairarapa Division. Over the years she held every possible position on the committee. In 1999 she was made a life member of the division. In 2008 she received the David Levene Volunteer Award in recognition of her outstanding service.

🔥 Canterbury Court Theatre Fundraiser

On 27 May the Canterbury division held a successful fundraising night at the new Court Theatre in Christchurch, with comedy group The Court Jesters entertaining. The night was the first in a series of events planned for this year to celebrate the 50th anniversary of Multiple Sclerosis and Parkinson's Society of Canterbury (Inc).

🔥 Otago Seminars

Otago members have been privileged to hear from two Parkinson's experts in recent months. In March, Psychiatrist Dr Matthew Croucher spoke on the non-motor symptoms of Parkinson's with a focus on anxiety. In May, Dr John Reynolds, Associate Professor in Neuroscience and Medicine at the University of Otago, updated members on the latest research into how some treatments operate in Parkinson's. He then outlined the work his laboratory and others at Otago University are doing on treating dyskinesia.

🔥 South Canterbury farewell

South Canterbury recently held a farewell afternoon tea for Field Officer Margaret Bates. Margaret was one of Parkinson's New Zealand's longest serving field officers having worked for the division for 19 years. Past-President Alec Barltrop spoke and pointed out how Margaret's vision had developed the Society. Many members took the opportunity to speak from the floor thanking her.



Parkinson's New Zealand

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