

New Zealand researchers have stem cell breakthrough

Late last year a New Zealand team of researchers announced they had succeeded in turning human skin cells into brain cells. This advance shows a lot of promise for the treatment of Parkinson's and other neurological conditions. *The Parkinsonian* talks to principal investigator, Associate Professor Bronwen Connor about her research.



BRONWEN CONNOR

What got you interested in Parkinson's research?

I was born and bred in Auckland and attended Westlake Girls High School. At High School I competed in rowing which led to me studying sports science at Auckland University. In my first year I signed up for physiology classes which I liked, but I found out involved a lot of physics – not my strong suit.

I also signed up for psychology classes. After I got the textbook I went home and started reading it. I remember being completely wowed by this incredible organ that is the brain and everything it can do. That was a huge turning point in my interest and from then on I focused on neuroscience studying a mixture of psychology and neuro-physiology. In my final year they were offering pharmacology papers and I was looking for two more papers to do to make up my degree. I thought wow, drugs and the brain, and that was how I came to gain my degree in Pharmacology and Physiology.

After I'd finished my PhD in Neuropharmacology at Auckland University, I went to Chicago and worked for three years at Northwestern University on gene therapy to treat Parkinson's. This therapy uses vectors to deliver GDNF, a natural protein found in the brain. GDNF's job is to protect and maintain

dopamine cells so this therapy aims to deliver GDNF to stop these cells from dying. This treatment has just gone into clinical trials which is really exciting for me, especially as one of my PhD students is working on this clinical trial at the University of California. It is exciting to think that a project I worked on 15 years ago may soon be used to treat people with Parkinson's. This is where my interest in Parkinson's research came from.

What do you see as the future for the treatment and/or a cure for Parkinson's?

I think what we are looking for in terms of treating neurological diseases in the future, particularly Parkinson's, might not be therapies that come in the form of a pill, deep brain stimulation is a good example of this sort of therapy. We are looking in the future at things like gene therapy and stem cell therapy. The issue we face with Parkinson's is that when people go to their GP or a Neurologist they are already starting to have the clinical symptoms of Parkinson's as they have already lost a very large proportion of their dopamine cells. What we need to do is prevent the remaining cells from dying as we can't bring dead cells back to life. So what we are looking at is finding a therapy, to stop the remaining cells from dying. But what we really want to do is replenish or replace those lost cells. My interest in stem cell therapy came about from that potential to actually replace those dying cells. This will hopefully reverse some of those clinical symptoms and get the patients back to a pre-clinical stage where they are not showing the symptoms of Parkinson's.

There is a common perception that a cure for conditions like Parkinson's is 'just around the corner', how long away do you think it is?

Let's be realistic here, I think it is a little way off. I hesitate to say how long, 10 years or maybe five, we just don't know. The reason I am hesitating is because when we talk about stem cells there are a lot of types of stem cells. The stem cells that people think of are the human embryonic stem cells and those are the ones that most of the major international research has been focused on.

Of course, they have some ethical issues, but the major issue that is holding those stem cells back from going into clinical trials is that an embryonic stem cell is what we call pluripotent.

Pluripotent means that the stem cell can turn into any cell in the whole body. This makes them very exciting but it also means that we have to develop strategies to make sure that 100% of these cells turn into brain cells. When you transplant human embryonic stem cells, you don't transplant the human embryo stem cell. What you do is put them in a dish and expose them to chemicals that tells them that you want them to become immature brain cells. So what gets transplanted is immature brain cells. If you transplant a cell that is still an embryonic stem cell, it is still pluripotent, so it can decide not to become a brain cell, it can decide to become another type of cell, or it could decide to become tumour. Stopping this from happening is what people are working on now.

There are many studies in primates and rodents showing that we can take human embryonic stem cells, we can tell them to become dopamine cells and we can transplant them into the brain and they survive. They seem to help by replacing the cells that are missing and they seem to help the clinical symptoms of Parkinson's. The problem is that we haven't managed to come up with a strategy that means that 100% of the cells turn into immature brain cells, so this is the risk associated with this therapy. This treatment can't go to clinical trials until that risk is removed as once you put the cells in, they can't be taken out again. It isn't like if you take aspirin and you get a negative side effect, you stop taking aspirin and the side effect goes away. If you put stem cells into someone's brain, and some of those cells decide to turn into a tumour, or they don't work properly, we can't get them back out. The tumours that form from stem cells are very large, so we wouldn't want to cure Parkinson's, just to give someone brain cancer. That is what is holding stem cell therapy back and it is hard to know how quickly that research will advance. People have been working on this issue for a number of years now and haven't been able to overcome it.

You reported a breakthrough last year, turning skin cells into immature brain cells. What is the significance of this?

What we and other groups have been doing is what we call direct reprogramming of cells. This was first done by Shinya Yamanaka (who recently won a Nobel prize for this work) back in 2007. He showed that he could turn human skin cells back into stem cells, called 'induced pluripotent stem cells'. This avoided all the ethical problems associated with using human embryonic stem cells.

Our discovery was that we could take human skin cells and turn them directly into immature brain cells, so we skip the whole issue of having an embryonic stem cell and the risk of tumours. There are a couple of groups around the world that have done this using rodent cells, but we are the only ones to do it using adult skin cells. We have also done it more efficiently using just two specific genes that are used during brain development, the other groups have used 5 – 11 genes. It was a very unique eureka moment and the research has moved pretty quickly.

Once we have turned the skin cells into immature brain cells, we can then directly turn them into dopamine cells which is what is lost in Parkinson's. In addition, what is exciting is that when people try to do this using induced pluripotent stem cells, only 10 to 30% of the cells turn into dopamine cells. We can turn about 50 – 70% of the immature brain cells we create from skin cells into dopamine cells, so it is a lot more efficient.

How will this breakthrough change the search for treatments/a cure for Parkinson's?

I think the research field may switch towards this direct reprogramming strategy for transplantation. It resolves the issue of the pluripotency with stem cells and the risk of a potential tumour, so it is a safer option. It also gives the option, if the Parkinson's isn't genetic, to use the patient's own skin cells to create the dopamine cells for transplantation. Collecting the skin cells is reasonably non-invasive, it is just a skin biopsy that is taken, and there is a high yield of dopamine cells. I think it is probably the best direction to go.

The other thing we can do with these cells is to use them not only for transplantation but also to model Parkinson's. One of the reasons we don't have a lot of new therapies for Parkinson's is that we don't have a lot of access to human tissue. We have a fantastic brain bank at the Centre for Brain Research where I work but all of that tissue is usually quite 'end stage'. We don't ever really get to look at what actually happens at the beginning when we have a healthy dopamine cell and the Parkinson's sets in. What we can do is take skin cells from Parkinson's patients, turn them into dopamine cells and watch them grow. We can see how they look and act differently from the cells from a healthy person. We can try putting new drugs on them to see how they react and from this we can try to identify new drugs to treat Parkinson's.

What other conditions will benefit from this breakthrough?

Parkinson's and Huntington's are the best neurological disorders for transplantation therapy because it is a single population of cells that are lost. For conditions like Stroke and Alzheimer's transplantation is not so successful as you need the cells to turn into a whole mixture of different types of brain cells.

For using the technology to model neurological disorders, we can look at a wide range of disorders, eg Autism and Schizophrenia. This is because we are getting immature brain cells and we can watch them grow up into mature brain cells so we can see what happens as a cell develops.

Associate Professor Connor is head of the Neural Repair and Neurogenesis laboratory at the University of Auckland. The other members of the team that successfully converted human skin cells into immature brain cells are: Dr Christof Maucksch, Dr Kathryn Jones, Ms Erin Firmin, and Ms Rebecca Pearman.

A WORD FROM THE CHIEF EXECUTIVE

Tena Koutou Katoa

I hope you enjoy reading about Bronwen Connor's research into stem cells and how these may one day lead to new treatments for Parkinson's. We are fortunate to have a researcher of Bronwen's calibre working in New Zealand and congratulate her and the team she works with on their breakthrough last year turning skin cells into immature brain cells. We will continue to watch the work of this team with interest.

Nominations for our 30th Anniversary Recognition Awards have just closed. The panel of judges now have the difficult task of deciding who, of the many deserving nominations we have received, will be given an award in each category. I look forward to sharing the inspiring story of each recipient with you in the next edition of *The Parkinsonian*.

This coming year there are two very good opportunities for people with Parkinson's and their families and carers to learn more about this condition. The Asia Pacific Parkinson Association meeting will be held in Sydney in June 15-16, and The World Parkinson Congress in Montreal, Canada October 1-4.

You can read more about these meetings on page 11. Even if you can't attend, you can get involved via social media and we will be sure to report on the presentations in upcoming editions of *The Parkinsonian*.

On the back page you will see our latest fundraising appeal and ask that those of you who can support us make a donation. With your help we can ensure our publications, like our latest booklet *The Drug Treatment of Parkinson's*, are distributed to those who need it, be they with Parkinson's, carers or medical professionals. If you donate before 31 March you can claim back the tax you paid on this gift almost immediately.

Nga mihi

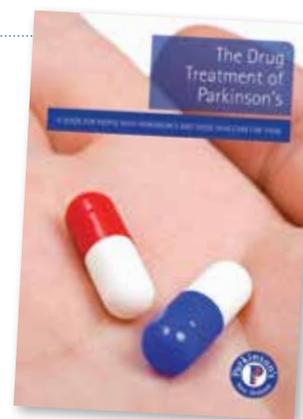
Deirdre O'Sullivan

NEW RESOURCE AVAILABLE

Parkinson's New Zealand is pleased to announce the publication of *The Drug Treatment of Parkinson's: a guide for people with Parkinson's and those who care for them*. This is the third edition of our very popular guide to the medications used in the treatment of Parkinson's.

The booklet provides general information about the drug treatment of Parkinson's and details information about each drug in a user-friendly manner. The new edition has been extensively updated to reflect developments in treatment since the last edition was published in 2007.

For a free copy of *The Drug Treatment of Parkinson's* please call 0800 473 4636 or contact your local division.



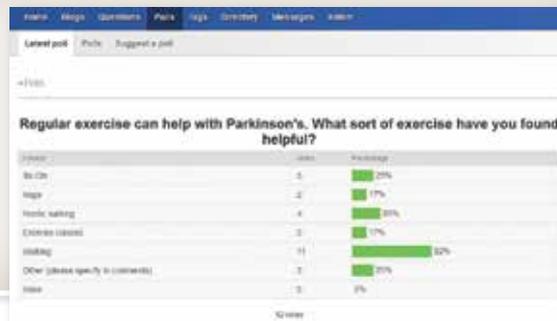
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ONLINE COMMUNITY

Parkinson's New Zealand has a growing online community on HealthUnlocked.

This is a space where you can share your experience, support one another, and become better informed about Parkinson's. You can blog, comment and ask questions, include suggesting polls like this one on exercise. Please join us at parkinsonsnz.healthunlocked.com/



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WOEFUL GAPS IN PARKINSON'S KNOWLEDGE IN THE UK REVEALED

In December 2012 Parkinson's UK ran a public awareness campaign that highlighted how hard everyday tasks can be for people with Parkinson's.

The campaign included advertisements appearing on billboards and in newspapers across the UK, showing 'scrambled' images of everyday objects such as a cup of tea and a pair of shoes. The 'mixed-up' images represent how Parkinson's can affect messages the brain gives to the body. The campaign was supported by the stories of six people who shared how Parkinson's makes simple tasks like making a cup of tea more difficult.

The campaign was aimed at increasing public knowledge about Parkinson's. Research commissioned by Parkinson's UK ahead of the launch showed what they described as a "woeful lack of knowledge" about Parkinson's. A survey of over 2,000 people in Britain found that 77% had little or no knowledge of Parkinson's. Nearly three in four people (73%) could not recognise any symptom other than tremor.

Steve Ford, Chief Executive of Parkinson's UK, commented "These findings underline what we've been hearing from people with Parkinson's across the UK – that the general public simply don't understand the condition."

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"To continue with this status quo, where Parkinson's is seen as no more than a tremor, is plainly wrong. We hope that this new campaign will help to dispel some of the lingering fallacies surrounding the condition once and for all."

The importance of the other symptoms of Parkinson's, particularly the non-motor symptoms, was highlighted by another Parkinson's UK research report. Also published in December in the *Journal of Neural Transmission*, it focused on patients' perspectives on non-motor symptoms. Drawing on answers from over 10,000 people with Parkinson's to a postal survey in 2008, the report looked at the different types of non-motor symptoms people experience, and how they change over time.



"These findings underline what we've been hearing from people with Parkinson's across the UK – that the general public simply don't understand the condition."

Key findings included –

- Around 20% of people diagnosed within the year prior to completing the survey reported one or more non-motor symptoms.
- There was a considerable increase in the number of symptoms experienced by people who had lived with Parkinson's for over 10 years.
- People who had the younger onset form of the condition reported a greater impact of non-motor symptoms, particularly in the areas of memory, depression and sleep function.
- Many people experienced problems such as constipation and losing their sense of smell before their movement symptoms appeared.

HEARING IMPAIRMENT IN PARKINSON'S – ANOTHER NON-MOTOR SYMPTOM?

An Italian study (106 people with Parkinson's) recently published in *Movement Disorders Journal* evaluated hearing impairment in people affected by Parkinson's compared to age- and sex-matched controls.

They found that the people with Parkinson's were more affected by age-dependant hearing impairment compared to both the matched control group and the levels previously reported in the literature on hearing loss.

Those with hearing loss were more likely to be older, male and have a higher age of onset, but no other clinical or demographic differences were found. They were also unaware of any problems, with none of them having reported subjective hearing impairment prior to the testing.

The authors noted that it remains to be determined if auditory problems are intrinsic to Parkinson's or secondary to more complex changes in sensory processing.

ROUND-UP OF CURRENT PARKINSON'S RESEARCH IN AUSTRALIA

There are a number of interesting Parkinson's research projects currently underway in Australia. Parkinson's NSW and Parkinson's Queensland recently updated their members on some of the projects that they are helping to support. A variety of approaches to the condition are being used.

At the more practical end of the scale, a project in Sydney is looking at the benefits for mobility and balance of a muscle power training programme using specially designed equipment. Early results seem promising but the study isn't complete as some participants are still in the three month follow-up phase.

"With the serious consequences ICD can have on people's lives, there has been considerable interest in finding risk factors for identifying who may develop them."

In Brisbane a group are working on a project entitled 'Malnutrition in Parkinson's and an individualised approach to its management'. The first phase of the project assessed the nutritional status of 125 people with Parkinson's living at home. The researchers assessed 15% of participants as malnourished. They felt that this highlights the fact that malnutrition can be an issue in Parkinson's and needs to be monitored. The second phase was a randomised controlled nutrition intervention led by a dietician. This phase is still being analysed.

Another approach being taken is looking at the therapeutic benefits of transcranial stimulation for Parkinson's. Two groups at the University of Queensland (UQ) are investigating this. One is looking at transcranial direct current stimulation (tDCS) where weak electrical currents are delivered to the brain through electrodes placed on the scalp, increasing brain activity. The treatment has been used for people recovering from strokes. The Queensland group are interested in its potential to improve walking, learning and function in Parkinson's. The trial is in the early stages.

The other UQ group are looking at repetitive transcranial magnetic stimulation (rTMS). This uses a magnetic field to simulate brain activity. They are looking at it as a treatment for speech disorders (dysarthria) caused by Parkinson's. By stimulating the region of the brain controlling the tongue, they hope to improve tongue function and speech intelligibility. Early results show some success and research with more participants continues.

Research into the root causes and mechanism of Parkinson's is also being undertaken. Parkinson's NSW is contributing to the work of research groups at Neuroscience Research Australia. One group is developing a mouse model for looking at the role of copper in Parkinson's. The researchers have previously demonstrated that copper levels are reduced in the vulnerable brain regions in Parkinson's. They need an animal model to investigate the consequences of reduced copper in Parkinson's for cell function and survival.

A second group is investigating the role of brain lipids (fats) in regulating α -synuclein (the protein that forms clumps in Parkinson's brains). They are looking at a particular lipid called sphingomyelin and its interaction with both α -synuclein and ABCA5, a protein that has been associated with a reduced risk of Parkinson's.

SILENT STROKES POTENTIALLY LINKED TO PARKINSON'S

Silent strokes happen when a blood vessel in the brain is blocked for only a very short amount of time. Often someone won't even know they have had one, as they can show no outward symptoms. However the strokes can still have lasting effects on the brain. Researchers at the University of Manchester have suggested that developing Parkinson's may be one of these effects.

The research team found that a mild stroke can result in the loss of dopamine neurons in mice. They caused a mild stroke in the striatum area of the brain. As well as resulting in inflammation and damage to that area, they also found damage in the substantia nigra (the area affected in Parkinson's). After six days there had been neurodegeneration in the area and a number of dopaminergic neurons had died.

The researchers hope to set up a clinical investigation on people who have had a silent stroke to assess dopaminergic neuron degeneration. In the meantime they are working to better understand the mechanisms of inflammation in the substantia nigra.

IMPULSE CONTROL DISORDERS IN PARKINSON'S – IT'S DEFINITELY THE DRUGS

Impulse control disorders (ICD) are potentially serious side effects of dopamine agonist therapy in Parkinson's. While on the medication, people can develop compulsive gambling, shopping or eating behaviours. While this is being increasingly recognised and publicised, in the past people have felt that they were not adequately warned of the potential. A number have sued the manufacturers.

In Australia, a national class action has been filed against the makers of dopamine agonist medications Permax (Aspen Pharmacare and Eli Lilly), Cabaser and/or Dostinex (Pfizer). The documents filed in the Federal Court in 2010 allege the companies failed to adequately warn consumers that compulsive behaviours were a possible side effect of the drugs. The action is on behalf of all people in Australia who took the medication between 1996 and 2010, developed an impulse control disorder (ICD) and who suffered a loss or damages as a result. About 200 people are reported to have joined the action.

Late in 2012 there were developments in the case with notice going out to all people who are potentially members of the group that they have until 15 February 2013 to opt-out (or be bound by the settlement). All three companies are defending the claim but in November 2012 it was reported that Pfizer would be holding initial settlement discussions.

With the serious consequences ICD can have on people's lives, there has been considerable interest in finding risk factors for identifying who may develop them. Two new studies have recently added to the picture.

A study published in *Neurology* involved 168 people who had recently been diagnosed with Parkinson's but had not yet taken any medications. They were compared to 143 people of similar ages who did not have the condition.

The study found that those with Parkinson's were no more or less likely to have the impulse control symptoms than those without it, with about 20% of each group having some symptoms.

The lead researcher commented

"These results provide further evidence that impulse control disorders that occur in people with Parkinson's are related to the exposure to the dopamine-related drugs, not the disease itself. More long-term studies are needed to determine if the 20% of people who have some symptoms of these disorders are more likely to develop impulse control disorders once they start treatment for Parkinson's."

Another study reported in *Movement Disorders Journal* followed a group of 164 people with Parkinson's for four years. The group had no previous history of ICD. Researchers were interested in the incidence and timing of developing ICD. Of the group 46 were being treated with dopamine agonists or started taking them during the study. Eighteen of them (39%) developed new-onset ICD during the course of the study. The timing of onset varied widely from three months to nine and a half years after starting treatment (median 23 months). Demographic factors were similar for both the group that developed ICD and those that didn't. Those who did develop ICD had higher rates of cigarette smoking, caffeine use, motor complications, and higher peak dopamine agonist dosage.

Note: If you or someone you care for have any concerns about dopamine agonists and impulse control disorders please discuss them with your doctor. For more information see the factsheet in the July 2012 issue of *The Parkinsonian* (also available on the website) or talk to your Field Officer.

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CYCLING AND PARKINSON'S – IT IS NOT ABOUT THE BIKE, IT IS ABOUT THE PEDALLING

There have been a number of reports that cycling can have benefits for people with Parkinson's beyond the general benefits of aerobic exercise. A new study has found that 'forced' pedalling may be key to improvements in co-ordination and balance.

In the study 26 people with Parkinson's used exercise bikes three times a week for two months. Some pedalled at their own pace, while others undertook 'forced-rate' cycling, in which they were made to pedal faster by motors fitted to their bikes.

The researchers found immediate and sustained improvements in the motor function of participants after the forced exercise, but not the voluntary exercise group.

The study also carried out brain scans of all participants using a technique called functional connectivity magnetic resonance imaging (fcMRI). The scans revealed that pedalling, particularly vigorous pedalling, boosted connections between brain regions linked to movement.

Researchers feel that the results show that forced-rate bicycle exercise is an effective, low-cost therapy for Parkinson's. They are now studying how people fare with exercise bikes in their homes. They also want to see whether other forms of exercise such as swimming and rowing have similar benefits.

The idea of testing the benefits of forced exercise came about because of an observation made by the head of the

study, US neuroscientist Jay Alberts. He and a companion who has Parkinson's undertook a long-distance tandem bike ride. After the ride he noticed improvements in her condition. As the lead cyclist he was pedalling fast, which forced her to pedal faster, and he wondered if that had had an effect.

SOURCES:

Parkinson's UK; EDPA, Parkinson's NSW, Parkinson's Queensland, Michael J Fox Foundation, sciencedaily.com, *Movement Disorders Journal*.

DISABILITY RIGHTS IN NEW ZEALAND

Late last year *Disability Rights in Aotearoa New Zealand 2012: a report on the Human Rights of Disabled People in Aotearoa* was released. The report was prepared by the Convention Coalition, a collaboration of New Zealand's Disabled People's Organisations. It monitors how New Zealand is meeting its obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). New Zealand ratified the Convention, which aims to protect the dignity of all disabled people, in 2008. This is the second report since then, the first was published in 2010.

The 2012 Monitoring Report found that disabled people in New Zealand continue to face major barriers to participation in community life and that there is a lack of disability awareness and responsiveness.

Other key findings included:

- The New Zealand government and its agencies need to partner far more extensively with disabled people, through Disabled People's Organisations.
- The government's implementation of both the New Zealand Disability Strategy and the UNCRPD through its policies, programmes and laws is fragmented, with each department developing its own implementation plans.

You can also download a copy of the report (in various formats) from www.dpa.org.nz/other-publications. Parkinson's New Zealand has hard copies of both the current report and the previous one in the library.

CHANGES TO SINEMET

Internationally there have been some changes to the appearance and formulation of Sinemet (levodopa + carbidopa). The result is that the tablets are no longer scored and **must not** be halved as there is no guarantee that halving a tablet will give an accurate half dosage.

If you use half doses of Sinemet you may need to visit your doctor to be reassessed. There is an alternative medication available called Sindopa. This is fully funded and can be used as a half dose.

If you have any concerns, please talk to your doctor.

Enduring power of attorney

Following on from the factsheet in the December edition of *The Parkinsonian* about Advance Care Planning, this edition we are looking at enduring power of attorney.

If you were no longer able to make or communicate decisions for yourself about your health or property it is important that you have someone to act on your behalf. An enduring power of attorney gives this person the legal right to do this.

There are two kinds of enduring power of attorney, one covers your property which includes not only any land or homes you own, but also other assets like shares, money in bank accounts, cars etc. The other is for your personal care and welfare. It is important to understand these arrangements as not only should you consider arranging an enduring power of attorney, you may at some point be asked to hold the enduring power of attorney for someone else. For the purpose of an enduring power of attorney, the person given the authority to act on your behalf is called an attorney.

ENDURING POWER OF ATTORNEY FOR PROPERTY

An enduring power of attorney for property can be set up to take effect either immediately or to only take effect when you can no longer manage your own affairs. You can give the attorney full power over all of your property and assets or limit the power to specific investments or property. If the enduring power of attorney is limited then this must be specified. For example if you want someone to manage your bank accounts while you are out of the country, it needs to be specified that the enduring power of attorney is only for your bank accounts, not all of your assets. For property, more than one person can act as your attorney and the enduring power of attorney can be granted to a trustee company.

ENDURING POWER OF ATTORNEY FOR PERSONAL CARE AND WELFARE

This enduring power of attorney will only come into effect if you are no longer capable of making or communicating decisions for yourself. Only one person may act as an attorney for personal care and welfare. They may act in relation to your personal care and welfare in general, or only in relation to specified areas. These areas include not only medical treatment but also things like admission into residential care or a rest home.

There are limits on what a personal care and welfare attorney can decide. They legally can not:

- make decisions about you entering into a marriage/civil union or divorce
- adopt out your children
- consent to you receiving some sorts of medical treatment (eg electro-convulsive treatment or brain surgery to change your behaviour)

- refuse consent for reasonable life saving medical treatment
- consent for you to be involved in most medical experiments

WHO DECIDES IF I AM MENTALLY CAPABLE?

It is not your attorney who decides if you are still mentally capable.

In relation to property, you are considered mentally incapable if you are no longer completely competent to manage your own property affairs. If your enduring power of attorney for property only comes into effect once you are mentally incapable, then a certification of mental incapacity will be required before the attorney can make any decisions for you.

For a personal care and welfare enduring power of attorney to come into effect you will need to be unable to: make or understand decisions, understand their consequences, or communicate these decisions to others.

Where there is doubt there is an automatic presumption that the donor is mentally capable until it is proven they are not.

For significant matters, certification of mental incapacity may be required from a relevant health practitioner, or a court may need to determine whether the attorney is able to act. You can specify the type of health professional you would like to make the assessment of your mental capability when you set up your enduring power of attorney. You may wish this to be your GP who knows you well, a specialist like a geriatrician, or some other medical person so long as they are experienced at this sort of assessment.

SELECTING AN ATTORNEY

You need to think carefully about who to appoint as your attorney. You need to be sure that they will always act in your best interests and that the decisions they make are in line with the decisions you would make. An attorney managing your assets should have the skills needed to do this.

There are some legal restrictions on who you may appoint as an attorney. The person must be at least 20 years old, they must be mentally capable and not be bankrupt. For property, you can appoint more than one person and you need to specify if each attorney can act alone or if they need to act together.

It is often suggested that you don't appoint the same person to be both your personal care and welfare attorney and your property attorney. Different skills are needed for these roles and you will probably be better served appointing one person to look after your personal care and another to oversee your property affairs. Also, where different attorneys are appointed they are required to consult each other regularly to ensure there is no

FACT SHEET

"If you were no longer able to make or communicate decisions for yourself about your health or property it is important you have someone to act on your behalf. An enduring power of attorney gives this person the legal right to do this."



break down in communication that might affect your interest. Should there be a conflict between them the personal care attorney's decision is given priority. However, either attorney can apply to the Family Court for direction.

WHAT IF I CHANGE MY MIND ABOUT WHO I HAVE APPOINTED?

So long as you are considered mentally capable, you may change or cancel your enduring power of attorney at anytime. Making a new enduring power of attorney does not automatically revoke your existing enduring power of attorney. If you change or cancel your enduring power of attorney you must ensure you write to your attorney advising it has been changed or cancelled. You should also advise banks and anyone else who may operate under the enduring power of attorney of the changes or cancellation.

You can also appoint a successor to your attorney. This means that should your preferred attorney be unable to act on your behalf, you have another person who can make these property or personal care decisions for you.

WHAT HAPPENS IF I DON'T HAVE AN ENDURING POWER OF ATTORNEY?

If you don't have an enduring power of attorney and become incapable of managing your own affairs the Family Court has the power to make orders on your behalf. However the Family Court will only intervene if it is absolutely necessary.

HOW DO I MAKE AN ENDURING POWER OF ATTORNEY?

While you are not legally required to have a lawyer to make an enduring power of attorney there are many advantages to using one. A lawyer can give you independent advice

and suggest terms you may wish to include in your enduring power of attorney.

Under the *Protection of Personal and Property Rights Act (1988)* an enduring power of attorney must be created using a special form. These are available from lawyers and trustee companies. The form must be signed by both you and the attorney you are appointing and witnessed. There are strict guidelines over who may witness your signature. This witness has a legal obligation to explain the legal consequences of the enduring power of attorney. They must also sign a document certifying they have no reason to suspect you are mentally incapable.

HOW DOES AN ENDURING POWER OF ATTORNEY VARY FROM:

POWER OF ATTORNEY

An ordinary power of attorney may be for a fixed term with an expiry date, or may be valid until it is cancelled. However an ordinary power of attorney is only valid while you are mentally capable as under this authority the attorney can't have more power than you.

ADVANCE CARE PLAN FOR PERSONAL CARE

This is a plan for your health and welfare that allows you to set out your wishes for your care should you be no longer capable of making or communicating these wishes. An advance care plan is not legally binding and should be set up in association with an enduring power of attorney for personal care and welfare. For more information on Advance Care Planning, see the December 2012 edition of *The Parkinsonian* or our website.

Communication skills – being more assertive

Carers have to interact with a wide variety of people in the context of their role which makes being able to communicate effectively very important. As well as the person they care for, carers will be communicating with a variety of health professionals, family and friends. Often this will involve asking for advice or support. Not everyone finds asking for help easy. Especially if in the past it has not been forthcoming or it seemed like a battle to be heard and understood.

Carers may need to be able to give clear instructions or relay information, say from their GP to other family members. You may also be required to make some difficult decisions and stick to them.

In all of these situations assertiveness is an important communication skill to have. Being assertive gives you the best chance of successfully delivering your message. If you communicate in a way that's too passive or too aggressive, your message may get lost because people are too busy reacting to your delivery.

SO WHAT DOES BEING ASSERTIVE MEAN?

Being assertive is about 'making sure your voice is heard' and being able to clearly explain how you feel about something, what you need, or why you feel something should be done a certain way. Assertive communication is based on mutual respect. As well as asserting your right to express your ideas, emotions and thoughts, you respect the other person's right to express their perspective and feelings. You also demonstrate that you are willing to work on resolving conflicts.

Some people seem to be naturally assertive. But if you're not one of them, it is a skill or communication style that you can learn.

HOW CAN YOU BE MORE ASSERTIVE?

The best place to start is to examine how you currently communicate with other people. Do you voice your opinions or remain silent? Do you have trouble saying no to people? These are both indicators you have a passive communication style. Are you quick to judge or blame? Do people seem to dread or fear talking to you? These are signs you tend towards being aggressive. Understand your style before you begin making changes.

When making changes look to your body language. Your body language makes a big impact on the way other people perceive and treat you. Act confident even if you aren't feeling it. Keep an upright but relaxed posture. Make regular eye contact and avoid dramatic hand gestures. Maintain a positive or neutral expression.

Use 'I' statements to let the other person know what you are thinking or feeling without sounding accusatory. Say 'I disagree' rather than 'you are wrong'. Remember that you have choices, so say 'I could' or 'I might' instead of 'I must' or 'I should'.

Keep conversations clear and specific. Know, as much as possible, before the start of the conversation what you want to say and/or

what you want to achieve. Stick to the specific topic and the present situation.

Practice saying 'no'. Many people feel bad about saying no to others. But agreeing to something you don't really agree with or don't actually have time for just to keep the peace is not good for you or your relationships in the long run. You are allowed to say 'no' and in most situations you do not have to apologise or justify yourself for doing so. Be clear and direct. If an explanation is required, keep it brief.

Keep your emotions in check. Conflict is difficult for most people. It can make you feel angry, frustrated or teary. While this is natural, it can get in the way of resolving the situation. If possible wait until you are feeling more centred before starting difficult conversations. If not, work on keeping calm. Breathe slowly and try to keep your voice even and firm.

Becoming more assertive takes time and practice. Start out small and in low risk situations. Practice with a friend who you trust to give you honest feedback. Once you have identified ways to be more assertive, your confidence will improve.

More information: there are many books and resources available on assertiveness, including some specifically for carers, e.g. on carewelluk.org. Training on assertiveness is also available, and may be offered by your local school or community centre.



If you or someone you know would like to raise funds for Parkinson's New Zealand, please contact Louise 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.

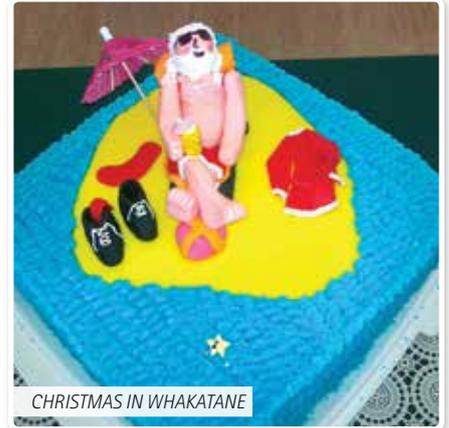
NEWS FROM AROUND THE COUNTRY



ANN ANDREWS QSM



LAVENDER LANE TARANAKI



CHRISTMAS IN WHAKATANE

"This Christmas one of their members was in hot demand as Father Christmas at local events. He was paid for his 'work' and donated the proceeds to Parkinson's."

CONGRATULATIONS TO BEVERLEY CHAPPELL MNZM AND ANN ANDREWS QSM

Two very deserving members of the Parkinson's community were recognised in the 2013 New Year's Honours List.

Beverley Chappell of Waikanae was made a Member of the New Zealand Order of Merit (MNZM) for services to senior citizens and the community. Beverley has spent hundreds of hours volunteering for our Society and our members, particularly in the Kapiti area. A nurse and midwife, she was honoured not only for her work with Parkinson's, but also a number of other community organisations. Her work with older people includes membership in the Ministerial Advisory Council for Senior Citizens from 1997 to 2002.

Auckland member and author of *Positively Parkinson's* Ann Andrews was awarded the Queen's Service Medal (QSM) for services to the community. Ann's award recognised her contribution to the Parkinson's community, as well as to teaching and to the deaf, to documentary film and theatre and Auckland's heritage and environment.

TARANAKI

At the end of January a small group from Taranaki visited Lavender Lane, a lavender farm and distillery just out of Stratford. They were shown around the steam distillery and learned about the process to extract lavender oil, by Karen whose father has Parkinson's. They also wandered through the lavender fields and enjoyed the beautiful colour on a wonderful fine day.

SUCCESSFUL FUNDRAISING

The Waikato division held a successful Garage Sale at the end of 2012. Eight volunteers decked out in black felt hats decorated with pink ribbons and flowers sorted, priced and sold goods ranging from 10c magazines to an \$80 treadmill. They had a great day and raised about \$800.

Members for Kapiti Horowhenua have been finding some novel ways to raise funds for their division. This Christmas one of their members was in hot demand as Father Christmas at local events. He was paid for his 'work' and donated the proceeds to Parkinson's. Another has a yearly flutter on the Melbourne Cup. In November she not only picked the winner, but she won an office sweepstake too and donated them to her division. Thanks to both members, donations were boosted by almost \$200.

CHRISTMAS CELEBRATIONS

December saw fun-filled lunches and morning teas up and down the country as divisions celebrated Christmas and the end of another eventful year. The lunch held in Whakatane had a wonderful turnout and featured a gorgeous cake (pictured). Made by retired Field Officer Lynette and decorated by a friend it was a highlight of the event.

COMING UP - BRAIN AWARENESS WEEK

In 2013 Brain Awareness Week runs from 11-17 March. There are a number of seminars and public lectures on brain research happening around the country including

- Queenstown Public Lecture: Monday 11th March
- Brain Day Auckland: Saturday 16th March
- Brain Day Dunedin: Saturday 16th March
- Brain Day Wellington: Saturday 23rd March
- Brain Day Christchurch: Saturday 23rd March

For more details see www.brainweek.co.nz/events or contact your local division.



The Congress brings together physicians, scientists, allied health professionals and people living with Parkinson's to share information on a wide range of topics from living with Parkinson's to highly scientific research presentations.

Auckland member, Lloyd Jenkins who attended the last congress three years ago described it as "really worthwhile".

As part of the congress there is a video competition and we strongly encourage our members to enter this. Further information is available at worldpdcongress.org.



To take advantage of the international experts attending the Movement Disorders Society Congress in Australia (this congress is targeted at researchers and clinicians) the Asia Pacific Parkinson Association will be holding a patient meeting in **Sydney June 15 – 16**.

This meeting will cover a wide range of topics of interest to people with Parkinson's their families and carers.

Further information is available at movementdisorders.org. Registrations open March 12.

EXERCISE

Daily stretches can help maintain flexibility.

CHEST STRETCH

- (1) Stand up tall and clasp your hands behind your back
- (2) Gently lift your hands up as you breathe out, pulling your shoulder blades together at the same time
- (3) As you breathe in lift your chest up
- (4) Hold for 5 slow breaths



"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

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
Mobility Manawatu, 222 Ruahine St, Palmerston North

Call 0800 882 884
Email info@ustep.co.nz

THANK YOU



WE NEED YOUR HELP

We need your help educating healthcare workers about Parkinson's and its treatment.

The medications for Parkinson's can be very effective at controlling symptoms, but taking the right medication at the right time is critical. Unfortunately, not everyone caring for people with Parkinson's knows or understands this. During short-term stays in hospital or longer-term moves to a rest home, not getting their medications on time can cause serious set-backs for people with Parkinson's.

That is why it is vital that Parkinson's New Zealand's information, education and resources reach healthcare workers as well as people with Parkinson's. It is why the new edition of *The Drug Treatment of Parkinson's*, our new guide to the medications used to treat Parkinson's (see page 3), is aimed at those who care for them, as well as people with Parkinson's.

You can help ensure that the workforce caring for people with Parkinson's have the information they need to do a good job by supporting our education programmes.

PLEASE MAKE A DONATION TODAY TO HELP US PROVIDE RESOURCES AND EDUCATION FOR PEOPLE WITH PARKINSON'S AND THOSE WHO CARE FOR THEM.



Yes! I want to make a donation today to help people with Parkinson's:

Name: _____

Address: _____

Phone number: _____ Email: _____

Here is my gift of:

- \$25** provides information packs for two newly diagnosed people
- \$50** covers the cost of 30 people calling our free phone line for advice and information
- \$100** helps pay for training for a field officer
- \$ _____ my choice
- Please send me a free copy of *The Drug Treatment of Parkinson's: a guide for people with Parkinson's and those who care for them*

CALL OUR CREDIT CARD DONATION HOTLINE: 0800 473 4636 (answerphone after hours)

My cheque is enclosed made payable to Parkinson's NZ Please charge my Visa Mastercard

Card number: _____ / _____ / _____ / _____ Expires: _____ / _____

Card holders name (as it appears on your card): _____

Signature: _____

Online banking - Parkinson's New Zealand, Account Number: 03 0502 0727744 00
Please include your Supporter Number (if known) as Reference and 'Education' as the Code.

Please return in the envelope provided or send to **Parkinson's NZ, PO Box 11067, Manners Street, Wellington.**

Remember donations over \$5 are eligible to receive a tax rebate of up to 33.3%.

Thank You!