World Parkinson's Day is 11 April 2017 – Join us

This World Parkinson's Day join the global Parkinson's community and #UniteforParkinson's.

11 April is a very important date in the calendar for Parkinson's organisations throughout the world. World Parkinson's Day commemorates the birthday of James Parkinson. The son of an apothecary/surgeon, James Parkinson was born on 11 April 1755. World Parkinson's Day is now held on 11 April each year.

James Parkinson studied at the London Hospital Medical College, qualifying as a surgeon in 1784 when he was 29. He is most famous for publishing “An Essay on the Shaking Palsy” in 1817, which first described “paralysis agitans” and established Parkinson’s as a medical condition. Surprisingly, given the condition was named after him, this was James Parkinson’s only work on the subject.

James Parkinson had many other medical and surgical interests. His practice was a large, lucrative one at Hoxton Square, Shoreditch, London, which also cared for the poor of the parish. He had a keen interest in the wellbeing of people with mental illness, working at a local asylum for more than 30 years. He was also a social reformer and political activist who championed many causes.

It is likely that James Parkinson would marvel at the progress that has been made in diagnosing, understanding and treating the condition that bears his name. But Parkinson probably would be surprised and disappointed to discover that two centuries after his essay was published we are yet to find a cure.

2017 is 200 years since Parkinson’s was recognised as a medical condition. This World Parkinson’s Day provides a great opportunity to unite the global Parkinson’s community. Parkinson’s organisations and supporters around the world are coming together to raise awareness. The theme for the day is unite for Parkinson’s.

By uniting for Parkinson’s we can spread the same message on the same day all over the world, and going forward we can make World Parkinson’s Day a global platform to encourage a bigger focus on Parkinson’s.

GET INVOLVED

We want New Zealand to take up the challenge and connect with new people or a new community to unite for Parkinson’s in New Zealand. To keep up to date with what’s happening keep in touch with your local branch or division. A number of divisions will be holding seminars and other events to celebrate 200 years of progress in understanding Parkinson’s, its treatment and progress toward a cure.

All branch and division contact details are on our website or email us at info@parkinsons.org.nz or call 0800 473 4636 for more information.

We need as many people as we can muster to show support and be part of the international unity on World Parkinson’s Day. To get involved online use the hashtag #UniteForParkinsons on World Parkinson’s Day. Spread the word, share your stories and unite for Parkinson’s wherever you can on your social media channels. Encourage your followers to get involved too.

Be sure to follow us on Facebook www.facebook/parkinsons.nz or Twitter: @parkinsonsnz and visit our website www.parkinsons.org.nz for links to media coverage.
Report from the market place

The information showcased offers practical advice about living with Parkinson’s.

It’s great to know that there are always innovators applying their ingenuity and experience to make life easier for people with Parkinson’s and their carers by developing new products.

It’s often the simple little ideas that change people’s lives.

For example at the World Parkinson Congress (WPC) in Portland, Oregon (USA) in September, Parkinson’s New Zealand spoke with a retired Canadian physiotherapist, Nancy Ellen McGovern. Nancy has pioneered some new technology to make bedding more comfortable, with less friction and easier to move on.

Nancy had consulted with nurses who said that there were often issues with patients not being able to roll over or prop themselves up in bed easily with their help, let alone unassisted, because of the friction between their garments and their bottom bed sheets.

Nancy searched high and low to develop fabrics that created less friction and while she was at it developed much more attractive bed sheets because people with Parkinson’s and their carers didn’t necessarily want their home to look like a hospital. There were already some products but they were not available outside hospitals, were only suitable for beds the same size as hospital beds and were visually unattractive. Nancy managed to mitigate all of these issues.

She says she had the risk of skeletal-muscular injury that helpers were exposed to at the front of her thinking. This was especially relevant with heavier patients who were spending considerable time in bed and typically didn’t have the benefit of an adjustable bed.

She also added a safety border to beds to reduce the risk that people would roll or fall out of bed which is another issue faced by carers and people who spend more time in bed than usual because of health conditions.

People’s rough heel skin can test the durability of a bed sheet too and Nancy put considerable thought into this alleviating this problem. She changed her satin weave so that the filaments were finer but there were more of them packed into each space, making the sheets much tougher and durable.

LifeWalkers are an interesting variation on the usual walkers you see around the place, and were exhibited at the WPC. The LifeWalker keeps you upright and at eye level, allowing for face to face contact. The LifeWalker Upright, its website claims, addresses the deficiencies of current walkers, including fall risk, slouching, and lack of user confidence and comfort.

They have what is claimed to be a “high tech metal frame” and, crucially, are adjustable to give your upper body support in a way more traditional walkers are not. www.lifewalkermobility.com.

Global Kinetics Corporation exhibited at the WPC too, with its just released Personal KinetiGraph, a movement recording device to assist doctors in treating and managing their patients with movement disorders.

The PKG Data Logger is a wrist-worn device that records movement associated with bradykinesia, dyskinesia and fluctuations. The unit is a watch capable of providing important mobility information to your doctors.

The system provides continuous assessment of movement disorder symptoms, such as tremor, dyskinesia and bradykinesia during activities of daily living and in the patient’s home environment.

It also correlates the frequency and severity of symptoms and the use of Parkinson’s medication.

Events such as the WPC provide a useful opportunity but local services also stock helpful products and can help you on an
In this issue of *The Parkinsonian* we celebrate 200 years of progress in understanding and treating Parkinson’s. I hope you will find our overview of 50 years of treatment of Parkinson’s on page 6 of interest. Researchers are currently exploring many areas that hold promise for improvements in the treatment Parkinson’s.

As you will know, each year Parkinson’s organisations and people across the world observe 11 April as World Parkinson’s Day. I am delighted to announce the launch of a campaign that we have helped develop with our friends at the European Parkinson’s Disease Association and Parkinson’s UK: #UniteForParkinsons. All you need to do to join the social media campaign is to use the hashtag #UniteForParkinsons on 11 April so we will raise the same awareness message about Parkinson’s all around the world on the same day. Please share news on this campaign from now until the big day with all your friends, family, colleagues and networks, especially the tech savvy younger people you know.

In the UK last year a grant of about $25,000 was awarded to the inventor of a smart walking stick, which is designed to prevent freezing of gait and enable its user to walk normally. When the device detects a pause in motion, it sends rhythmic vibrations to the handle, helping the user regain their natural walking motion.

A product design technology university graduate, Neha Shahid Chaudhry, was inspired to invent a mobility aid after witnessing her late grandfather struggle with freezing of gait and subsequently falling, because of his Parkinson’s. Neha said: “People with Parkinson’s get jammed in one place and can’t step forward—it can cause falls. They need any kind of rhythm or sequence to get them started again, because it acts as a reminder. The beat is inside the handle—it senses when you stop and turns off automatically when you start walking again. People with Parkinson’s say it encourages them to walk and they learn to keep pace with it.”

The device is designed to look like a conventional walking stick. Its vibrations can only be felt and not heard; to ensure that it doesn’t draw attention to the user and reduces the likelihood they will be embarrassed about their condition.

In Singapore, a wearable device designed to shorten the freezing episodes of people with Parkinson’s won an innovation award in January. The wearable monitoring device, designed by a team of three students from the city-states’ National University, wirelessly monitors patient’s movements, and when a freezing episode is detected, helps initiate normal activity. Judges rated the products on criteria including social impact and commercial viability.

These innovations and products and many others have the potential to change lives.
PARKINSON’S MAY BE TRACED TO GUT BACTERIA

Gut microbes may play a critical role in the development of Parkinson’s, according to ground-breaking new research published in December in Cell.

The US research team showed that treatment with antibiotics was able to reduce movement symptoms and the build-up of clumps of alpha-synuclein in mice with a gene that causes the condition.

The findings could lead to new treatments that can slow, stop or even prevent the development of the condition.

Researchers based at the California Institute of Technology studied mice with a small genetic change that causes them to produce too much of the protein alpha-synuclein.

As the mice age, they naturally develop clumps of alpha-synuclein inside brain areas in controlling movement, and mobility problems similar to those experienced by people with Parkinson’s.

The researchers raised the mice in either normal conditions or in a germ-free environment. Remarkably, mice raised in the germ-free cages had almost normal mobility and much reduced build-up of protein clumps in their brains.

Treating mice in normal conditions with antibiotics had a similar protective effect.

Crucially, when mice raised in the germ-free cages were treated with chemicals released by gut microbes or gut microbes from people with Parkinson’s their movement problems worsened.

In recent years, evidence has been growing that Parkinson’s may begin in the gut, but the chain of events has so far remained a mystery. This study provides a fresh insight into how Parkinson’s develops and exciting new opportunities to develop treatments that can intervene.

Current antibiotics are not a viable option as we know that long-term, high-strength antibiotic uses comes with significant health risks.

Up to a trillion microbes live in our gut. Many are beneficial so the next step is to pinpoint those that are harmful so that treatments can be developed to target the damaging ones while leaving the beneficial ones unharmed.

However, studies of mice may not translate well to human situations. It takes many years to turn a scientific discovery like this one into a new treatment that can be tested in people.

Source: parkinsons.org.uk | michaeljfox.org

MAKING PARKINSON’S DRUGS WORK BETTER FOR LONGER

Interim results from an early-stage clinical trial of a new gene therapy treatment for Parkinson’s suggest it could help people with the condition respond better to medication.

The therapy, developed by US pharmaceutical company Voyager Therapeutics, aims to use genes to treat those in more advanced stages of Parkinson’s.

Levodopa is a chemical building block that is converted in the body to dopamine—the chemical that is lost in people with Parkinson’s.

It’s one of the main drugs used to treat Parkinson’s but it can become less effective as the condition progresses.

In people with more advanced Parkinson’s it can be harder to convert levodopa to dopamine as they have lower levels of a key enzyme, called AADC.

The new gene therapy treatment, called VY-AADC01 aims to increase the levels of this crucial enzyme which people with Parkinson’s lack so they can produce dopamine more easily.

In this Phase 1b trial, 10 people with advanced Parkinson’s received an injection of VY-AADC01 into the area of the brain affected by Parkinson’s.

The results showed that the group who received the highest dose of the treatment responded better to levodopa and were even able to reduce their medication after six months.

The study also reported increased activity of AADC enzymes in the part of the brain affected by Parkinson’s after six months.

The company are now planning a larger study—including a placebo group who won’t receive the treatment—towards the end of 2017.

It’s still early days and more time is needed to evaluate the results, but this treatment offers significant promise for helping current Parkinson’s medications work better for longer.

Source: parkinsons.org.uk | michaeljfox.org

NTCELL CLINICAL TRIAL UPDATE

The clinical trial involving injecting specially encapsulated pig-derived cells into the brains of people with Parkinson’s has passed another milestone.

In December Auckland biotech company Living Cell Technologies announced it has completed treatment of all six patients in a second group of its cell therapy NTCELL for the potential treatment of Parkinson’s.

NTCELL is a capsule that contains clusters of neonatal porcine choroid plexus cells sourced from a unique herd of designated

Source: parkinsons.org.uk | michaeljfox.org
pathogen-free pigs bred from stock originally discovered in the remote Sub-Antarctic Auckland Islands.

As part of a trial led at Auckland City Hospital, four patients had 80 NTCELL microcapsules implanted into the putamen on each side of their brain, and two patients had sham surgery with no NTCELL implanted.

The next step was to look at another trial of six patients with another dose of NTCELL, this time involving the implantation of 120 microcapsules.

The current phase of the trial aims to confirm the most effective dose of NTCELL, define any placebo component of the response and further identify the initial target Parkinson’s subgroup.

If this preliminary trial was successful, the company would apply for provisional consent to treat paying patients in New Zealand by the end of next year.

Source: lctglobal.com | Nzherald.co.nz

NEW FINDINGS FROM “100 FOR PARKINSON’S” STUDY

The team behind the “100 For Parkinson’s” global study have released more data showing some of the differences in mood, stress and sleep quality in people with Parkinson’s, compared to those who don’t have the condition.

Launched in February 2016, the study has been gathering data donated by participants who track symptoms of their choice—depending on what matters most to them—via their smartphones for 100 days. To date, more than 4,000 participants from the UK and the US have logged information, making it one of the world’s largest ever health studies.

The most recent analysis shows that people with Parkinson’s experience a lower-than-average mood, feel more stressed and report that their quality of sleep is significantly poorer than other people who have contributed data to the study.

People with Parkinson’s have rated their stress levels as 3.75 (with 1 being ‘depressed’ and 5 ‘very happy’) on average, versus 4.05 for non-Parkinson’s participants.

People with Parkinson’s have rated their mood as 3.65 (with 1 being ‘anxious and stressed’ and 5 ‘no stress’) on average, versus 3.95 for non-Parkinson’s participants.

People with Parkinson’s have rated their sleep quality as 3.30 (with 1 being ‘very poor’ and 5 ‘very good’) on average, versus 3.80 for non-Parkinson’s participants.

Of the participants, 39% have Parkinson’s, 6% care for someone with Parkinson’s and 56% are people who don’t have the condition. The study has captured over 1.24 million symptoms data points so far and hundreds of thousands of other data points that participants have logged from diary entries, medication tracking and the scores from neurology games.

New participants could join the study until 1 December 2016. The team of researchers are conducting further in depth analysis from January 2017.

Source: parkinsonslife.eu | 100forparkinsons.com

VIBRATING SMART WATCH

Emma Lawton is 33 and lives with Parkinson’s. One of her challenging symptoms is a tremor in the hand that she normally writes with, which is less than ideal as a professional graphic designer. But a new television documentary shows her rediscover her ability to draw again, thanks to some brilliant innovation.

Designer Haiyan Zhang created the technology as part of a new BBC documentary series called “The Big Fix with Simon Reeve” that follows some of the UK’s top engineers and designers as they invent life-changing solutions for people living with chronic conditions.

Zhang, innovation director at Microsoft Research, was determined to help Watson by creating a device to restore control over her pen. Haiyan’s idea is informed by her previous work as a software engineer where she created applications for the biomedical and data-mining industries.

In building the tremor-reducing device to help Lawton, Haiyan based her invention on the gyroscope principles used in vibrating cutlery technology (e.g. Liftware’s electronic spoon). The wearable watch vibrates in opposition to the uncontrollable tremor in Lawton’s hand and allows her to control the pen with much more accuracy.

Lawton says the watch—named the “Emmawatch” after her—has changed her life.

Though the watch works well for Lawton, because the symptoms of Parkinson’s vary between individuals, Zhang will have to test the device more before knowing how widely it can help. The team is currently exploring how they might take the project forward.

For more about Liftware please see the June 2014 issue of The Parkinsonian.

Source: parkinsonslife.eu | mirror.co.uk
Building on 50 years of levodopa therapy

As the Parkinson’s community enters the 200th anniversary since James Parkinson wrote “An Essay on the Shaking Palsy” which first described Parkinson’s, it reflects on advances in the current medication treatment of Parkinson’s from the past half century.

Remarkably, although London doctor James Parkinson evaluated only three patients in his clinic and observed another three on the street, he accurately described almost all the classical clinical features of Parkinson’s in 1817. Some 50 years later, French neurologist Jean-Martin Charcot recognised the importance of Parkinson’s work and named the condition after him. In the intervening years, there have been a number of advances in the medication treatment of Parkinson’s.

Early in the twentieth century it was found that an area of the brain called the substantia nigra is affected in Parkinson’s. But the association between Parkinson’s and loss of dopamine (a chemical in the brain) was not made until the 1950s and 1960s, when chemical differences in the brains of people with Parkinson’s were identified. Low levels of dopamine cause the degeneration of nerve cells in the substantia nigra.

It was this discovery that led to the first effective medication treatment to manage symptoms of Parkinson’s. In the 1960s the drug levodopa was first administered to treat the motor symptoms of Parkinson’s and has since become the “gold standard” in medication. Levodopa is a chemical that is converted to dopamine in the body, which then replenishes the deficiency of dopamine in the brain. Levodopa is highly effective in controlling most motor symptoms of Parkinson’s. It remains the cornerstone of Parkinson’s therapy nearly 50 years after it was introduced, and a large majority of people with Parkinson’s receive levodopa therapy.

Many doctors find levodopa treatment very effective, but some doctors delay treatment with levodopa because of its side effects, particularly the development of involuntary movements (dyskinesias) and motor fluctuations. An update of levodopa treatment was recently presented by experts at the 2016 World Parkinson Congress (WPC) in Portland, Oregon (USA). Neurologist Dr John C Nutt’s (Oregon Health and Science University, USA) special lecture was received with interest.

In the initial years of levodopa treatment it is usually not necessary to avoid taking it with meals. Over time, however, people will have a better response to the medication if they take it before meals. One of the reasons for this is that dietary protein can interfere with the absorption of the medication. Levodopa is absorbed into the bloodstream and then into the brain via the stomach. Levodopa is chemically similar to some amino acids, which are the building blocks of protein. This means that proteins use the same pathway for absorption into the bloodstream or brain and can compete with levodopa for absorption.

These factors contribute to the fluctuating response to levodopa. A variety of methods to produce continuous delivery of levodopa via the gastrointestinal tract or to bypass the gastrointestinal tract altogether are entering the market or are in clinical trials. Dr Nutt says it is possible to imagine methods to improve the entry of levodopa into the brain by changing the levodopa blood-brain transport system. However, it is not known whether overcoming these challenges will be enough to produce a continuous “on” state.

Dr Nutt says the response to levodopa changes with long-term administration and progression of Parkinson’s. Motor fluctuations which have been mild and often unnoticed early in the treatment appear. But another change is the long-duration response, a response to dopaminergic drugs that develops over weeks with repeated dosing. If the origin of the long-duration response was understood, it could be manipulated to therapeutic benefit.

Oral administration and even new methods to administer levodopa continuously cannot mimic how dopamine is released in the brain. Dr Nutt suggests that feedback loops based on physical or brain activity could tailor delivery of levodopa in relation to need. In advanced Parkinson’s it can be harder to convert levodopa to dopamine, but researchers are looking at remodelling areas of the brain by grafting or gene therapy to overcome these challenges.

The past 200 years have seen many exciting developments in our understanding of the condition first formally described by James Parkinson. The introduction of levodopa has provided miraculous control of the motor symptoms of Parkinson’s, but has also resulted in side effects with dyskinesias and motor fluctuations. Fifty years later, there are a number of challenges in levodopa treatment, but there are also many opportunities to improve the use of levodopa in Parkinson’s.

BRAIN AWARENESS WEEK FROM 11 MARCH

A series of lectures and Brain Days are held around the country to mark Brain Awareness Week.

Go to www.brainweek.co.nz to find out more.
Parkinson’s and eye problems

Some people with Parkinson’s experience eye problems.

Experiencing eye problems is not uncommon among people with Parkinson’s. Such problems are often related to Parkinson’s or its treatment but may be due to other causes such as cataracts or glaucoma.

Not everyone will have eye-related symptoms. If you’re having problems with your vision or your eyes, please see your GP, specialist or talk with your Parkinson’s Community Educator.

Many people with Parkinson’s have issues with balance and walking and may experience falls. If you have visual problems this may further increase the risk of you having a fall.

The most commonly reported eye problems by people with Parkinson’s are dry eyes, blurred vision, double vision, excessive watering of the eyes. As with many other aspects of Parkinson’s these problems may be worse if you are tired.

Other common problems include involuntary closure of the eyelids (blepharospasm), visual hallucinations and glaucoma.

DRY EYES
People with Parkinson’s often blink less frequently. Blinking helps to cleanse the eyes by removing dust and impurities. If you blink a lot less, impurities can build up making your eyes dry or sore. Some Parkinson’s medications can cause dry eyes.

BLURRED VISION/DIFFICULTY FOCUSING
Blurred vision, especially when reading, can be due to Parkinson’s itself but it can also be a side effect of Parkinson’s drugs, particularly those with an anticholinergic effect. The problem may arise when you first take the drugs, and may improve over time. Alternatively, it may occur when you have taken the drugs for some time or when you adjust your dose.

DOUBLE VISION
Double vision is often caused by problems in converging the eyes onto a near object (e.g. newsprint or mobile phone). There are other causes of double vision that are unrelated to Parkinson’s and you should seek advice from your GP or specialist.

EXCESSIVE WATERING OF THE EYES
If you are producing too many tears, this can lead to blurred vision among other problems.

REduced CONTRAST
You may find that you have more difficulty than previously in seeing when you’re in lowly lit environments. You may also be unable to clearly make out the shape of images, such as a light coloured object on a light background. Fine print may be harder to read.

COLOUR VISION
A minority of people with Parkinson’s may have difficulty in discriminating between small differences in colour. This problem may be worse for shades of blue or blue/green. However, these changes are usually very subtle and not cause any noticeable symptoms.
VISUO-SPATIAL ORIENTATION

Some people with Parkinson's have difficulty in judging the space around them. You may find it hard to assess the distance between objects and might experience problems in negotiating your route when walking past objects or through narrow spaces. Remember that problems with visuo-spatial orientation may affect your driving.

VISUAL HALLUCINATIONS

Many of the Parkinson's medications can be associated with hallucinations in some people. These hallucinations are generally images of non-existent people or objects. If you experience hallucinations you should report this to your doctor or Parkinson's nurse.

GLAUCOMA AND PARKINSON'S

Glaucoma is where the pressure within the eye builds up and when severe may result in damage to the optic nerve.

If you have glaucoma, eye pressures may increase with some Parkinson's medication. Tell your GP, specialist or Parkinson's Community Educator if you have this condition.

TREATMENT/PREVENTION

People with Parkinson's can experience a range of problems with their eyes and eyesight. Although these problems are sometimes related to Parkinson's or the drugs used to treat it, it's important to remember that your difficulties with eyesight may be due to other factors. Whatever the cause of the problem, it is important to seek professional advice.

Regular eye tests will help spot any problems and help you look after your eyes. Your GP, specialist or Parkinson's Community Educator can refer you to an eye and vision health professional to help treat your problem. It's also important to drink plenty of water for optimal eye health, especially if you're suffering from dry eyes, or believe you may be susceptible to this.

Some of these eye-related problems may improve with a change to your medication regime, whether it is changing the medication, increasing the dosage, or reducing it.

If you wear glasses, a modification to these may improve blurred vision. If you are stooping because of Parkinson's you may find keeping your glasses on more difficult. A strap may be required.

Adjusting your dose of Parkinson's medication may improve double vision. If you experience double vision, it's good to rest as this may give you some relief.

Artificial tears, available from pharmacies can help with dry eyes and it's recommended you avoid dry, hot and smoky environments. Wearing sunglasses outdoors can help too.

With visuo-spatial problems, an occupational therapist may advise you on organising space and carrying out everyday activities.

On rare occasions, dry eyes can lead to conjunctivitis which may need treatment with antibiotics. Blepharospasm may be treated by botulinum toxin (Botox).

You need to inform the New Zealand Transport Agency (NZTA) and your insurance company that you have Parkinson's and if your vision, specifically, is affected.

If you would like information about Parkinson’s to pass on to a health professional, please contact your Parkinson's Community Educator or phone 0800 473 4836.

This factsheet was last updated in March 2017.
CARERS CORNER

Tips for Home Design

Making your home easier and more pleasant to live in.

If you care for someone with Parkinson’s you may have noticed that these days a number of what were once “small things” about their living space may have taken on a new importance for them. This may affect your caring relationship with them considerably; what you do for them, and how you do it.

It’s not unlikely they have to do things slower than they used because they have less control over their own movement. Therefore whereas indoor/outdoor flow and the times of day their house catches the sun may have once been paramount, maybe these days, mundane factors such as the ease of opening drawers and cupboards suddenly matter much more.

Maybe it’s been obvious, or maybe it’s crept up on you both. But things have changed and will continue in that direction.

Or it may be that your partner is newly diagnosed and you’re wondering about the future. Totally understandably.

Whatever the case you are very far from alone and there’s a lot of help, advice and support available. You may not be aware of the thinking that has gone into even the smallest detail of making houses more “Parkinson’s friendly.” You might, too, be pleasantly surprised at what help is available from Government agencies, including financial assistance, to help you make their home easier and more pleasant for them to live in, into a sometimes uncertain future. Visit the following websites to find out more:

• www.accessable.co.nz;
• www.disabilityfunding.co.nz.

Intelligent preparation for the future is vital and you may know about or have heard about universal design. It’s a concept which a lot of people find useful to reimagine their current living space or make the best choices surrounding anywhere new to buy or rent, or even have built.

As far as its application to Parkinson’s, ultimately universal design is having a whole dwelling designed to plan for all contingencies so that you can age in place, or stay in your own home as long as you can. However, that’s at one end of the spectrum: there are a number of smaller actions you can take to make your home more Parkinson’s friendly.

In New Zealand the universal design movement is represented by Lifemark, a seal of approval for residential buildings. You can find out how future proof your current home is on the Lifemark NZ home score page at www.lifemark.co.nz.

If you’re thinking of designing your home, you may wonder what a Lifemark design standard home looks like. If you’re concerned that a design which emphasises safety and accessibility can make your home look unappealing and institutional, you’ll be surprised to find creativity, safety and access can go hand in hand. You can visit the BRANZ website to see some universal design homes at www.branz.co.nz.

(BRANZ describes itself, on its website, as “an independent and impartial research, testing and consulting organisation inspiring the building and construction industry to provide better buildings for New Zealanders.”)

SMALL, BUT VERY HELPFUL STEPS

Universal design doesn’t need to involve expensive home improvements. It can be as simple has installing grab bars for balance, lever door knobs and step-free showers. These changes can help us remain in our homes for longer, and be more healthy and independent.

LIFELONG DESIGN CHECKLIST

Here are some ideas:

**EXTERIOR PATHWAYS**

• Slip resistant path.
• If using paving stones consider the distance between for easy step length.
• Consider raised garden beds.
• Minimise the change in gradient to enter your home—if not possible provide handrails. When a step less entrance is not possible, ensure your entries have stairs that provide a uniform rise and tread within each flight. Consider use of a higher tread depth.
• Where possible avoid uneven floors and pathways, to reduce the risk of falls.
• Make sure your main entry is protected from the weather.

Tracey's Tips

Parkinson’s carer Tracey Gilmour, who lives in Taumarunui, Waikato, has some tips on universal design.

Tracey recommends:

• Rails near steps.
• Chair or steps to sit on at door to put shoes on.
• Open plan living is always good.
• Sliding internal doors are good because they take up less space and you don’t have to step back to open them.
• No clutter lying around the house.
• Rugs attached to the floor so they don’t move.
• Rails in shower and by the toilet.

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GARAGES AND DRIVEWAYS

- You want a parking space that is wide enough for everyone getting in and out of cars and for possible loads.
- If possible, ensure vehicle access routes allow a vehicle to be driven on and off the site rather than having to be reversed on or off it.
- Ensure there is direct, adequately lit and possibly covered access from the garage to the house.
- Install lights with two-way, motion or heat sensors between the home and where vehicles are parked.
- Wide and clear door openings—810 to 910mm.
- Lever-style door handles.
- Light switches at a consistent height throughout and within easy reach—similar height to door handles.
- Light switches at all entrances to rooms so there is no need to walk in the dark.
- Power points at a consistent height—preferably waist height and away from corners.
- Good lighting in all rooms.
- Windows that open, preferably with hinges at the top.
- Consider window placement for ease of access especially for those that open.
- Have a good fire escape route.
- Clear space to ensure access around sides of beds.
- Put light switches or lamps by beds and ensure you have easy-to-operate switches that don't require too much strength to use.
- You might want a bedroom and a bathroom on the main living level.

BATHROOM

- Strengthen walls to accommodate future handrails and shower seat.
- Lever handle taps and hand held shower rose on a slide rail.
- Select a floor surface that is slip resistant and easy to clean
- Make sure the edges of cupboards, doors and benches are rounded
- Make sure all bathroom glazing is made of safety (or toughened glass)
- Ensure the bathroom has good natural ventilation and consider installing an extractor fan or other form of mechanical ventilation.
- Avoid stairs between a bedroom and the closest toilet.
- Avoid the risk of burns by positioning the shower mixer so the water temperature can be adjusted before the user enters the shower.
- Consider installing a level entry shower.
- Work out if it's possible to remove glass and replace with shower curtain at a later stage.
- Avoid locating a heated towel rail where it may be used as a grab rail.

KITCHENS

- Position the kitchen so that it's possible to see indoor and outdoor play areas.
- Design your house so people don't walk through the kitchen to other parts of the house.
- If possible, design the kitchen so it can be temporarily fenced off (ideally with a stair gate) from young children.
- Plan appliance heights to reduce bending.
- Make sure appliances are easily accessible and positioned away from corners.
- Choose appliances with easy to use knobs, handles and controls – preferably near the front of the appliance.
- Allow for a space next to oven, and microwave to place hot dishes on.
- Frequently use items should be located on bench tops or stored between hip and shoulder height.
- Heavy pots and pans are best kept near your stove and sink and on a shelf which is easy to pick them up from.
- Consider drawers instead of cupboards.
- Choose slip resistant flooring.
- Avoid sharp edges on benches, cabinets and handles.
- Keep the distance hot food must be carried between the kitchen and dining area to a minimum.
- Make the floor between the kitchen and the dining area level to reduce trips
- Ensure your kitchen has a permanent means of ventilation at the cooking source to remove the heat, smoke and steam that occur during cooking
- Ideally install low level night lights turned on by motion sensors.
- Make sure doors don't open into hallways.

THANK YOU
“Brain Disorders: Progress and Prospects”

Neurologist Dr Jon Simcock recently gave his popular talk across New Zealand.

Sponsored by the Neurological Foundation and Ryman Villages

Neurologist Dr Jon Simcock, Medical Advisor for the Neurological Foundation, recently gave his popular talk on “Brain Disorders: Progress and Prospects” across New Zealand. Dr Simcock discussed how the 21st century has introduced new neurological investigation techniques, paving the way for enhanced diagnosis and treatment.

Dr Simcock began his career as a Clinical Neurologist in 1968, and since then there has been an accelerating increase in the knowledge of the brain through neuroscience research. Advances in technology have been translated into better management of patients, with the best example of this being magnetic resonance imaging (MRI).

“When I started practise as a neurologist, I had a reasonable knowledge of all branches of Clinical Neurology,” Dr Simcock said.

“With the huge increase in knowledge there has been a necessary increase in specialisation, so that most neurologists now have a sub-specialist field, for example in multiple sclerosis (neuro-immunology), movement disorders, neurogenetic disorders, dementia, epilepsy, stroke, or nerve and muscle disorders. This increase in specialisation has been both a cause and a result of increased knowledge.”

Knowledge is increasing exponentially in many fields of neurology. Further sub-specialisation is inevitable and will result in better care of patients, Dr Simcock said.

NEW BOARD MEMBER REQUIRED

Parkinson’s New Zealand is looking for a new board member. We are particularly interested in people with experience in clinical environments, business development and organisational change management.

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

Healthy Ageing Strategy

The Ministry of Health has launched a new strategy to drive healthy ageing in New Zealand. The Healthy Ageing Strategy replaces the Health of Older People Strategy 2002. It aims to improve health and disability support systems for older people.

In the foreword to the strategy document Minister Peseta Sam Lotu-liga states the name change recognises the diversity of older people and the aim to maximise health and wellbeing throughout people's older years. The new strategy recognises diversity and takes a broad view on wellbeing. It has a strong focus on prevention, wellness and support for independence. It emphasises equity and giving attention to the most vulnerable.

Health inequalities in New Zealand are recognised, affecting Maori, Pacific peoples, people with disabilities and mental health conditions and addictions, refugees and migrant communities and people with low incomes. Achieving equity means understanding and removing barriers that prevent groups from experiencing equitable health outcomes.

The next step is to develop an implementation plan for work over the next 10 years. This will involve both the health and social systems, as well as service providers, NGOs, communities and older people.

The strategy prioritises actions and nominates partners for implementation. Here are a few examples that caught the eye of The Parkinsonian:

- Increase the availability of strength and balance programmes in homes and community settings (oriented towards fall prevention)—led by ACC.
- Review the Green Prescription programme and improve its use by older people—led by Ministry of Health
- Promote volunteering, networking and paid work among older people to support their sense of wellbeing and social connection—led by Ministry of Social Development
- Support older people’s uptake of technologies for communication with health providers and their family and whanau (application in rural and remote areas specified)—led by DHBs
- Improve the support for carers, including various types of respite care, guidance, information and training—led by Ministry of Social Development

You can download and read the strategy on the Ministry of Health’s website at www.health.govt.nz. Let us know what you think of the vision, direction and priorities for action email info@parkinsons.org.nz or call 0800 473 4636
It certainly wasn’t a typical Kiwi summer with wind and rain disrupting picnics and events in parts of the country but people still managed to enjoy a slice of summer. There are some fantastic events to look forward to in the next few months. Keep an eye out for updates on www.parkinsons.org.nz.

AUCKLAND

Parky Bowlers recorded their first win in a tournament in Mt Albert, Auckland. The team which plays with a minimum of two people with Parkinson’s has come a long way since recording a monumental loss in the first round of their first game of the tournament in November 2016. Congratulations to the Parky Bowlers!

WAIKATO

In the December issue of The Parkinsonian Waikato fundraiser Peter Heron’s name was misspelled. We apologise for this error. Peter and his team members took on the challenge of running the 6km Round the Bridges event. They raised a total of over $5,400 for Parkinson’s Waikato. Well done!

MANAWATU

Pictured above at Dr Jon Simcock’s talk at the Julia Wallace Retirement Village in Palmerston North are Clinical Leader Sharon Mackie, Communications Coordinator Jananne Ryan, Parkinson’s Wanganui Community Educator Sue Wilson and members from Parkinson’s Manawatu and Parkinson’s Wanganui. For more about Dr Simcock’s talk see page 11 of this issue of The Parkinsonian.

WAIRARAPA

The 18km climb up Admiral Hill, one of the Wairarapa’s notorious hills, was the backdrop to the annual Pedal for Parkinson’s challenge. The Pedal for Parkinson’s fundraiser was part of the Wairarapa’s Huri Huri Bike Festival. Riders participated in the bike race to raise funds for Parkinson’s Wairarapa. Thank you to everyone who took part!

UPCOMING SEMINARS

Contact your local division or branch for details about upcoming events in your area.

AUCKLAND

Parkinson’s Auckland will hold a free World Parkinson’s Day seminar on Tuesday 11 April 2017, 1:00pm at Greenlane Christian Centre, 17 Marewa Road, Greenlane. For more details please contact Bev Rakich on 09 278 6918 or email auckland@parkinsons.org.nz.

WAIKATO

Parkinson’s Waikato will view a film for World Parkinson’s Day at the Tivoli Cinema in Cambridge on Wednesday 12 April 2017. Contact Community Educators Janine Mair and Anne Hall on 07 839 9038 or email waikato@parkinsons.org.nz.

HAWKE’S BAY

Parkinson’s Hawke’s Bay will hold a World Parkinson’s Day seminar on Monday 20 March 2017. For more details please contact Lee Patrice on 06 844 9135 or hawkesbay@parkinsons.org.nz.

OTAGO

Parkinson’s Otago will hold a World Parkinson’s Day seminar in Dunedin on Sunday 26 March 2017 to commemorate 200 years since Parkinson’s was first described in Dr James Parkinson’s medical essay. A researcher will reflect on advancements in the understanding of Parkinson’s. For more details please contact Ellie Swann at otagoadmin@parkinsons.org.nz.