



# The Parkinsonian

The Quarterly Magazine of Parkinsons New Zealand

## Time for Trains and Tramping



Photo: John Leitch

**John Leitch on a visit to the National Railway Museum, York, UK**

**W**hen I discovered I had Parkinsons we were living on a 10 acre lifestyle block that was going to be our retirement project. However, it seemed easier to move into town where life would be simpler.

Some of my friends were concerned that it would be difficult for me to adjust to town life and find enough things to keep me busy. This didn't happen, as I'm still pursuing my hobbies and I'm busy most of the time.

Those of us with Parkinsons can suffer from a common symptom, the 'can't be bothered's'.

Yes, things are harder for me, I'm slower than I was, I need help with some things and I've had to give up driving,

but I have a lot of interests and there are always several projects waiting in the wings.

I might start the day with the 'can't be bothered's' but before long I'm up and doing and onto the next challenge. There isn't enough time to do all the things I want and long may that last.

As a member of the Pleasant Point Railway Museum I can indulge in my lifelong passion for anything rail. Where else can you play with trains and look as if you're working?

I help with cleaning the loco, polishing brass, painting, preparing for special days and cutting firewood. This year I've been working on restoring a small shunting engine, and during

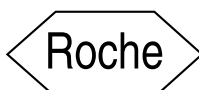
Easter at a Thomas the Tank Engine day I was the Fat Controller.

And when I'm not playing with the real things, I like to create in miniature. Our garage is given over to displays of model trains and scenery that I've collected over a lifetime. I enjoy creating the scenery and buildings to scale; dried weeds, branches, rocks and other

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## From the President

It has been a busy and rewarding few months since I last wrote to you.

I was very pleased to spend some time with many of the Divisions' field officers at their recent annual conference in Wellington. It was a delight for me to see the dedication of those present and their enthusiasm for education, discussion and sharing of experiences. It is no wonder our members trust them with their concerns and also gain so much encouragement, comfort and support from the field officers.

However, if it was not for the tremendous work done by our divisional committees the field officer service would not be available to assist so many members. Our local committees work hard to raise money and support this service and I congratulate these volunteers for their efforts and dedication. In turn, Divisions are ably supported by our national body and office.

This brings me to the wonderful opportunity the national management committee and others had to learn from the recently retired CEO of the Parkinsons Disease Society in the UK, Mary Baker, MBE. Her wisdom and enthusiasm inspired all who were lucky enough to hear her speak. There will be tapes supplied to Divisions so everyone has the opportunity to hear her messages.

Mary and her husband, Bob, were delightful guests and we look forward to them returning to see more of our beautiful country in the not too distant future. By then we will have underway some new projects based on the insights Mary so generously shared with us.

I am proud that in our Society we are all working together for the same goal: better support for people with Parkinsons, and I congratulate everyone on the excellent job you are doing.

**Eleanor Marra**

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useful things make their way into my pockets.

The shed is also where projects happen. I've built all sorts of things for the grandchildren, a sit-on train, a wheel-barrow, rustic armchairs. Mr Fixit is my second name.

The outdoors has given me a lot of pleasure and I intend to keep enjoying it as long as I can. I belong to the Geraldine Tramping Club. There's a wide range of abilities, speeds and ages and we all look after each other. It's great mixing and talking with different people and getting exercise at the same time.

Last year I took up bowls and look forward to becoming involved on a more regular basis. But right now, would you believe I don't have time!

## See a specialist

Dr Mark Weatherall, a geriatrician with a strong interest in Parkinsons, wrote for the Waikato Division newsletter. "Usually the first point of contact for medical problems is your GP. GPs are trained to deal with a huge variety of problems and to recognise when more specialist knowledge is needed.

"However, there is a good case for seeing a Parkinsons specialist at the time of diagnosis; for example a neurologist or geriatrician.

Usually a GP has only have a few patients with Parkinsons and is therefore not always experienced enough to deal with what can be a difficult illness to diagnose and treat."

Dr Weatherall went on to explain how it can be difficult even at the specialist level to get a correct Parkinsons diagnosis.

A recent British study found that, when their brains were examined after death, only 76% of people diagnosed by a specialist were confirmed with Parkinsons.

Parkinsons is diagnosed solely by examining the person, and some related conditions with similar symptoms may be mis-diagnosed as Parkinsons, e.g. drug induced parkinsonism, essential tremor, and multiple strokes.

As Parkinsons is so very difficult to diagnose, it may take a while to get to the right diagnosis. The more experienced someone is in working with people with Parkinsons, the more familiar they are with its complex presenting symptoms and possible treatments.

It is worthwhile everyone with Parkinsons seeing a specialist at least once.

## Parkinsons and the bladder

*Bladder problems are common in people of all ages and both sexes. However, having Parkinsons can cause particular problems.*

The filling of our bladder is not a conscious process.

When the bladder is full, it sends a signal to the brain that it's time for emptying. The brain, now consciously, keeps the bladder from emptying until you find a toilet. The brain then gives the bladder the go ahead to release its contents.

The part of the brain that controls this process is in the basal ganglia, the main area affected by Parkinsons. But because the basal ganglia is faulty, the bladder-brain connection may go awry.

Not everyone with Parkinsons will have these problems and some people may only have them mildly or intermittently.

### Parkinsons problems

There are two main problems that can occur with the bladder of a person with Parkinsons.

- § An overactive or 'unstable' bladder
- § Difficulty in emptying

#### The unstable bladder

Parkinsons can result in an unstable or irritable bladder that contracts when it contains low amounts of urine.

These contractions aren't strong enough to directly cause the bladder to empty, but they do create a strong urge to urinate. This is called urinary urgency.

Sometimes messages from the brain telling the bladder to hang on or relax do not get through properly.

When this happens instead of being able to delay until you find a toilet, you experience urgency, and 'have to go'.

If you can't reach the toilet in time, incontinence may result. This is called 'urge incontinence'.

Your bladder may also need emptying more often than before, and may wake you at night, or even empty while you sleep.

#### Difficulty emptying

Your Parkinsons may mean problems with emptying your bladder, because:

- § You have trouble keeping a bladder contraction going till the bladder is completely empty.
- § The bladder does not start contracting when you want it to.
- § The sphincter doesn't relax to allow urine out.
- § A combination of these.

As a result a residual amount of urine is left in the bladder which can cause a feeling of needing to empty the bladder very often. If the residue is quite large it may overflow as a dribbling incontinence you can't control.

This incomplete emptying can be worse if you are taking anticholinergic drugs such as Artane or Disipal.

#### Practical problems

Some of the practical problems that people with Parkinsons who have

bladder problems may experience include:

- § Mobility problems that make getting to the toilet a slow process.
- § At night reduced dopamine levels may mean it is difficult to get out of bed, get to the toilet or start to pass urine.
- § Your sleep being interrupted by several fruitless trips to the toilet.
- § The toilet being too high or too low and not having grab rails to assist you manage getting on or off it.
- § Undoing clothing, such as zips or buttons, may be difficult, which is a problem when you want 'to go' urgently.

### Other bladder problems

There are several other bladder problems common to many people, and not just those with Parkinsons.

#### Stress incontinence

Many people experience leakage of urine upon physical stress or exertion such as coughing, laughing or exercise.

Stress incontinence is more common in women, especially after childbirth and menopause.

#### Prostate problems

As men get older a small gland around the neck of the bladder (the prostate) gradually gets bigger. This is normal in many men over 50.

However for some men it causes problems, by blocking the outflow of urine and making emptying the bladder difficult or slow for them.

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Without specific tests it may be difficult to distinguish between an enlarged prostate and Parkinsons problems.

## Help yourself

*Keep up your fluid intake:* It's important not to cut down on the amount of fluid you drink. However you may find that it helps to cut out caffeine (which acts as a diuretic) and alcohol.  
*Pelvic floor exercises:* As stress incontinence is mostly caused by weak pelvic floor muscles, the first treatment is usually pelvic floor exercises.

These are designed to strengthen the internal muscles around the bladder outlet. Your doctor, continence nurse or physiotherapist will be able to advise you.

*Bladder retraining:* This is a treatment for people who have an urgent need to pass small amounts of urine more frequently than normal, who may also experience leakage with urgency.

It involves keeping a record for several days of how often you pass urine, and then trying to hold back when you feel the urge to go, gradually increasing the interval between going to the toilet.

This can demand a lot of willpower and patience. It may be impossible for some people.

## Seek medical help

Your doctor can prescribe medications that should assist. These can have side effects and may not be suitable for all.

§ Drugs are available to treat an unstable bladder which works too often and too

urgently. These calm unwanted bladder contractions and allow the bladder to relax more during filling.

§ For people troubled by being woken at night to pass urine, a drug is available that reduces urine production for 8-10 hours after being taken.

§ There are surgical options available for women with stress incontinence and men with enlarged prostates. However, as these may not be the best treatment for people with Parkinsons, ask your neurologist or urologist for advice.

In many areas a continence nurse is available to give you specialist advice and support.

## Make toilets easier to use

*Height:* If the toilet is too low, it can be very hard to get down onto it and up again. Raising the height of the toilet seat by up to 15 cm may help. Get a seat that has adjustable clips that fix it securely and directly to the bowl.

*Rails:* Rails can be fixed to the walls or floor. It's important to have the right design to ensure it will help with each individual's personal difficulties.

*Toilet frame:* This fits over the toilet and gives a person something to hold on to when getting on and off the toilet.

## Simple adaptations

*Clothing:* Clothing is easier to remove if it is not too tight-fitting and has as few fastenings and layers as possible. Velcro fasteners are easier to use than buttons and zips, and many people find

tracksuit trousers very useful. Talk to an occupational therapist/field officer for other suggestions.

*Use continence products:* A wide range of continence products is available, e.g. pads, uridomes and sheaths, specialised underwear, bed and mattress protectors.

*Use alternative toilet arrangements:* If getting to the toilet, especially at night, is a major problem then a commode in the bedroom can be a solution.

A variety of hand held urinals for men and women are available. These can be useful if you can't get out of bed quickly and there is no-one to help you.

## Consult the Continence Society

This Society offers a wide range of specialist advice, products and resources. To contact the Society call 0800 650 659 or check their website [www.continence.org.nz](http://www.continence.org.nz)

There is also a community continence service that receives referrals through GPs. It is run by specialist continence nurses who will assess the client's situation and give advice.

**If you have a question about anything in this issue of The Parkinsonian or you would you like an audio cassette of this issue ...**

**... contact Eva Petro, the Parkinsons New Zealand Information Officer, on**

**0800 473 4636**

## Stem Cells

*The following is intended to give you a basic understanding of why stem cell research is important for people with Parkinsons.*

### What are stem cells?

Our bodies are made up of more than 200 different types of specialised cells, each adapted for a particular type of tissue and function, such as blood cells, heart cells and nerve cells. But some tissues also contain unspecified cells called stem cells.

A stem cell has two important properties. Firstly, unlike most specialised cells it can multiply and make copies of itself. Secondly, it can produce specialised cells.

Stem cells are present in tissues like blood and skin, in which new cells are produced to replace those that are being continually lost.

In other tissue, including the brain, stem cells are very rare or not present at all in the adult. As a result, these tissues have little capacity for repair or regeneration if any damage occurs.

### Scientists' interest in stem cells

Scientists are interested in studying stem cells from embryos because they may be able to provide those cells that our bodies can't normally regenerate. These are present only in an embryo for 1-14 days after fertilisation.

In an embryo stem cells are relatively common. A few days after fertilisation and before implantation into the womb, the first and most important type of stem cell is formed. This cell can make all the types of cell found in the foetus and adult. The stage of embryo from which stem cells can be isolated is around the size of a full stop, with neither a heart or a nervous system.

However, these particular cells are only present in the embryo for a few days. After this they turn into cells specific for individual tissues. But if they are removed from the embryo it's possible to keep them in their original state in the laboratory. This was first demonstrated in mouse embryos in 1981 and in 1998 for human embryos.

Stem cells growing in a laboratory can be multiplied indefinitely, so that literally billions of cells can be produced to make a broad range of specialised cell types. This process is now quite well understood for mouse stem cells and

although there has been much less opportunity to study human cells evidence suggests they behave in quite similar ways to mouse cells.

### Debate on using embryonic stem cells

Early human embryos are a relatively easy way to obtain human stem cells. There has been a great deal of public debate worldwide over the ethics of allowing scientists to do this. (Stem cell research is different from foetal cell implant research, ie transplanting already specialised dopamine producing cells from a foetus.)

In some countries, e.g. the UK, the government has changed the law to allow research to isolate stem cells from human embryos for potential application in treatment of serious diseases.

While there is no current stem cell research using early embryos in New Zealand, the Independent Biotechnology Advisory Council and the Royal Society are inviting people to send in their views about stem cell research.

### International legislation

#### Australia

Stem cell research is allowed under strict guidelines and restrictions. These prohibit developing embryos for purposes other than use in assisted reproductive technology (ART) programmes and culturing an embryo for more than 14 days.

#### United Kingdom

Recent legislation allows for stem cell research to be carried out on cells from embryos up to 14 days old that were produced for fertility treatment.

#### USA

A recent law change allows federal funding to be used for embryonic stem cell research.

## Pain: Part of Parkinsons

*Young Parkinsons Newsletter Spring 2001*

Among the many non-motor symptoms of Parkinsons, painful sensations can be most troublesome. In some cases pain may be so significant that it overrides the motor symptoms of the condition.

The reason for pain in Parkinsons is problematic. It is now well established that the basal ganglia not only plays a major role in movement but also in processing sensory information. As the basal ganglia is disordered in Parkinsons this leads to movement problems, and also sensory and pain complaints.

### Health providers' role

Many doctors are unaware that disturbances of sensations can be a part of Parkinsons and therefore long and frustrating delays in diagnosis and treatment can result. Diagnosing pain as a symptom of Parkinsons can be difficult and may require in-depth probing to rule out other causes.

A strong indication that pain is related to Parkinsons is when it occurs during an 'off' period (eg when a dose of medication is due or before the first dose of the morning) but goes away when appropriate medication is taken. Sometimes however there is no relationship between pain and motor state, making diagnosis and treatment more difficult.

A range of health providers need to be aware of the relationship of Parkinsons to pain, eg dentists who get complaints of burning mouth. Internal medicine specialists and gynaecologists should be aware that chronic and severe oral and genital pain in some people who have no underlying physical reason for this, can be a result of their Parkinsons.

### Pain is common

It is estimated that around 10% of people with Parkinsons have pain as their initial symptom, and before any mobility problems. Also, approximately 40-50% of people with Parkinsons have pain and/or sensory complaints as part of their condition.

### Types of pain

A wide variety of painful sensations can occur, including tingling and numbness, burning, hot and cold sensations, aching discomfort and deep/boring pain. The pain can mimic other types of pain, eg nerve or joint pain. This can lead to incorrect diagnosis and fruitless treatments.

## Conferences

### Australia

In August Judy Buchanan and Eva Petro, National Office, and several field officers attended the 6<sup>th</sup> Multidisciplinary Conference on Parkinsons Disease in Melbourne.

For two days we heard moving personal stories, about a range of medical treatments and new research, and met many wonderful people. The keynote speaker was the charismatic Mary Baker, former CEO of Parkinsons UK and President of the European Parkinsons Disease Association.

Only two people with Parkinsons and their spouses from New Zealand attended this conference. The next one will be in Brisbane in 2003, so start saving your pennies to attend – it's sure to be very worthwhile.

### Field Officers Conference

*Facing Changes* was the theme of the annual national field officers' conference held in July in Wellington. This year a number of the sessions were on the changes that occur in the lives of people with Parkinsons, their carers and families. Topics included relationships and how they are affected by disability, sexuality and intimacy, grief/loss and change, and neuro psychology.

### Future Happenings

Many people with Parkinsons are great travellers and many have a thirst for knowledge. As Mary Baker said to us, "People with Parkinsons are the best educators about the condition." So maybe you would like to attend the following:

### APPDA

Hong Kong, 1-4 December 2001.

This will be a fantastic gathering with over 1700 delegates expected to attend and bring their vast international experience.

For further information call National Office on 0800 473 4636 or check [www.hku.hk/medicine/APPDA.2001](http://www.hku.hk/medicine/APPDA.2001)

### New Zealand Parkinsons International Conference

23-26 October 2002, Wellington.

To be on the mailing list for further details please contact National Office by letter, phone or email [parkinsonsnz@xtra.co.nz](mailto:parkinsonsnz@xtra.co.nz)

## Staying Creative, Staying Positive

By Linda Hall, Napier Courier

While having Parkinsons has meant lifestyle changes for Napier man Ian McLeod, it hasn't stopped him leading a busy, creative life.

Ian was principal of a school in the Coromandel when he was diagnosed with Parkinsons. He returned to Hawke's Bay where he was born and worked in education until his Parkinsons prompted him to take early retirement.

However, Ian, who was determined he wasn't going to sit around and feel sorry for himself, is far from idle. He keeps busy making dried flower arrangements for weddings, funerals, church meetings and numerous other occasions.

Ian says it all started with some photos of topiary trees his mother had taken at a wedding. "I thought that when the time came I would have a go at making some."

His opportunity came when he and his wife Dot celebrated their 25<sup>th</sup> wedding anniversary. Six years on he is still learning and "when I run out of ideas it'll be time to call it quits."

"I've met a lot of lovely people through my work. Often when I phone a bride-to-be to say the flowers are ready, she says 'can I bring my mum or a friend'. I've had up to 10 people at a time in my home to collect flowers, it's great."



Photo: Napier Courier

Ian says working with artificial flowers suits him well. "If I get too shaky I know I can walk away and they won't wilt."

Ian says that while having Parkinsons has changed his life, his work with flowers and talks at meetings have helped him stay positive. Ian often accompanies field officer Morag Murray at awareness talks to present his perspective of living with Parkinsons.

"If my talks inspire just one person to have a go at something different it will be worth all the nerves I get beforehand."

## International guests



**Eleanor and Paddy Marra with Mary and Bob Baker, and friends, in Rotorua**

While in Wellington, Mary Baker, former CEO of the Parkinsons Society UK and Peter Snell our patron, along with National Society committee members and staff met for very productive talks with Ruth Dyson, Minister for

Disability Issues, other Members of Parliament, and Ministry of Health officials.

Both Mary and Peter made a big impact on everyone they met and helped us improve our relationships with those people in government who make key decisions that affect our ability to improve the quality of life for people with Parkinsons.

Mary and Peter also spent time with the national management committee and spoke to local Parkinsons members and health professionals from around the

region at an afternoon tea gathering.

Parkinsons New Zealand is very grateful that these two very busy and influential people gave so generously of their time and knowledge to assist us in our work for people with Parkinsons.

Mary Baker and Peter Snell were also guests of honour at the Auckland Division's excellent one-day seminar on 3 September.

# Happenings

## Get Creative

The highlight of our national Awareness Week Get Creative activity will be an art exhibition in the Wellington Public Library. Judith Tizard, the Associate Minister for the Arts, and Penny Eames, Director of Arts Access Aotearoa, will be our special guests at the launch on 1 November.

We know that around the country many groups of members are having great fun trying out new creative activities or getting busy on their own hobbies. We are looking forward to seeing many of the works displayed at the national exhibition, and photos of the local exhibitions.

So if you haven't already, free up the emotions and let the creativity flow. If you want ideas on what you could do, please contact Eva Petro, Information Officer, on 0800 473 4636.

## Upbeat is Happening

Upbeat, the special interest group for people affected by early onset of Parkinsons is thriving.

To help establish a network for these younger people to use to communicate with each other, many of the members have attended a residential weekend. This means although they are spread around the country, they can put a face to a name and be in contact with someone who has had similar experiences.

Also, during the weekend they meet the local field officer and some learn about the Society's services for the first time.

Members of the group are involved in producing a newsletter and a pamphlet to inform people of its existence. They also have a 'chat group' on the internet to keep in touch with each other, and plans for regional get togethers.

Similar groups exist in most countries where there is a Parkinsons Society, and earlier this year people from 24 countries attended a younger persons with Parkinsons conference in England.

The New Zealand group is learning from its international colleagues and will be having their first national meeting next year, alongside the international conference in Wellington.

If you would like to know more about Upbeat or to join the 'chat group' contact Bruce Cutfield, 06 307 8853.

## Webguide

Where spouses and supporters of young onset Parkinsons people unite, unwind, share with others who face similar issues: [http://groups.yahoo.com/group/Young\\_Parkinsons](http://groups.yahoo.com/group/Young_Parkinsons)

Information on alternative medicine for people with Parkinsons can be found on: [www.parkinson.org/med.54.htm](http://www.parkinson.org/med.54.htm) .

Remember to consider all information on alternative medicine and therapies with **caution**. Before starting, talk with your Parkinsons doctor or field officer.

The excellent website of the National Parkinson Foundation has much useful information and advice:

[www.parkinson.org/](http://www.parkinson.org/)

For example you can ask questions from Parkinsons expert Dr Lieberman or a speech therapist, obtain information on the latest in Parkinsons research, etc.

Kathrynne Holden, who wrote the Parkinsons nutrition book PSNZ supplies, answers questions on diet and nutrition on the NPF site. To post your question go to:

[www.parkinson.org/](http://www.parkinson.org/)

then click on 'Ask the Dietician' and follow the instructions.

There is also a Parkinsons Nutrition Tip of the Day on:

[www.nutrionucanlivewith.com/](http://www.nutrionucanlivewith.com/)

**To help Parkinsons New Zealand continue our work on behalf of people affected by Parkinsons, please donate \$20 by calling:**

**0900 FOR PD (0900 36 773)**

**If you call this number, \$20 will automatically be added to your telephone bill. Telecom sends this on to PSNZ each month.**