



UPBEAT

The Newsletter for People with Early Onset Parkinson's
Understanding Parkinson's by Belief in Education, Attitude and Treatment



Parkinson's and Deep Brain Stimulation

An update of brain circuits in Parkinson's and Deep Brain Stimulation (DBS) for Parkinson's was presented by a team of experts at the 2016 World Parkinson Congress (WPC) in Portland, Oregon (USA).

Dr Andres Lozano's (University of Toronto, Canada) lecture on getting the best results in surgery for Parkinson's was received with interest.

Disclaimer: Dr Lozano is also the founding director of Functional Neuromodulation Ltd, a non-profit company that receives funding directly from the DBS device manufacturers Medtronic to investigate and promote DBS, and he holds patents related to these devices.

Dr Lozano focussed on a number of advances in surgical therapies. Surgical therapies may be considered during the course of Parkinson's, especially if symptoms cannot be adequately controlled with medication. Like all of the presently available Parkinson's medications, surgical options offer symptomatic benefits.

DBS is the most commonly performed surgical treatment for Parkinson's. Dr Lozano says 150,000 people with Parkinson's worldwide have received DBS. The surgery takes place in 700 centres with 10,000 people per year receiving DBS.

"As surgery becomes safer and safer the timing of surgery will move earlier and earlier in the course of Parkinson's," Dr Lozano says.

In DBS neurosurgeons implant a device that delivers electrical signals through probes to inner brain structures involved in movement. In most Parkinson's patients who receive the treatment symptoms of dyskinesia, motor fluctuations and tremor rapidly diminish after the device is activated. Receiving DBS is also related to an improved quality of life. DBS does not work as well for imbalance or non-motor symptoms.

As with any surgery there are risks involved, including death, stroke or heart attack. Infections, should they occur, can be difficult to treat as the

wires to the probes can allow infection to get into the brain. This risk of adverse effects from hardware related events is about 5% - 10%. In some people, DBS surgery can induce apathy, anxiety or depression. Some of this can be reversible, but not always. Other problems with which DBS has been linked are worsened cognitive function, mania, psychosis and suicide. The risk of stimulation-induced adverse effects is about 20%. Through careful selection of who will receive the operation, many of the risks can be minimised. The risk of a serious complication occurring during the operation, e.g. stroke or death, is about 1% - 2%.

Among the recent technical advances in DBS, Dr Lozano says, are better imaging, the potential for operations to take place under general anaesthesia, the use of magnetic resonance imaging (MRI) during surgery to verify the placement of probes, rechargeable batteries, the development of smaller skull implanted systems, and new ways of stimulating the probe (e.g. directional DBS and adaptive DBS).

In New Zealand DBS is only carried out on a small number (less than 20) of highly selected patients each year. The majority of these people have Parkinson's although DBS is also used to treat some other conditions. A careful selection of the patients who will receive the operation takes place to minimise the adverse effects and limitations of DBS. Usually a neurologist will refer a person to the Movement Disorders Clinic, Neurology Department, at Auckland City Hospital (the Centre for DBS in New Zealand) if they think they are a good candidate for DBS.

People who have received DBS surgery can still get good results after 10 or even 15 years. However, DBS does not change or influence the rate of progression. In the long term, a majority of people will eventually have problems that do not respond to reprogramming of the DBS, Dr Lozano says.

There are only certain people for whom DBS will work well. It is usually done in people who have had Parkinson's for five years or more and still get a benefit from medication but have motor

Parkinson's and Deep Brain Stimulation

fluctuations and/or problems with dyskinesia. Once all the other available options have been exhausted DBS can be considered if the person is likely to meet the criteria for treatment.

A general rule is that DBS will likely improve Parkinson's symptoms that respond to medication. (The opposite is also true: symptoms that don't get better with medication probably won't respond to DBS.) A person must be fit enough to undergo the operation and healthy enough there is a reasonable expectation they will maintain the benefit for a long time.

The part of the brain that is stimulated is closely connected to the area that controls emotions. Because of this people with unstable or untreatable emotional conditions may not be suitable to receive DBS. DBS may also exacerbate thinking or memory problems so it is not recommended for people with advanced cognitive decline.

"Adverse effects are being reduced and if the trend continues, we are reaching the point where it is safer to be operated than not to be," Dr Lozano says.

"There is still a large opportunity for improvement and to tackle some of the unresolved problems including the currently non-responsive symptoms."

For more information about DBS please refer to our Deep Brain Stimulation factsheet at www.parkinsons.org.nz

Parkinson's New Zealand President and Parkinson's Hawke's Bay Chairperson Kathy Jenkins was diagnosed with Parkinson's in 2004. Here Kathy shares her experience with DBS.

"In 2014 I spent four months touring the USA with my husband, Bruce. For most of the time in the USA I was good. I did several walks as you do when away. I was taking Ropinirole, Amantadine and Sinemet in not very high doses. However, the dyskinesia was very tiring.

"After seeing the improvements after DBS in a couple of people's lives at the 2014 UPBEAT Conference, I decided to see how things progressed through the eligibility process for DBS. I didn't want to leave it for five years and then be told I should have been there five years ago.

"I was fortunate to be accepted for DBS. I was told to be at Auckland Hospital on 8 March 2016. First thought: I knew it would be then because we had scheduled our Cape Sanctuary Walk fundraiser for Parkinson's

Hawke's Bay four days later on 12 March 2016.

"As we prepared to pack the car, I rang Auckland Hospital to confirm there was a bed available, but they had changed the surgery date and omitted to tell me. I was devastated—even the bright side of being in Napier for the Cape Sanctuary Walk wasn't that shiny.

"After tests, the first part of the procedures went ahead on 23 March 2016 and I must say it was pretty painless—local anaesthetic does sting somewhat. I last saw Bruce around 9am and he saw me again at 4.30pm. You are given an MRI once you are attached to the halo and then again after you have been stapled up. Amazingly, the next day we returned to Napier. I felt really good despite not being 'wired up'. I kept forgetting to take any pills—no tremor or dyskinesia to remind me. I flew to Wellington for Parkinson's AGM. By the end of that week I was *not* forgetting my pills.

"Back to Auckland on 19 April 2016 and surgery the next day—under general anaesthetic this time—as they put the wires under my scalp, down left side of neck and connected to my "power pack" under skin on left side of chest. Now this hurt and was probably the most uncomfortable time in the whole process. I had a lot of bruising on the left side of my chest and often woke (still do) because the power pack had moved and stabbed me.

"Although I have a little tremor in my right hand at various times and I have put on weight, I feel really good. I still take pills: Sinemet morning and night, Amantadine 7am and noon, and Ropinirole noon and night (mainly for restless legs). I can get out of bed when I wake up and have a shower without waiting for pills to kick in (no clawing of my toes) and only seem to be affected by dyskinesia after Dr Simpson has played around with my power pack.

"Would I go through DBS again? Yes, I would!"



Parkinson's New Zealand President
Kathy Jenkins

Parkinson's and money matters

Everyone's experience of living with Parkinson's is different. But there are lots of issues and challenges that are shared by many people living with the condition. If you or your partner has Parkinson's, or you care for someone with the condition, you may have some concerns related to money.

The decisions you make about money will depend on your personal circumstances. But the best thing anyone can do is to get as much information as you can about your options. With that in mind, we have provided some considerations for you.

Discuss money matters with your family

Money can be a difficult subject to talk about, but it's important you plan how you want your finances to be managed if you become unable to look after them yourself. Money management is also an issue of independence. Most adults are accustomed to managing their own affairs and do not recognise that health problems can interfere with their ability to continue doing so. Sometimes the focus on maintaining health is so intense that other aspects of daily living can be shoved aside.

For these reasons, you may want to contact your bank and look at other ways of managing your money, such as:

- having a separate account with a smaller amount of funds that can be accessed
- set up direct debits for all utilities accounts
- have an alternate contact person noted on file for when assistance might be required

You may also wish to consider stopping junk mail and unwanted sales calls.

Stopping junk mail and unwanted telephone calls

The New Zealand Marketing Association operates "do not mail" and "do not call" registers. It's also free to add your home contact details to this register. Note this isn't fool-proof as the registers only apply to the 500 New Zealand Marketing Association members.

Visit marketing.org.nz and add yourself to the 'do not call' and 'do not mail' registers or write (with your full name, address and telephone number) to:

Do Not Mail and Do Not Call Registers
Marketing Association
PO Box 47681
Ponsonby, Auckland

Please include your full name, address and telephone number.

Working when you have Parkinson's

Many people with Parkinson's continue to work after their diagnosis. Not everyone with Parkinson's experiences the same combination of symptoms and they affect each person differently.

How Parkinson's affects someone can also change from day to day and even hour to hour. If your treatment is carefully managed and you have plenty of support, it is possible to continue working. This depends on the type of job you have and how Parkinson's affects you. Some people may feel they would benefit if some adjustments were made.

Think about the type of job you have and how your condition affects you. Some jobs are more compatible with Parkinson's than others, so you may find it helpful to consider alternative employment.

Finally, having connections with people who have more experience living with Parkinson's is extremely valuable. With the right support, education and information you can live well.

For more information about Parkinson's and work please see the May 2015 issue of UPBEAT.

2017 UPBEAT Weekend

We are pleased to announce that planning for the 2017 UPBEAT Weekend is underway. We are applying to secure more funding to hold this event in Hamilton later in the year. This is your weekend so if you have ideas for topics please email us UPBEAT@parkinsons.org.nz

Get involved



Parkinson's New Zealand's You Tube Channel

There are short (3-5 minute) presentations and interviews with people from recent conferences including UPBEAT on our You Tube channel. Here are just a few of our recent and upcoming topics. Visit our You Tube channel on [youtube.com/user/ParkinsonsNewZealand](https://www.youtube.com/user/ParkinsonsNewZealand).



Focused ultrasound

Dr Andres Lozano, Chair of Neurosurgery, University of Toronto, discusses a new treatment for tremor.



Intimacy and sexuality

Dr Sheila Silver is a consultant in the area of sex and intimacy for people with Parkinson's.



Technology

Dr Sue Lord, Senior Research Fellow, Newcastle University, discusses advances in technology to help people with Parkinson's.



Beats Medical App

Beats Medical discusses the release of their new app to help people with hand dexterity.



Like us on Facebook

We would love to hear from you on Facebook. Our Facebook page is a place where you can connect to ask questions, talk to each other and share ideas on living with Parkinson's. Like our page on [Facebook.com/Parkinsonsnz](https://www.facebook.com/Parkinsonsnz)

Nutritional study in Waikato

The Waikato Hospital neurology department wishes to invite people from the Waikato region to join a study of the effects of diet on the symptoms of Parkinson's. They will be comparing the effects of a low fat diet with those of a high fat "ketogenic" diet. This will be a randomised controlled study with half the participants randomised to either diet. The study will run for ten weeks, starting in June/July 2017.

They seek 20-40 people with Parkinson's under 70 years of age who are enthusiastic and able to follow a meal plan for either diet. It is important that participants are willing to try something new, as the diet may be considerably different from what they are used to.

If you are interested in participating or just have some questions, please email Matthew at Matthew.Phillips@waikatodhb.health.nz or Linda at Linda.Gilbertson@waikatodhb.health.nz for more information.

UPBEAT newsletter is online



Many of our UPBEAT members are choosing to receive UPBEAT newsletters by email. To reduce printing and postage costs, we would love it if more people received the UPBEAT newsletter by email. For those of you with email we will no longer send a printed copy unless you request one. If we don't have your email please let us know by emailing UPBEAT@parkinsons.org.nz.

UPBEAT is a special interest group of Parkinson's New Zealand

UPBEAT Mission Statement: *To improve the quality of life of people with the early onset of Parkinson's and their families by sharing information, experiences and strategies through interpersonal communication and support, until there is a cure.*

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