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## Deep Brain Stimulation

## Support Group Newsletter

### March 2009

Welcome to our very first DBS newsletter. It has been approximately 10 years since Deep Brain Stimulation has been available to some New Zealanders with Parkinson's disease. To those of you who have experienced DBS first hand and have been awaiting some informal support - Thank you for your patience.

It will be great to meet up with some of you at the Christchurch UPBEAT weekend in March and I am hoping this will be an opportunity to hear what it is that is needed from a group like ours, do some brain storming and come up with a plan that will meet your needs.

I would like to set up a data base of those of you that have had Deep Brain Stimulation and would appreciate if you could fill out the following form.

Remember this is *your* newsletter and if you have some information or articles that you would like to share or you think may be helpful to others please contact me.

If there is anyone out there with some experience or in interest in putting the newsletter together I would be grateful for some assistance. My intention is that this newsletter will be produced bi annual.

Paula Ryan  
DBS Support Group Coordinator



## History of DBS

In the early 1950s, doctors found that lesioning, or destroying, specific areas within the brain could help treat certain movement disorders. When areas of the brain involved in the disorder were lesioned, the symptoms often improved. Soon, lesioning surgeries became a standard treatment for reducing problems in motor control caused by conditions like Parkinson's disease.

Unfortunately, lesioning surgery was not an ideal solution. They weren't always effective in reducing negative symptoms, and sometimes they resulted in damaging side effects. One of the main problems with lesioning surgeries is that their effects cannot be undone; a lesioned brain structure is permanently destroyed. As a result, unwanted side effects are usually irreversible.

In the 1960's a new drug therapy for movement disorders was introduced. Treatment with the new drug, called **levodopa**, could be used to control some of the same types of symptoms as lesioning, but without the risky brain surgery. Levodopa therapy quickly began to replace lesioning surgeries, mainly because of the advantages it provided patients. One of the benefits was dosages that could be adjusted to suit individual needs.

After many years, however, long-term levodopa therapy was found to cause new problems. The brain eventually compensates for the effects of the drugs. The result was often serious. Patients were developing new movement control problems that were considered worse than the original symptoms.

Then, in the late 1980s, a new discovery was made. Experts found that the same effects caused by lesioning brain tissue could be achieved by stimulating the tissue with harmless pulses of electricity. This was an exciting find, because the effects of electrical stimulation are completely reversible. In fact, when the stimulation is turned off, the brain resumes its normal behavior. Similar to drug treatments, doctors could tailor the electrical stimulation to fit the exact needs of each patient. Unlike drug treatments, the electrical stimulation could be localized so that only intended parts of the brain were affected.

Treatments with deep brain stimulation (DBS) were used on an experimental basis for several years, and positive treatment results were observed. In 2002, the use of DBS for conditions such as Parkinson's disease was approved by the Food and Drug Administration (FDA). DBS remains the standard treatment for several brain disorders similar to, and including, Parkinson's.

To date, more than 35,000 patients around the world have had DBS surgery. Approximately 30 people of those are here in New Zealand. Though it's no longer considered experimental, DBS is, for now, still used as a second- or third-line treatment, reserved for patients with relatively advanced cases of the disease and those for whom medication alone is inadequate or can't be adjusted precisely enough to keep their tremors and dyskinesia under control.

**The Ministry of Health continues to fund people to travel to Australia to undergo Deep Brain Stimulation (DBS) surgery. At present this is in Brisbane.**

When Neurologists consider a person may benefit from the surgery a referral is made to the NZ DBS committee for DBS for Movement Disorders.

Many people feel that they are in limbo while awaiting a decision. During this time they may struggle with their Parkinson's disease and general health.

It is important to recognize that relatively few people with PD will benefit from DBS. It is also important to recognize that not all aspects of PD improve with DBS. While motor fluctuations often improve, people may find that there is no improvement in their balance, their speaking and in particular, any disturbance of their mood. The committee will take all these factors into account before recommending surgery.

The committee decision process may take weeks or months. A number of experts review the videos and data and this will stimulate a discussion as to whether or not the person would benefit from the procedure.

The committee will pay special attention to psychiatric and psychological assessments because some people find that they deteriorate psychologically after the procedure. The procedure may not improve all aspects of Parkinsonism. It will also not improve general health. Thus, it is vitally important for people who are awaiting consideration for surgery to remain in close contact with their family doctor, Neurologist, and PD Field Officer during this period. Any change in general health should be monitored closely and treated appropriately.

Following surgery, ongoing care is managed by the Neurologist who made the initial referral to the DBS committee.

There are designated Neurologists in Auckland, Wellington and Christchurch who are familiar with the stimulators and are in a position to test out or re programme the stimulators when necessary.

**DISCLAIMER:** News and information in this newsletter is not meant as medical or health advice, you must always check with your doctor. It is provided for educational and informative purposes only. Any article or other material in this publication is not necessarily the opinion of Parkinson's New Zealand.

A recent study at the University of Florida examined 174 Parkinson's patients that had been referred for Deep Brain Stimulation. Out of the 174 referred only 10% were acceptable candidates. Suitable patient selection is vital in ensuring the best outcome of the surgery.

### **Who is an ideal candidate for the surgery?**

Careful patient selection is the first and most important step for success of DBS. Your Neurologist will assess your situation to see if you are a suitable candidate. He will take the following points into consideration.

Candidates who have idiopathic Parkinson's.

Tend to be younger (below age 70, but may be older),

Responds well to Parkinson's medication

Have no or little cognitive dysfunction

You must also be physically able to endure the surgery, and must be able to cooperate by answering questions and following directions during the surgery. You must be able to understand the nature of the therapy and be able to operate the Neurostimulator Controller. You must also be available for periodic follow-up visits.

### **Does DBS affect cognition and behaviour?**

A series of papers published last summer in the journal *Neurology* raised a number of important concerns about this. Despite improvements in motor symptoms, some patients develop the onset of depression or of elevated mood (mania) after DBS. Others may become much more apathetic. Many DBS patients had social and professional adjustment difficulties, and sometimes personal relationships suffered. Furthermore, studies of cognition after DBS consistently show mild declines in language fluency, attention, and word recall. For these reasons, detailed multidisciplinary cognitive and behavioral assessments as well as adequate education for patients and families before and after surgery are strongly recommended.

*I encourage you and your family to explore all avenues of Parkinson's disease care prior to choosing Deep Brain Stimulation (DBS). The procedure has its success but it is not without potential pitfalls. Educate yourself about DBS before embarking on this new journey. Ask the neurologist for a list of patients and couples who have had DBS that you and your spouse could talk to by phone or in person. Some find they get comfort in talking to other patients before having DBS surgery and this had helped them reach a decision about surgery.*

# Deep Brain Stimulation Support Group

## Membership Form

There is no fee for membership

NAME: .....

M/F: (please circle)

PARTNERS/CAREGIVERS NAME: .....

ADDRESS: .....

.....

PHONE: .....

EMAIL: .....

DOB: .....

ETHNICITY: .....

DATE OF OPERATION: .....

WHAT YEAR WERE YOU DIAGNOSED WITH PD: .....

PLACE OF OP: .....

LOCAL DIVISION: .....

I would like to receive the bi annual DBS newsletter (please circle)

YES    NO

In accordance with the Privacy Act 1993 I/we give consent to the collection of this information by Parkinson's New Zealand for the purpose of membership activities, mailings and other communications required for the conduct of Parkinson's New Zealand's business affairs. It will not be used or published outside the above without my permission.

SIGNED \_\_\_\_\_

DATE \_\_\_\_\_

Please return to DBS Support Group, PO Box 9060, Dunedin