

UPBEAT

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



UPBEAT Conference 2010

In November, Sandy and I attended our seventh UPBEAT weekend conference in Palmerston North, along with about 55 others from around the country. Even having attended so many UPBEAT weekends in the past 10 years, I can still say that I learnt new things and of course both met up with old friends and hopefully made new ones.

Dr Pietro Cariga, Neurologist, gave a good introductory overview of Parkinson's disease, medications and treatments. He gave quite a focus to the effects that some drugs can have in causing compulsive behaviours and the need to be aware of the degree to which this can occur. Doctors are not always good at explaining this to patients.

Similarly with the second topic on the Friday that looked at sexuality - another issue that some in the medical profession can have difficulty with or perhaps chose to ignore. I liked Dr Kirsteh Holst's summary: "we (doctors) may not be good about talking about sexuality, but there are things we can do to improve the situation if we know there are problems". This issue, like many others, is a two - way street and is best faced by talking about it.

Eleni Nikolau, Psychiatrist from Waikato Hospital, gave an exceptional presentation on Saturday. She has a great ability to speak with empathy and compassion. She spoke on emotional issues in relation to Parkinson's - clarifying such things as depression, apathy and anxiety. There was much of interest in her talk but one thing that stuck in my mind was her description of individuals: the person you were before Parkinson's is still the same person after developing Parkinson's (notwithstanding that things have changed). I think we can sometimes forget that as time goes on.



UPBEAT Conference 2010 attendees

A lot of other good things happened on the weekend and these comments barely scratch the surface. If you can be at the next weekend that is organised I am confident you will learn a great deal and really enjoy the experience.

Kevin Miles/Sandy Wright



Bruce Cutfield and Kevin Miles celebrating 10 years of UPBEAT

Are you or someone you know planning to organise or take part in a challenge or event this year? Why not raise money and awareness for Parkinson's New Zealand while you are having fun?

Tramping. Golfing. Bridge drive. Morning tea. Ironman events. Sky diving. Walk/run events. Walks. Car rally. Run/swim events. Overseas treks. Half marathon. Quiz night. Mountain climbing.

Go to www.parkinsons.org.nz/fundraising or email getgoing@parkinsons.org.nz for more information about how you or your family and friends can raise awareness and money for Parkinson's New Zealand.

GET GOING FOR PARKINSON'S 

Wii-habilitation study for Parkinson's

Parkinson's UK fund research into the benefits of the Wii

Parkinson's UK has announced a grant of GBP£35,000 (approx NZ\$73,000) to investigate the potential benefits of the Nintendo Wii for people with Parkinson's. The decision to commission this research was the result of overwhelming feedback received from people with Parkinson's who reported that using the Wii helped them with their balance, movements and mood. As well as being fun and convenient, the Wii has the ability to help people improve their movement, not just fitness.

Prior to the study, Parkinson's UK had conducted a short survey of around 100 people with Parkinson's who use the Wii. They found that two-thirds felt that using the Wii helps them better manage their symptoms. They also reported:

- an improvement in their balance, helping to prevent falls
- that it's more convenient than going to the gym and some people don't feel confident in that environment
- that you can track your progress through the exercises, which helps keep you motivated
- that the social side of using the Wii with family and friends, combined with the adrenaline, really helps improve mood and combat anxiety and depression.

This is not the first study into the beneficial effects of the Wii. In a pilot study, conducted by Dr Ben Herz at the University of Georgia, 20 Parkinson's patients spent an hour playing the Wii three times a week for four weeks. The participants played one game of boxing and two games each of tennis and bowling - games requiring exercise, bilateral movement, balance and fast pace. By the middle of the trial a number of participants could beat their opponent in the first round of the game.

At the end of the study, participants showed significant improvements in rigidity, movement, fine motor skills and energy levels. Most participants' depression levels decreased to zero.

On completion of the study 60% of the participants bought a Wii for themselves. Dr Herz next plans to test the Wii Fit balance board with Parkinson's patients.

Studies have shown that exercise and video games independently can increase the production of dopamine which is deficient in people with Parkinson's. Dr Herz thinks this is the case with the Wii's exercise effect. Dopamine also helps improve voluntary, functional movements.

Tina, 54, was diagnosed with Parkinson's in 2003. When she first started playing the Wii, she kept being beaten by her granddaughter. But Tina, an occupational therapist by profession, was intrigued by the Wii's potential to improve hand - eye coordination.

After playing for a few months, she could give her granddaughter a run for her money.

What she really loves is that the games are motivating. Her 'Wii age' - the measure that the device gives you of how well you have mastered the virtual sports on offer - has gone down from 71 to 41.

"Since using it, my fitness and coordination have definitely improved. When I started I couldn't even hit a tennis ball on the Wii Sports game, but I can now control the complex movements that Parkinson's makes difficult."



UPBEAT is a special interest group

Upbeat Mission Statement: To improve the quality of life of people with the early onset of Parkinson's Disease and their families

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How do Wii Sports games work?

Wii Sports games are controlled using simulated movements such as swinging a tennis racquet, throwing a bowling ball or boxing. Players hold a controller which can sense their movement and acceleration and these games require a lot of physical movement. The player can see their progress on screen. Many of the games can be played individually or against an opponent, making the games social as well.

What is Wii Fit?

The Wii Fit system employs a weight - sensitive balance board extension, which looks similar to a bathroom scale. The balance board allows the player to interact with and control onscreen elements of the game or activity. The majority of the activities in

the game have to do with standing on the balance board and shifting your centre of balance in different directions by leaning or standing on one foot or the other.

There are several types of activities available on Wii Fit, from workouts in yoga and balance, aerobic exercises and muscular training workouts to games like hula hooping and skiing.

When using the Wii Fit with balance board we suggest the following:

- Ensure the Wii Fit board is on a carpet or non-slip surface
- Remove shoes to stand on the Wii Fit board
- Always use the wrist straps on the controllers
- Clear a space around the board so you have room to move your arms and step on and off the board

- Take care when stepping off the board, especially when stepping backwards
- Have a chair nearby so you can rest easily
- Caution is needed if your balance is unstable; place a high-backed chair at the side or in front of you so you can steady yourself if required
- Ensure there is someone else around when you are using the Wii Fit.

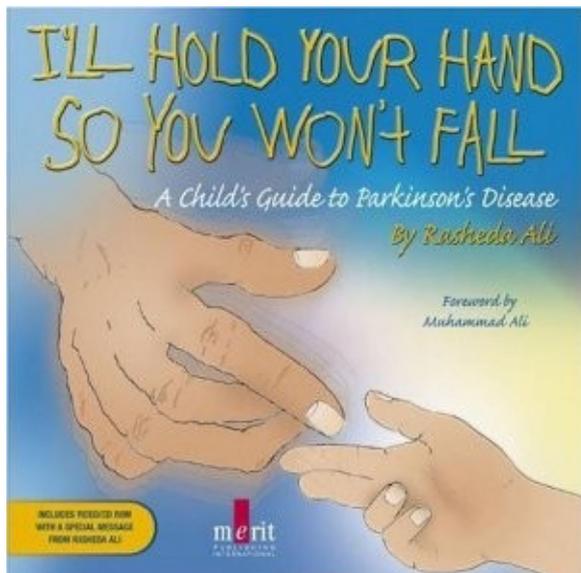
Nintendo Wii can be purchased from most electronic shops. The basic console with a sports game costs around \$380. Wii Fit+ and balance board cost an additional \$200.

Wii consoles and games can also be hired from video rental shops.

Sources: *Parkinson's UK*
ehow.com
sciencedaily.com

I'll Hold Your Hand So You Won't Fall

Rasheda Ali

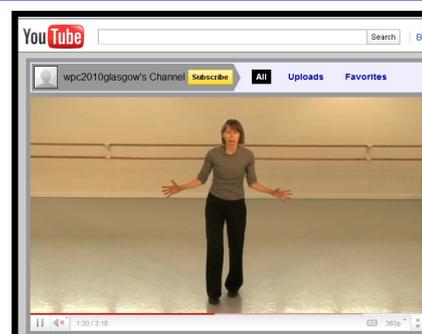


Children deserve to understand. Sometimes Parkinson's is difficult for adults to deal with, so you can imagine how much more perplexing it must be for children. In this unique book, adults will have an opportunity to read and discuss with children the most common symptoms of Parkinson's in a safe and creative environment that utilises words, illustrations, and medical facts about the condition.

This book is available for loan from the Parkinson's New Zealand National Office Library. You can purchase this book from National Office for \$30 (we are the only supplier in NZ).

World Parkinson's Congress Videos

Nearly 50 videos were submitted for the WPC 2010 video competition. The competition was designed to raise awareness about Parkinson's and to put a face on the disease. The videos, which had to be under 3 minutes 30 seconds, are available to view online at www.worldpdcongress.org/about/videos.cfm.



From Melissa

Dear UPBEAT members

I just wanted to say how lovely it was to meet all those who attended the UPBEAT conference in November. I hope you enjoyed the weekend and went away with new lines of support and information.

UPBEAT is a group for people with early-onset Parkinson's and their partners. Please be encouraged to get involved in your area so that all early-onset Parkinson's people can access support if they want it.

Look out for more information in the future about the next UPBEAT conference - it is not to be missed!

I have really enjoyed my time working for Parkinson's New Zealand, but unfortunately I am moving on to warmer pastures in Auckland in 2011 so I will not be the UPBEAT Coordinator any longer. Thank you to all the members I met, I really enjoyed talking with you.

Take care, *Melissa*

