



# UPBEAT

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



## Parkinson's and work

*A Parkinson's diagnosis at any age has unique challenges. Learning you've got early onset Parkinson's at age 50 or younger can be a very emotional experience and it can disrupt your future plans – physically, mentally, socially, emotionally and financially.*

If you need to work or want to work the question of how best to hang on for as long as possible is critical. The length of time you continue working will depend on different factors, some of which will be related to your symptoms while others are likely to have to do with the economy and your employer.

### Should I tell my employer?

If you are required to disclose your health condition in a job application form, you must disclose relevant information at that point. In disclosing your disability or health condition, be positive, constructive and specific in how you disclose the information. Think of how living with a disability or health condition might serve as an asset in your workplace (e.g, developing leadership skills).

*"All I said was quite simply, 'I have Parkinson's. I do not want to be treated any differently, but on occasion I may have a medical appointment, I may shake or stumble. But I will continue to give 100% of my effort.'"*

-UPBEAT member Lyn Jones

In some circumstances you are obliged to disclose your condition. The Employment Relations Act (2000) requires that employers and employees deal with each other in good faith. If your job poses any hazards, openness and honesty are crucial not only for your own well-being but that of your co-workers. Your employer may need to know of your condition to help him or her fulfil

their health and safety obligations toward you as an employee. Under the Human Rights Act, it's unlawful to discriminate on the grounds of a disability in employment.

*"Straight after I was diagnosed I told my boss about the diagnosis. He was fine with it and said he wanted to keep me on as long as I wanted to and was able to drive. I do get some strange looks at times when operating the swing lift with a heavy container—the trailer is shaking with the weight and my right arm is shaking with the controls!"* -UPBEAT member John Sluys

If you are not asked the question in an application form prior to applying for a position, at some point you are going to have to disclose your condition. Deciding when to tell your employer that you have Parkinson's is a very personal decision and depends very much on your circumstances. Bide your time until you know what you want and can present solutions. For example, is going part time an option if full time work becomes too difficult? Would it be possible to work from home? Do you need a change in role or a career change? It is important to discuss privacy issues if you and your employer agree to formally let other people know about your condition.

*"Employed at the time as a Contracts Manager for a civil construction company, pricing and managing construction contracts within the greater Waikato/King Country area. Work required driving 50,000 to 60,000km per year. At the time of diagnosis I told my manager immediately who was very supportive. Unfortunately he left for another position. The company I was working for was sold to another Australian civil construction company who closed the branch I was working for in 2012. I was very*

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*concerned this would be the end of my career and that I would struggle to get employment at similar terms. After three months unemployed I secured a position with a local civil construction firm on a similar salary package. Worked here for nearly three years and still doing 50 hour weeks."*

-Anonymous

### What support is available?

You can discuss any issues with a medical professional or your Parkinson's New Zealand Community Educators. Our Community Educators can advocate on your behalf. They are well qualified to explain what Parkinson's is and what it means in employment terms.

If you have questions about employment, the Department of Labour ([www.dol.govt.nz](http://www.dol.govt.nz)) is a good place to start. Workbridge ([workbridge.co.nz](http://workbridge.co.nz)) is a professional employment service for people with all types of disability. Besides matching jobseekers and employers, Workbridge also administers three training and employment support funds available to disabled people on behalf of the Ministry of Social Development. An occupational therapist can assist in maintaining independence both at work and at home.

*"My recommendation is that a low stress job is a must. I find myself at times wound up that much I shake like a leaf and have trouble walking and if someone was to say "boo" I would jump out of my bloody boots. Some days I cannot face work so I curl up in a ball and call in sick. I guess some stress is unavoidable but I can thoroughly recommend that you don't look for any extra."*

-Anonymous

### PARKINSON'S AND FINANCES

Common issues you may have to face include health care costs, insurance, employment, disability benefits and legal matters. Your ability to handle legal and financial problems will be greatly improved if you have a good working relationship with your doctors and health care professionals, as they will be able to manage much of your ongoing medical care and to assess your employment capabilities.

*"My employer has been extremely understanding and supportive and I'm proud of what I am able to do. My finances concern me because even though we have separate finances (second marriage) I am not entitled to any assistance once I am not able to work which will put pressure on us in the future."*

-Anonymous

### If and when you decide to leave work

Thinking about leaving work is a very important decision for younger people with Parkinson's, because of the impact the condition can have on the ability to continue to work over time. You are the only one who will know when it's time to leave work due to your Parkinson's. This decision should depend on the severity of your symptoms, and also the type of job you perform. Parkinson's progresses slowly, and there is no urgency to make decisions about work.

Setting up a discussion to talk about financial planning is important to initiate after receiving a diagnosis. You may wish to consult a financial planner (often free) or accountant to receive professional advice on planning your finances.

Although employment rights for those with a disability have improved over time a number of problems can still occur in receiving disability or claiming insurance benefits under policies

### Transition to a disability benefit

If and when you decide to transition from work to a disability benefit, realise it is a major life event. A range of feelings are associated with a decision to leave work. These may take the form of depression, which can present as an inability to concentrate, or create a general feeling of hopelessness and fear about the future. The important thing to remember is that these symptoms are a natural part of the transition. If you are experiencing these symptoms for more than one week you should talk to a medical professional or your Parkinson's New Zealand Community Educator.

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purchased before a diagnosis. Given the importance of being able to access these types of programmes when you need them, you should seek out advice from a solicitor when problems arise or just to know your rights ahead of time after your diagnosis.

If the option is available to you, you may be able to take redundancy. This is a different process to early retirement or a disability benefit. If your employer is making redundancies and you feel you're being treated unfairly, employment tribunals can decide whether you're being discriminated against because of your condition. If you are a trade union member, you can ask the union for advice about any work issues and for help negotiating.

### What happens financially if you can no longer work?

If you become unable to work, there are programmes that address the needs of individuals with disabilities in the areas of employment and income support. As a New Zealand citizen you are entitled to receive health care from the public system and depending on your financial circumstances, you may qualify for subsidised GP visits and medication. Check what financial benefits you could be entitled to with your Parkinson's New Zealand Community Educator or your local Work and Income office ([www.workandincome.govt.nz](http://www.workandincome.govt.nz)). Eligibility for benefits depends on your circumstances. Find out the rules for benefits before making a decision.

### Support and advice

You can speak to your Parkinson's New Zealand Community Educator for more information.

- Work and Income  
[www.workandincome.govt.nz](http://www.workandincome.govt.nz)
- Disability Support Services on 0800 373 664 or email [disability@moh.govt.nz](mailto:disability@moh.govt.nz).
- Community law centres  
[www.communitylaw.org.nz](http://www.communitylaw.org.nz)
- Your local Citizens Advice Bureau
- Senior Services on 0800 552 002.

### Diagnosed in 2010 aged 46

*"I'm now working full time as PA/Administrator for a local health board and life is busier than ever. Never one to 'push back' at work when the pressure rises, I'm now mindful that as anyone with or without a chronic condition, this is important to do at times. When first diagnosed I didn't want anyone to know, just family and close friends least of all work colleagues, I didn't want to be different and to me at that time I felt I was. My confidence in my ability took a bashing. With the support from local Parkinson's groups, close friends and getting the management of my drugs in tune with my attitude, I eventually realised I was still the same person. I can still work, maybe with a few tweaks, but I can do it."*

-UPBEAT member Lyn Jones

**UPBEAT Update:** The UPBEAT brand was designed over 20 years ago and is in need of an update. Originally designed by Dianne Oliver, it symbolised cupped hands. We hope this won't be as controversial as changing the flag! Please let us know which of the three design choices you prefer in an email to [UPBEAT@parkinsons.org.nz](mailto:UPBEAT@parkinsons.org.nz) by 30 June 2015.

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## Outward Bound 2015

Each year Parkinson's New Zealand runs an Outward Bound course for members of the UPBEAT special interest group for people with early onset Parkinson's. Here UPBEAT members Lia and Derek Lardenoye describe their experience:

*"As an introduction we rolled in the mud on the beach (swamp), painted each other's faces with mud to later take the masks off and start a new 'life' while at Outward Bound. After that the group was feeling the 'ice is broken', but for Outward Bound it was the christening by jumping of the jetty in cold water to assess our ability to 'float' or swim. I must say it took our breath away and getting out the water onto the jetty to*



*have a group shower was not appealing to many of us. Anakiwa has plenty of hidden spots on their grounds and soon we would get to know many of them. This large umbrella of hidden water between the trees, with cold water cascading onto our already freezing bodies was going to be a feature every morning after our early morning exercise on completion of the 3km run or walk and a muddy walk into the sea with a real dip, proven by wet shoulders and hair. Some of us had a little difficulty completing this challenge therefore the Outward Bound leaders would send us back in.*

*"After a hearty breakfast, we loaded everything back on our cutter 'boat' and the Outward Bound leaders stated that they were confident in our ability to sail the cutter 'Endeavour III' home to Anakiwa and left us to it! This took the wind out our sails but as a group we did it. Sailing in the wind and rowing with those terrible heavy oars. What an experience! I never thought my body was able to push through the barriers. Limitations are in our minds. Live your life the fullest you can but be real to yourself. I did it, or we did it!" -Lia and Derek Lardenoye*



Parkinson's New Zealand wishes to thank:

**douglas**

### UPBEAT newsletter moving online



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](mailto: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.

Parkinson's New Zealand, P O Box 11 067, Manners Street, Wellington  
website: [www.parkinsons.org.nz](http://www.parkinsons.org.nz)

FREephone 0800 4PD INFO email: [UPBEAT@parkinsons.org.nz](mailto:UPBEAT@parkinsons.org.nz)  
Facebook.com/parkinsonsnz Parkinson's New Zealand Charity Registration Number: CC27373