



# UPBEAT

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



## Parkinson's and your identity

The physical symptoms of Parkinson's are well known, but researchers are also looking at the impact of Parkinson's on the personal and social challenges that people face after receiving a diagnosis. A number of studies have shown links between non-motor symptoms and physical symptoms and the experience of living with Parkinson's. Social and psychological difficulties added to physical changes can be very testing for those of us living with Parkinson's. For example, some people may not be able to take part in all the meaningful activities that they used to do, they may have fewer social contacts, or they may not be able to work. These changes may in turn have a negative impact on identity or one's sense of self.

### What is identity?

Identity has been defined in a variety of ways. It is the core sense of who you are, as well as your roles within your family or within your job. Identity includes how you see yourself as well as how others act towards you. These two factors may influence each other. For example, the identity that others assign to you, such as "employee" or "caregiver" can also shape your sense of self. Communication is central to your identity as well. How you negotiate and present yourself in your social interactions helps to form your identity. It is also important to remember that aspects of a person's identity change over time.

### Effects of Parkinson's on your identity

Parkinson's may have different effects on your identity and roles. For some people, having Parkinson's may not change the core sense of who you are. For example certain roles such as those within your family or within your job may not change. You may recognise you are the same person except for your Parkinson's symptoms. For many people it is important to retain their old identity and this is often achieved by trying to maintain a 'normal' life. You may try to distance yourself from other identities such as 'being a Parkinson's patient'.

However, some people do experience and mourn losses and changes in their identity. The losses can relate to changes in specific roles such as being a father or having a job / being an employee, or more general elements of identity including losses in femininity or masculinity. Having Parkinson's may also have an effect on your activities. There may be meaningful activities that you used to do that were

important parts of your identity, for example being able to go shopping, to drive whenever you wanted to, to cook meals, or to provide for your family.

You might feel that your identity is threatened because of potential embarrassment linked to some symptoms, for example appearing slow or shaky in public. As a person living with Parkinson's you also may experience forms of discrimination or misunderstanding.

In social situations you may feel that having Parkinson's represents your only identity. This might be inadvertently worsened by people who always ask you how you are getting on with your Parkinson's when they meet you, even though they mean well.

Sometimes psychiatric or mental health complications of Parkinson's such as depression or anxiety can threaten our usual way of thinking about ourselves and our role in the world. Getting good treatment for these is also a way of helping to protect our identity.

Something that may help is to observe that there is often a difference between how you feel about yourself in your own mind and what your symptoms may represent to others. Which view is most important at the end of the day? Consider the fact that every person is different from who they were in the past, however the past person is still truly them. Our own identity is continuous, despite big changes, for example growing into an adult. In your life you have carried out a single continuous series of actions from conception. You also have the same identity as your past self because you share memories and personality traits with that person, yet that identity evolves. You can lose parts of your body but you will still be yourself. You can gain new memories and experience different emotional states but you still will have connections to your past self. There is enough flexibility in your identity to remain who you are despite changes brought your way by this disease.

### Successful strategies

Some strategies to manage threats to your identity could be to renegotiate the identity others assign to you, to rethink the key elements that are important to your self-identity, or to offer your Parkinson's as an explanation for some of the changes that you are experiencing.

## Parkinson's and your identity

*Learning you've got early onset Parkinson's can lead to physical, mental and emotional challenges. It can also affect your identity, your sense of who you are, and your roles within your family or your job.*

When Judy ("Jude") Clarke was diagnosed with Parkinson's nine years ago, she was at the pinnacle of her career. A podiatrist and a member of the Podiatry Special Interest Group and part of the New Zealand Society for the Study of Diabetes, she had her own thriving practice. She is now retired and serving on the Parkinson's New Zealand Board as well as on the committee of Parkinson's Hawke's Bay. She has been married to Peter for 32 years and they have two wonderful children who are attending university, one in Auckland and the other in Wellington. Here Jude shares her experience of how living with Parkinson's has affected her sense of self and her roles within her job and her family:

"I try not to let it, but if I'm being honest, living with Parkinson's has affected me a bit. I suppose my main thing was that I was always on the go constantly. Now I find I have to pace myself a bit more—I do get a bit tired. I definitely try to do as much as I can though. Mornings are better and I'm aware that when the tablets wear off—I get a bit shaky and while I don't mind shaking in public, it does bring the fact that I have Parkinson's out to the forefront. I'm not worried now that people know, but initially it seemed a bit daunting to say you had Parkinson's—it seemed to bring out the 'sympathy' face look on people—like I seemed to have grown two heads! I suppose I've never wanted sympathy—you just have to get on with what life deals to you.

"Roles have changed a bit—especially my job. I was a podiatrist and after four years from my diagnosis I felt I really needed to consider retirement. I was lucky (or sensible) to have an insurance in place and that pays enough of my previous salary, so we're not about to go belly up! Not having the earning power I could have had

is a nuisance—certainly affected me in that way. I work a few hours a week for the guy who bought my practice. I'm now what they call the Clinical Manager, a fancy name for someone who is in charge of policies and procedures and who acts as a mentor for some of the podiatrists we employ. I really enjoy it and it keeps my brain active!

"I can still cook and clean but I do find putting washing on the line can be a trial. It's those little things like picking up things that I get frustrated about. Luckily I have a great hubby who is used to me spitting the dummy at times when my fingers don't want to work properly. I have wonderful friends that don't treat me any differently—they and my family are what make my world go round. I am lucky to have such great family and friends!

*"It took a wee while to accept having Parkinson's—probably a few months. I've always said that Parkinson's is life-altering, not life threatening. And it's up to the individual to make it work or not work for them. I am just lucky that I have very supportive networks of people who make my life so good."*



Parkinson's New Zealand Board member  
Jude Clarke

### Successful strategies

- Your ability to meet your expectations and goals may be influenced by factors such as how you perceive your condition. For instance, how much you perceive Parkinson's to be an 'interruption' to your life versus accepting living with Parkinson's and the changes it is associated with in your life.
- Having hope—hope for relief in managing symptoms, as well as hope related to social identities, activities, accomplishments, tasks and interactions is important. Don't forget that hope may be for new good things rather than just for restoration of old cherished things.
- Having connections with people who have more experience living with Parkinson's is extremely valuable. In addition to the resources offered by your health professionals there is also a wealth of information and knowledge that can be learned from those who are personally living with Parkinson's. With the right information, education and support you can live well.

## Outward Bound 2016



*The UPBEAT members who attended Parkinson's New Zealand 2016 Outward Bound course earlier this year experienced a lesson in the power of positive thinking to help make the most of what life has to offer and seize the day.*

Every year Parkinson's New Zealand runs an UPBEAT Outward Bound course. This course provides an opportunity for members and support staff to participate in a 6-day adventure in Anakiwa filled with mental and physical challenges and a chance to bond with other members. The course is very rewarding giving participants a chance to re-assess their capabilities and accomplish tasks with the support and supervision of the experienced Outward Bound team.

Dave Birss from Mount Manganui particularly enjoyed the challenge of the six day Outward Bound course. Dave attended with nine other people (four men and five women). The team was accompanied by several Outward Bound instructors and two Parkinson's New Zealand support staff.

"Throughout the week we were kept in the dark as to what lay ahead, so plenty of surprises and not a little apprehension."

The team was up before 6am and went to bed not long after 9pm each day.

"The time in between was a blur of constant activity—physical, mental and emotional."

Dave says a watershed moment was completing a number

of activities on the high wires, about 10 metres up. He was not confident with his balance and didn't think he could do it.

"It was very challenging."

However, he says, the entire team succeeded in completing the task.

"With varying degrees of persuasion, help and encouragement. I never would have thought that I would be able to walk unaided along a 10-metre log a metre from the ground, let alone 10 metres up, but I did."

They sailed, walked, rowed, and spent a night out in the elements.

"Solo is being left alone in the bush overnight and the next morning, freeing your mind to contemplate. Very interesting!"

Denis and Jan Russell from Whangarei found Outward Bound a "catalyst to refocus our own lives and personal goals."

Dennis and Jan have praise for the Outward Bound instructors, whose competent guidance and support they say, ensured the safety and wellbeing of the team members.

"With the help of the Outward Bound instructors we were soon put at ease. Within a week we developed and left this special place as a functional team.



### UPBEAT Weekend

Many of you expressed disappointment that the UPBEAT weekend has been postponed. We are pleased to announce that 2017 planning is underway. We are applying to secure more funding. This is your weekend so if you have ideas for topics please email us [UPBEAT@parkinsons.org.nz](mailto:UPBEAT@parkinsons.org.nz)

## Outward Bound 2016



Without exception, each member had expressed they had been challenged during the course, physically, emotionally or in some other way.

“Living closely with others who have similar Parkinson’s symptoms as Jan experiences (on a daily basis) was valuable.”

Talking openly, discussing, and observing how they as individuals cope with physical and emotional challenges faced was a great experience.”

Glenda Skinner from Wellington found going to Outward Bound a “life-changing experience.”

“Following my diagnosis at age 55, I have been told continually of the benefits of physical exercise but never really given the concept more than lip service!

“I’m fitter now than since high school! And that was just preparing for Outward Bound.

“The actual course was just something else. We had a lot of full and frank discussions about life in general and Parkinson’s in particular. Team camaraderie was high.

“It’s amazing what you can achieve with the support of your Watch mates, Outward Bound instructors and Parkinson’s carers. I feel I came away from Anikawa with much more self-confidence, a belief in myself that I can

face up in challenges and a determination to keep fit.

“Anakiwa is a beautiful place and the staff and instructors are incredibly supportive. If you get the opportunity, enrol. You won’t regret it.”

Karen Hicks from Waikato says, “Put your name forward and go.”

“You are surrounded by breath taking views, great accommodation, fantastic meals, spending your days with wonderful people and enjoying physical activities.”

“When I left home I was excited and nervous wondering what lay ahead for the week not knowing if I would be able to stand up to a week of Outward Bound.

“Once I arrived I knew it was going to be a great week. It was great living together with a group of adults with Parkinson’s and sharing our experiences of our crazy journey that Parkinson’s puts us through.

“I’m ready to face the world again and the challenges that Parkinson’s and life put in front of me.”



For more information about Outward Bound or to register your interest for Outward Bound 2017 please contact [info@parkinsons.org.nz](mailto:info@parkinsons.org.nz).

### Thank you for your support

Parkinson’s New Zealand would like to thank Douglas Pharmaceuticals for sponsoring the 2016 Outward Bound Course.



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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