

Parkinson's, Employment and Quality of Life

“Work and *Parkinson’s*?” A bemused look accompanies this common reaction when Swinburne University researcher LOUISE COOPER, tells people what she is currently investigating. Clearly the public’s perception is that people with Parkinson’s do not work. *How wrong can they be?*

Contrary to popular belief, the majority of people with Parkinson’s are of working age at the onset of their symptoms, if not at the time of diagnosis. Many are working full time and those with early onset may be at the peak of their working life. Mortgages, dependent children and family activities are very much on the agenda. Planning for later years may be underway, making the most of an income to fulfill retirement dreams.

Work is not only necessary to fill up the car with petrol and pick up the weekly groceries, it is also an important part of who we are and the role we play in our community, whether we have Parkinson’s or not. Swinburne University’s 4-year research project, ***Parkinson’s, Employment and Quality of Life***, is an opportunity for working people with Parkinson’s to tell how it really is.

Researchers, Louise Cooper, Dr Simon Knowles and Professor Susan Moore believe people with Parkinson’s will be only too willing to relate their experience.

“Preliminary interviews indicate that people with Parkinson’s are supporting each other by sharing their experiences in order to deal with the challenges presented at work,” says Louise Cooper.

“When it comes to Parkinson’s, there seems to be a gap in information and policy relating to employment for people with chronic disease. Awareness of the condition is increasing amongst health professionals and this means that diagnosis is likely to occur earlier and at a younger age. There will be more and more people with Parkinson’s in the workplace in the future. It’s important that health professionals, rehabilitation specialists and employers have access to information that will optimise working conditions for people with Parkinson’s.”

[In addition, Parkinson’s Australia believes that government must also respond accordingly to support people with Parkinson’s in the workplace, through appropriate legislation, guidance and policy.]

Ms Cooper’s father lived with Parkinson’s for over twenty years. “I’m sure he’d forgive me for describing him as “bloody-minded”! She says. “He never let his symptoms stop him from trying to continue doing the things that he wanted to do, including continuing to work for as long as possible. What I have learnt through my research so far is that it probably wasn’t as easy for him as it appeared at the time and for some people it would seem impossible”.

Although information is scarce, some things have been established: Not everyone feels able to tell their employer or work colleagues that they have Parkinson’s for fear that it might affect their job prospects and their relationships with others. It is not uncommon for people with Parkinson’s to be overlooked for promotion or considered unable to perform a job properly. Some people with Parkinson’s start themselves to feel inadequate in their usual role. For others, a Parkinson’s diagnosis presents an opportunity to reassess a work situation and make changes that give more emphasis to family life. For most people, the support and understanding of employers, work colleagues and friends or family appears to

be crucial. For everybody, there is a difficult period of adjustment following diagnosis and a desire for reliable information on which to base decisions.

“The main aim of this project is to identify where support and education is needed,” says Ms Cooper. “We are expecting to find a variety of experiences but hoping that common threads will emerge in relation to an ability to make work-related decisions.”

The Swinburne team is currently seeking participants to complete a short online survey about their experience as a person with Parkinson’s in the workplace.

The online survey can be accessed at <http://opinio.online.swin.edu.au/s?s=4356>.

The outcome of the study will be made available through Parkinson’s NSW in late 2009.

Editor’s note: The Access Economics’ report, *Living with Parkinson’s Disease: Challenges and Positive Steps for the Future*, commissioned by Parkinson’s Australia and published in 2007, was viewed as pivotal in the move to address issues related to Parkinson’s in the work place. This current study, which emphasizes the psycho-social aspects of employment for people with Parkinson’s, is further indication that the time has come to see Parkinson’s as a question of quality of life rather than a set of medical symptoms, and to urge governments and policy makers to fund appropriate action.