

Employment With PD: Working it Out

One of the first questions a newly-diagnosed person will likely ask is, “How long will I be able to work?” This question is especially important to young-onset patients, who may be many years from retirement age, and who are often raising families and facing numerous financial responsibilities.

As with most aspects of this “designer disease,” there are no standard answers; they vary from person to person. Factors in the decision-making mix include the nature and physical demands of a job, the acceptance and support offered by employers and co-workers, the individual’s response to medication, financial issues and the rate of disease progression. Some people continue to work for many years after a Parkinson’s diagnosis, while others may find that the physical and mental stresses of their job become too challenging, too quickly.

It is important to recognize that a diagnosis of PD does not mean that your career is automatically over. I was diagnosed in 1995 at the age of 45, and have continued working as a college librarian for 10 years since then. Here I will share my experiences working with Parkinson’s, in the hope that the information may be helpful to others who are facing similar decisions about jobs and careers.

To tell or not to tell?

Should a person newly diagnosed with Parkinson’s tell his or her employer about the disease? For many, the symptoms can be effectively controlled by medications for several years, and colleagues at work may not even know that you have Parkinson’s disease. Your symptoms may not interfere with your ability to do your job, and — because in most cases your medical records are confidential — it is entirely your decision as to whether or not your Parkinson’s diagnosis is

made public.

How comfortable are you with keeping your condition a secret at work? The answer will be influenced by such factors as your existing relationship with your employer and co-workers, and your instincts about how they will respond to the news. Ideally, employers would do whatever they can to help employees continue working. Besides being the right thing to do, and being required under the Americans with Disabilities Act (ADA), it also makes good business sense for an employer to try to keep experienced and valued workers.

Unfortunately, not all employers are of this mindset.

My own decision was to tell most of my co-workers about my illness soon after receiving my diagnosis. People’s responses varied; a few individuals seemed to avoid me from that day on, but most have been supportive and have even become well-educated about Parkinson’s. I have also been able to enlist their support in writing to Congress to support increases in federal funding for Parkinson’s research. I found that involving friends and co-workers in PD advocacy efforts helped them to understand my illness and also provided them with a way to support

me. In fact, my library director has been a shining example of what should — and can — be done to help people with disabilities in the workplace.

Workplace accommodations

By law, people with Parkinson’s disease are protected under the ADA against discrimination in employment practices. This law requires employers to make reasonable accommodations for employees, as long as they do not impose an “undue hardship” on the employer’s business. A reasonable accommodation is defined as “any modification or adjustment to a job or

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(over please)

the work environment that will enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions.”

As my symptoms progressed and medication became less effective, my job responsibilities have been adjusted to be more manageable. For example, as teaching became more difficult for me, my class load was reduced. In place of these responsibilities, I have taken on other duties that can be performed in my office by computer, helping me cope on my own schedule with my now longer and less predictable “off” periods. I type all of my written communications, rather than expecting others to decipher my typical Parkie handwriting. I take shorter lunch breaks, so that I am able to leave work early if fatigue becomes a problem by the end of the day.

Some other examples of workplace accommodations that can be helpful for people with Parkinson’s include the provision of adaptive computer equipment, such as an ergonomic work station, voice recognition software or a trackball. Mobility devices, such as a scooter or cane, or speech amplifiers, might be requested. Depending on the nature of the job and company, requests for a more flexible work schedule, or reversion to a part-time arrangement, or telecommuting might be options. Accommodations to help deal with cognitive problems could include arranging for a workspace away from noise or other distractions, and the use of such memory aids as schedule planners and written instructions.

One outside source of information about the workplace is the Job Accommodations Network (JAN). JAN is a free consulting service that is provided by the US Department of Labor. Its services are “designed to increase the employability of people with disabilities by 1) providing individualized worksite accommodations solutions, 2) providing technical assistance regarding the ADA and other disability related legislation, and 3) educating callers about self-employment options.”

Visit the JAN homepage at www.jan.wvu.edu and be sure to check out the “Accommodation and Compliance Series: Employees with Parkinson’s Disease” at www.jan.wvu.edu/media/PD.html. The staff at JAN is also available for free consultations by phone at (800) 526-7234.

Making the choice

Part of working with Parkinson’s is also knowing

when it is time to stop working. In my situation, I have slowly realized that even with accommodations, I am no longer able to do my job as I would like to, with fatigue a constant problem. So after 22 years as an academic librarian, 10 of them with PD, I have concluded that fall 2005 will be my last semester working. Difficult as the decision certainly was, it helps me to know that my volunteer advocacy work on behalf of the Parkinson’s community will continue to make good use of my research skills.

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