Learning to live with Parkinson's disease (PD) is a process. For most people, the first step in that process is educating themselves about the disease and its management. What about learning to work with Parkinson's disease?

With an everincreasing number of people working well into their 60s, 70s, and beyond, and more and more people being diagnosed young, one of the critical questions becomes, "How long will I be able to continue working?" Similar to the process that occurs upon diagnosis, managing your PD in the workplace (knowing if/when to slow down, disclose your diagnosis; request an accommodation, and/or apply for disability) is a learning process as well.

You will want to clearly understand your rights, your limitations, and the various benefits to which you may be entitled. The more research and advanced planning you do BEFORE you make critical decisions about work, the more likely you will be to successfully negotiate PD-related employment issues.

**Work**

Most employees would say that, even under the best of circumstances, showing up on time every day and giving 110% to a job can be a challenge. For employees living with chronic illnesses such as Parkinson's disease, the average workday is made even more difficult by the demands of managing their condition.
If you have been diagnosed with PD and need or want to work, you are not alone. According to the Partnership for Solutions, an initiative to improve the quality of life for those who live with a chronic illness, 41% of working-age adults (20 to 65 years) have at least one chronic condition. The inevitable questions are: How can I hang on to my job? And for how long?

**The Law**

It may be reassuring to know that the law is on your side. The federal Americans with Disabilities Act (ADA) requires employers with 15 or more employees to make a "reasonable accommodation" for a disabled worker as long as it does not present an "undue hardship" to the company, and the employee can perform the job's essential functions. Reasonable accommodation can cover everything from allowing an employee time off for medical appointments to arranging for work to be done at home.

Under the Family and Medical Leave Act (FMLA), companies with 50 or more workers must provide eligible employees up to 12 weeks of unpaid leave during any 12-month period to deal with the birth or adoption of a child, their own illness, or that of a family member, without fear of losing their job or medical insurance.

**Disclosure**

To tell or not to tell...should you disclose your diagnosis to your supervisor, your co-workers? On the one hand, you may fear that disclosing a chronic illness will be bad for your career, assuming that your employer will favor healthy workers over ill ones. On the other hand, by not disclosing your illness you lose out on any protection, accommodation, and time off provided under the ADA and the FMLA.

Rosalind Joffe, founder of Boston-based CIcoach.com, coaches people with chronic illnesses on how to survive and thrive in the workplace. Joffe advises being "as public as you need to be and as private as you want to be."

If you do decide to discuss your problem with your employer:

- **Be professional.** Treat the discussion as you would any other work-related discussion.

- **Be specific.** Wait until you know exactly what kind of accommodation to request (e.g., time off, more frequent breaks, permission to work at home).

- **Offer solutions.** Propose changes that will be beneficial to your employer and you will show that you have put serious thought into maintaining the quality of your work and minimizing workplace disruptions.

- **Reassure your supervisor.** Explain how you've successfully managed your condition in the past, what you're doing now, and what you are planning to do in the future to keep symptoms under control.

- **Be prepared.** Always have work with you so you are able to be productive even when you can't make it to the office.

**Disability**

At some point, you and your doctor
may decide that leaving work is in your best interest. The timing of this decision varies from one person to another and will depend to some extent on your symptoms, your response to treatment, the time(s) of day you are most (or least) productive, the type of work you do, and the environment in which you work.

Whenever possible, allow adequate time to think over your decision and make a well organized plan for leaving work. If/when you decide to transition from work to disability, realize that it is a major life event, one that can have both physical and emotional repercussions. These may take the form of depression, present as an inability to concentrate or focus and accomplish a task, or create a general feeling of helplessness and fear about the future.

People who recognize the impact a decision to leave work can have on them are typically better prepared to deal with the range of feelings associated to it. The important thing to remember is that these symptoms are a natural part of the transition, and they will pass.

People often worry that after they leave work, they will have nothing to do. Surprisingly, many find that they are so busy, they have no idea how they were ever able to work full-time. Initially at least, there's a lot to do, applications and claims to file, health insurance to adjust, government benefits to apply for. If you are the type of person who was always busy before, you can be as busy as you want and are able to be once you go on disability.

**Pursuing Disability**

Pursuing disability benefits is undoubtedly a cumbersome process, one that more often than not takes considerable time, patience, and persistence. The more you can learn about common mistakes, the more likely you are to avoid them and make what can be a frustrating and time-consuming process much easier. While there are certain aspects of the Social Security Disability Insurance (SSDI) application and appeal process over which you have no control (such as your state or jurisdiction's case backlog), there are others you may be able to influence to some degree.

**Initial Disability Application**

- **File immediately!** Do not wait until you have exhausted short-term or long-term disability benefits through your employer or supplemental policies.
- **Consider hiring an experienced disability attorney.** There is often no charge unless the case is won.
- **Consult specialists.** Documentation from your healthcare providers (i.e., movement disorders specialists, psychiatrists, speech/language pathologists) will strengthen your case.
- **Include ALL assessments and reports.** Even those professionals not considered "acceptable medical sources" by the Social Security Administration (SSA), may help your case, they just won't be given as much weight.
• Request a Residual Functional Capacity (RFC) form. These are generally more effective than an independent narrative, and the form can be requested through your local Social Security office.

• Submit VERY detailed notes. Include the frequency, severity, and duration of each and every symptom and "functional limitation" (i.e., difficulty performing daily activities).

• Do not focus exclusively on physical impairments. Many claims ultimately win approval by providing evidence of both physical and mental impairments.

• File for spousal and/or children's benefits. Investigate this option and apply, if you are eligible.

• Keep copies of EVERYTHING. Duplicate copies allow you to replace any lost documentation quickly and easily.

• Make a transition plan. The period of time between initial application and the regular receipt of awards benefits is different for each case, but is often longer than people expect. Be prepared for the wait, and think ahead of time about how you will manage financially during this transition.

**Appeal of Unfavorable Decision**

• Appeal within 60 days of receiving a denial. Failure to do so is a common "killer" of disability applications. Appealing online can make the process faster: http://tinyurl.com/a32fd5.

• Submit a "Request for Reconsideration." Do not submit a new claim, but be sure to update your claim with any new information on your condition, limitations, treatment, etc.

• Send all written documentation via certified mail.

• Consider hiring legal representation. This may be worthwhile, especially if you have been denied benefits previously.

**Partial Work Activities**

Many people who are collecting disability benefits under either Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) would like to do some work. Working can provide a supplement to income, but more importantly, working improves the spirit and can help alleviate the depression that often accompanies disability.

For people with PD symptoms, there are days when some work is possible. Many people, however, are hesitant to try any type of employment out of fear that it may jeopardize their Social Security benefits.

Both SSDI and SSI have programs that permit some work to be done without losing benefits. Sometimes the same rules/limits apply for both programs and sometimes they are different. Therefore, it is extremely important that you thoroughly understand Social Security's rules about work before starting to earn any wages. Mistakes and misunderstandings can result in overpayments that must be refunded to Social Security as well as the possible loss of benefits.
The following points apply to both plans:

• **Give work a trial run.** Before you do any type of regular work for wages, make sure you can physically and emotionally handle a regular commitment.

• **Keep all paycheck stubs.** These will serve as a record of your work hours, your gross and net pay, and the time period in which the wages were earned.

• **Keep records of your expenses related to working and your disability.** Social Security allows you to subtract from your earnings expenses you have to incur for your work.

• **Notify Social Security of your plans to try and do some work.** People are often afraid this will trigger a review of their disability status. However, the time for the next Continuing Disability Review is set at the time one is completed, and this is usually not impacted by a decision to do some work.

• **Be careful of wage maximums.** If Social Security consistently notices you earning wages just below the maximum limit, it is likely to get "curious" and question the validity of your award.

• **Do your research.** The rules related to working while collecting disability benefits are complicated. The Social Security Website has a wealth of information about working while collecting benefits: See Working While Disabled at [www.ssa.gov/pubs/10095.html](http://www.ssa.gov/pubs/10095.html)

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**ADDITIONAL RESOURCES**

**www.allsup.com**

This SSDI representation company posts extensive information about SSDI, personal financial planning and Medicare information on its Web site and also offers site visitors financial planning calculators and helpful tips for managing health care costs.

**www.disabilitysecrets.com**

A wealth of information, tips, suggestions, and "secrets" to help applicants navigate the federal disability system and win disability cases, benefits, claims, and appeals.

**www.helpwithbenefits.com**

Includes articles by founder Jacques Chambers, CLU, who, with an in-depth knowledge of insurance, employee benefits, Social Security and Medicare, is able to break down seemingly overwhelming tasks into smaller, easy-to-follow steps and explain complicated topics in understandable terms.

**www.ssa.gov**

Provides detailed information about SSDI, SSI and Medicare. Search function is extremely useful in sifting through the vast array of programs, topics, and procedures.
SSDI Guidebook
Developed to assist people in deciding whether applying for disability benefits is right for them and, if so, to help them navigate the complex application process. Although written by the National MS Society much of the information is relevant and helpful regardless of diagnosis.

www.youngonsetcenter.org
APDA young onset center website, which provides information about many aspects of living and working with PD.

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The information contained in this supplement is solely for the information of the reader. It should not be used as legal advise, but rather for discussion with the patient's own consultant.

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