

## **GUIDE FOR THE NEWLY DIAGNOSED**

*Plain speaking about common concerns after a diagnosis of Parkinson's disease.*

(Note on text: PD = Parkinson's disease; PWP = person with Parkinson's)

### **■ Introduction**

There is no simple way to deal with a Parkinson's diagnosis. It is a life-changing event that takes a long time to adjust to. There are no hard and fast ways of tackling the condition from day one — everyone has a different set of circumstances and a different outlook, and Parkinson's is a highly individualistic disease that everyone experiences differently.

This guide represents a compilation of the experiences of six PWPs — Carey Christensen, Cindy Exton, Tom Isaacs, Daniel Stark, and Ann and Greg Wasson — who now thrive following their initial period of adjustment. Through their experiences with PD they have come to find acceptance, mental strength and quality of life. These are all perfectly reasonable expectations of a future with Parkinson's disease.

### **■ I've Got What?**

**My doctor said PD is an “incurable progressive degenerative neurological brain disorder.” What does that mean in plain English?**

You have a disease of the brain — the part that primarily affects movement — that will gradually worsen and for which there is presently no cure.

Several different treatments are available, however, that can permit PWPs to lead fulfilling lives for a number of years. Many symptoms can be relieved in the short-to-medium term by medications, though over time these can lose their efficacy and produce undesirable side effects, such as involuntary movements known as dyskinesia. There are also surgical interventions, such as deep brain stimulation (DBS), which involves the implantation of electrodes in the brain. Because of the risks inherent in this type of treatment, most patients normally do not consider it until the medications they had been using no longer provide meaningful levels of relief.

Research is continuing, both to improve available treatments and ultimately to cure the disease.

### **How did I get PD?**

Classic PD is called “idiopathic,” meaning that it arises spontaneously from an unknown cause. Idiopathic PD may be caused by one or more genetic defects combined with exposure to one or more environmental neurotoxins, such as pesticides or other chemicals. Studies are ongoing to determine the exact cause or causes of PD. One thing we know for sure: PD is not contagious.

## **My grandfather, mother, and brother all had PD. Now I have it. Does that mean my children will get it?**

Some PWPs can point to PD in several generations of their families, which seems to make a case for a hereditary factor. But while a handful of families in the world have tied their familial PD to a single inherited gene, further study is needed to understand the role of genetics in the vast majority of cases.

Scientists largely believe that the majority of PD cases are not caused by genes alone, but rather by one or more genetic factors combined with exposure to one or more environmental neurotoxins, such as pesticides or other chemicals. There is little consensus on the extent of the role played by heredity.

### **■ Questions You and Your Doctor May Not Have Discussed**

#### **What's going to happen to my body?**

Which symptoms develop, and how severely and quickly, is unpredictable in PD and varies widely from person to person. Common symptoms include tremor, slowness, stiffness, rigidity, difficulty initiating or controlling movement, balance problems, unpredictable movements, cramping, and speech and swallowing problems. Cognitive problems, such as short-term memory loss, difficulty following complex instructions, or a loss of multitasking ability, may also occur. Some people will have several symptoms. Others will have only a few.

#### **Can I die from PD?**

Most doctors say that PD itself is not fatal. You die *with* Parkinson's, not *from* it. However, as symptoms worsen they can cause incidents that result in death. For example, in advanced cases, difficulty swallowing can cause PWPs to aspirate food into the lungs, leading to pneumonia or other pulmonary conditions. Loss of balance can cause falls that result in serious injuries or death. The seriousness of these incidents depends greatly on the PWP's age, overall health and disease stage.

#### **How do I find good doctors?**

It's a lot like hunting for a good dentist or a good mechanic: You need to ask around. Your primary care doctor may have a neurologist or movement disorders specialist to whom he or she refers patients. If you attend a support group, ask other PWPs. Try contacting one of the national Parkinson's organizations. You can also post requests on Internet bulletin board sites. But remember that the Internet should be just a starting point for your research and education, not your only source of information, since it is so often difficult to source and verify the advice you find there.

## **What exactly is a movement disorders specialist, and should I see one instead of a general neurologist?**

A movement disorders specialist is a neurologist who has taken additional training in diseases that affect primarily physical movement, such as Parkinson's. Whereas a general neurologist may treat patients with any of more than 100 neurological conditions, a movement disorders specialist focuses on a handful of disorders. Specialists are often affiliated with big universities or teaching hospitals.

The benefit of seeing a movement disorders specialist is that he or she is usually on the cutting edge of knowledge and treatment of PD. But it can also be fine to see a general neurologist who stays current with the literature and is willing to listen to you — though you may have to take more initiative in your treatment. We know many people treated by specialists and others treated by general neurologists, and we've heard good and bad stories on both sides.

The most important element in your care is that you have as comfortable, open and productive a relationship as possible with your care provider. In choosing a doctor, your major considerations should be how much the doctor knows, and how well the doctor listens. Remember, no two cases of Parkinson's are alike. Having a doctor who understands this and who listens to you is crucial. When it comes to PD, "state of the art" treatment could mean a new exercise regimen for one person, surgery for another.

## **Should I get a second opinion?**

Getting a second opinion is largely a matter of personal choice. But keep in mind that PD is often difficult to diagnose accurately, particularly when symptoms are mild. There is no simple diagnostic test, and approximately 25 percent of PD diagnoses are incorrect. PD starts out with such subtle symptoms that many physicians not trained in it may not accurately diagnose it. Even the best neurologists can get it wrong.

We would recommend that unless your doctor is particularly experienced in this area, you consult with a movement disorders specialist. A good neurologist will understand your desire for confirmation. If it is affordable (insurance doesn't always cover second opinions) and brings peace of mind, a second opinion can help you and those around you to move forward in dealing with your disease.

## **Should I start to take medications right away?**

You and your doctor should decide together on the right course of treatment for you, including when to begin with medications and what other forms of therapy you might wish to pursue. Decisions often must be made about whether and which medications to try first. And to some extent, determining what is right for you is a process of trial and error.

Don't feel pressured into making a decision right away. If you have PD, you had it yesterday and you will have it tomorrow. You have time to educate yourself and decide how you want to treat your disease and yourself.

Things to take into consideration: No drug on today's market has been proven to slow or stop PD. Available drugs only mask the symptoms. Weigh the importance of symptomatic relief against the side effects of the medications, your doctor's advice and your own feelings about taking medication.

### **What about complementary and alternative medicine (CAM)?**

We have found that massage, meditation and other treatments or techniques designed to relieve tension and stress may bring temporary, symptomatic relief. Acupressure and acupuncture, certain diets, and vitamin supplements are other common complementary treatments. While we have generally chosen conventional medications and treatments, we believe that as long as your neurologist knows what CAM treatment you are using and it causes no harm, it falls under the category of personal choice.

### **Am I going to wind up like those people I saw in the doctor's waiting room?**

PD is sometimes referred to as a "boutique" disease: It is designed specially for each person. What symptoms you get, and when, is unpredictable. There are broad paths of similarity as the disease progresses, but there is no guarantee that what you see is what you'll get. Some people wind up in wheelchairs, others still ride in bicycle races. Some can't clasp a necklace, while others make necklaces by hand.

It can be frightening to see the more pronounced symptoms of people who are in mid- or late-stage PD, such as dyskinesia (the involuntary flailing or jerking body movements that can result from long-term use of levodopa, the most common PD medication) or freezing (the sudden inability to move) or festination (the short, almost running steps that seem to accelerate on their own). The knowledge of severe symptoms such as these can be understandably upsetting, but remember that PD is highly individualistic and your disease may never encompass any of these conditions.

### **I can't seem to get anything done anymore — what is that all about?**

One of PD's more insidious symptoms is fatigue. This is not your garden variety bone-tired. This is fatigue on a cellular, molecular level. Your body is working overtime just to accomplish the simplest of tasks: taking a shower, answering the phone, pouring orange juice. Add to that the possible cognitive problems associated with PD, which include difficulty initiating projects, inability to follow complex instructions, short-term memory loss and difficulty in switching gears midstream. This combination is known among PWPs as "Parkinson's apathy."

Some things that will help you fight PD apathy are to exercise, try to get regular sleep, take short naps, do not isolate yourself and make sure that you and your doctor are square on your drug regimen. The dishes still might not get done, but at least you will feel better.

### **Why is rest important?**

Sleep is one of the most restorative of human activities. On any given night, however, at any given time, you can find someone with PD hanging around online at PD bulletin boards or in chat rooms. Forty percent of PWP's suffer from sleep disturbances caused by their PD, their medications or both. And yet fatigue is a serious problem for PWP's even if sleep disturbance is not a factor. Rest is important in dealing with the disease. Often something as basic as a catnap of 20 minutes once or twice a day helps one stay as refreshed and alert as possible.

### **Does having PD or taking medication for my symptoms make it unwise for me to have a baby?**

Many women with PD have successfully carried healthy babies to term. However, there has yet to be a thorough study of the effects of PD meds on the mother or child. Talk to your doctor about taking PD meds during a pregnancy as you would about any substance, such as coffee, alcohol and other drugs. Your particular situation, of course, will be affected by the extent of your PD and your overall health.

If your concern is preventing pregnancy, talk to your doctor about contraceptive options other than birth control pills. Doctors don't know whether taking PD medications compromises the pill's efficacy.

### **■ The Emotional Aspects of a PD Diagnosis: Coping and Staying Optimistic**

**A special note on anxiety and depression:** There are two different forms of depression and anxiety associated with PD. One is a normal reaction to being diagnosed with such a serious disease. Who wouldn't be depressed? But depression and anxiety can also be clinical symptoms of the disease itself — like rigidity or tremor. In fact, it is estimated that at least half of all PWP's suffer from clinical depression. The good news is that, as with PD's other symptoms, clinical depression and anxiety can be treated.

Depression is real. One of the authors of this guide suffered relentless depression for months, jeopardizing her job, her reputation, and her relationships with family and friends, because no one told her that PD could have a major impact on one's mental health. Another one of the guide's authors finally won a years-long, sometimes suicidal, fight against depression upon her diagnosis of PD and proper treatment of both the disease and its symptom of depression.

These symptoms, if left untreated, are damaging at best and deadly at worst. Make sure you discuss depression and anxiety with your doctor, for not every one — either doctor or patient — always recognizes the signs of clinical depression and anxiety without asking.

Possible treatments include antidepressants, exercise and therapy or counseling from a qualified practitioner. Support groups are great outlets for sharing experiences and knowledge in this area.

It is important to remember that clinical depression and anxiety are underdiagnosed in PWPs and that they are symptoms of your disease, not character flaws.

### **How am I going to deal with this?**

Starting with the moment of diagnosis, you will probably find that you think of your life as having two distinct parts: before PD and with PD. You may have dreamed of, or even planned, events yet to happen: places you want to go, things you want to accomplish — all of which are now colored by the knowledge that they will be affected in various ways by your PD.

A Parkinson's diagnosis, although life-altering, is not a death sentence. Symptoms will change over time, as will your attitude; no one should expect, nor should you expect from yourself, that this will be easy to deal with. But PWPs and others alike should all value and make the most of every day. In a best-case scenario, a PD diagnosis can become a real wake-up call: a chance to re-examine your priorities and focus not on what you cannot do, but instead, on what you can. It can be an opportunity to strengthen character and uncover qualities in yourself that you might otherwise never have recognized.

### **My emotions have been all over the map since I was diagnosed. Is there a “normal” amount of time it takes for people to recover emotionally from this news?**

When you are told you have a chronic, progressive disease, the feelings that rise up are similar to those you might experience over the loss of a friend or family member. It is natural to go through stages of loss or grief. These include anger, denial and depression. There is nothing wrong with these; they are stepping stones on the way to acceptance. But when acceptance is reached, many look back at the period after diagnosis and realize that they were living in terror of a perceived tragic future that never materialized.

Still, the feeling of loss is real. There is no time limit on grief, and we all deal with grief differently. At some point, most people get tired of feeling angry, sad or in denial, and that is when they begin to consider accepting this change in plans. Though it varies for everyone in terms of how soon it arrives, that is the moment when life starts to again move forward.

### **I don't want to be defined by a disease. How can I retain my sense of identity?**

It takes time to learn that Parkinson's disease does not define who you are, even though you may feel that way when first diagnosed. You are a person with Parkinson's, but you are also still a husband, wife, friend and so much more. You can still do many things, you will still be loved, and you will still make a contribution for a long time to come.

There is also still a great lack of awareness about Parkinson's disease among the general public (although we have come a long way). Despite the fact that Parkinson's can affect people of all ages, many people still hold the misconception that Parkinson's is an "old person's disease." And despite the fact that PWPs are dealing with so much more than tremor, the other big misconception is that Parkinson's is "when you shake." Remember that these are nothing more than misinformed perceptions — they don't have any bearing on your actual experience.

### **I want to be proactive. Are there ways I can affect the course of my PD?**

There is, in fact, a lot you can do, and at least one very good reason to do it: Many neurologists report that symptom deterioration is often significantly slower in those who take a positive and proactive stance toward their condition than in those who do not. It would be ridiculous to suggest that a positive mental attitude is achievable all the time. But we have found various methods that help enormously to remain upbeat about life.

- Aside from working with your doctor on an ongoing plan primarily involving medications, the most important thing you can do is exercise. Many people cite swimming, walking and yoga as favorites. Not only will exercising make you feel better and improve your overall health, but research is ongoing to determine whether there is a neuroprotective benefit as well — which would be thrilling news for all of us.
- Neuropsychiatrists and psychologists recommend a similar regimen for the mind. Engage in challenging activities that you enjoy: classes, artwork, travel, community work, PD advocacy work. It is empowering to take some affirmative action, to exert some control over this disease that is so much about the loss of control. And the benefits have been shown to be physiological as well as psychological.
- Stress reduction is a must — stress worsens every PD symptom. But the source of stress is different for every person. You must take care of yourself, and pay attention to what is really important in your life.
- Connect with others and seek counseling to supplement medical treatment for mental ills. Don't let yourself become isolated. Pick up the phone! Send an e-mail! Write a letter! Join a group! Above all, don't wait for family friends to call first. Author Carey notes: "When I find myself feeling lonely, left out and forgotten, I pick up the phone and call a friend, who invariably says, 'It is so good to hear from you! I have been meaning to call but the kids have been sick and the car is in the shop and I'm worried about Mother, and...' Self-pity is dispelled the instant I'm reminded that everyone is engaged the complications of life — and that maybe I can lend a sympathetic ear."

- Learn all you can about your disease and anything else that interests you. Read, listen to the radio, explore the Internet. Knowledge is power, and continuous learning keeps you informed, in control and powerful.
- Ask questions of your doctors and be an active advocate for yourself. Remember, PD is different for everyone, and you can't get the best care unless you're specific about what you are experiencing. It's okay to ask why particular treatments or therapies are being recommended (or not), and it's okay to get another opinion.

### **Are there good reasons to be optimistic?**

In a word: Yes. While PD is a serious illness, and it will pose difficult problems along the way, a person diagnosed today has every reason to hope to benefit from major research advances. Numerous treatments to slow or reverse the progress of the disease are now in clinical trials or have shown promising results in the laboratory. Every year sees the advent of new research technologies and breakthroughs that continue to refine doctors' ability to diagnose and effectively treat PD.

Living with PD is a long journey (that's both the good news and the bad news!), one that changes gradually over time. While it is important to prepare for the uncertainty that Parkinson's can bring to your life, it is objectively not the best use of energy to look too far into the future in terms of the therapeutic management of your disease. Even within the last 10 years, quality of life for people with Parkinson's has improved immeasurably. The prospects for the next five to 10 years are even better. It truly is possible to live well and thrive with Parkinson's.

### **■ Reaching Out**

#### **Support groups**

Many people find that support groups are tremendously effective in helping them cope with the day-to-day realities of having PD. Support groups come in different formats — from large, formal meetings to smaller “living-room” get-togethers — and you may not be equally comfortable or get the same benefit from all. If you don't like the first group you find, look for another that will suit you better. If you can't find any you like in your area, consider starting one. If you are unsatisfied with the available options, it is likely that you're not the only one feeling that way.

Many resources are available to help you find a support group, including:

- Your neurologist or treating physician (or a member of his or her office staff)
- Local hospitals (community outreach or similar services)
- Community calendars in local newspapers
- The phone book
- Web sites of national PD organizations

## **Web sites, Internet groups, chat rooms, and bulletin boards**

Web sites, Internet groups and forums serve as online support for many PWPs. They can be informative and inspiring, and often alleviate the feeling of isolation that can make life with PD more difficult. As patient use of the Internet changes, we recommend performing searches frequently to see what is available. Stay in touch with the Web sites of the national PD organizations as well as state and local support group sites for news of opportunities, events and people in your area. Be sure to check out their links to other recommended Web sites. Or, start one of your own.

## **■ Sharing Your Diagnosis and Your Life as a PWP with Friends and Family**

### **How is this going to affect my relationship with my spouse or partner?**

Think of yourself and your partner as a team, just as you do in other areas of your life. The truth is that neither of you can know at the outset what this diagnosis will mean for you individually or as a couple. If you have friends or family with PD, yours may not manifest the same way at all.

If your partner wasn't with you at the time of diagnosis, be honest about what the doctor had to say, but reassuring at the same time. Talk openly about your questions and fears. Together, you will be able to deal more easily with PD. And by dealing with PD together, you and your partner may help your relationship grow stronger.

### **What do I tell my children?**

Regardless of your child's age, your focus should be on reassurance. If your symptoms are at all noticeable, all but the youngest children are probably already concerned, whether they have said so or not. The older a child, the more open you can be while maintaining the delicate balance between the progressive, degenerative side of PD and the fact that scientists are speeding their way to a cure. However, age is not the only factor to consider. A more mature child at any age can deal more easily with being told about a diagnosis of PD.

There is nothing wrong, or misleading, with stressing a positive outlook on future treatments and a possible cure to either your child or yourself. In fact, it can go a long way in making your disease easier — both physically and psychologically — for all involved.

### **What about telling teenagers?**

Oddly enough, telling a teenager may be more difficult than telling a younger child. Teenagers' worlds are already full of complex emotional and physical change as they grow into young adults, and their relationship with a parent can often seem strained and puzzling. Be forthright and open to any questions, and honest in your answers. Be willing to say you don't know if you don't know.

You can reassure your teenager that the disease progresses slowly and that new treatments are under study. You can also stress that exercise is an important component of your treatment. Exercise is something you can do together that will empower you and your family in combating the disease.

Also, giving teenagers some sense of control can help them to deal with this new development in their lives. For example, you can research a question online together if you don't have the answer. Again, reassurance is the key.

### **What do I say to my adult children?**

While the diagnosis may still come as a shock, depending on your age and theirs, the issues that arise might be more immediately pragmatic than emotional. You may need to discuss arrangements that counter the increasing dependence you may face, not being able to drive, for instance, or not being able to live alone. As with everyone you will tell, focus on remaining forthright, optimistic and open to questions.

### **What will my parents think?**

More likely than not, it will be difficult for you to tell your parents of your diagnosis, and difficult for them to hear it. Frequently parents feel guilty for somehow not protecting you from this disease (impossible, needless to say, since we don't know how anyone gets PD). They may feel frustrated or powerless and this may affect the reaction they show you. Denial is a common defense, which often feels like a betrayal, but don't give up. Given time, parents usually become supportive in whatever ways they can.

Of course, all families are different. Some families enjoy an openness that will allow you to let your parents in as you would your spouse, as just something that happens in life, around which you will rally. And PWPs whose parents are very old or infirm may decide not to share their diagnosis with their parents at all.

### **I don't want to focus on communicating when I have so much to deal with right now.**

Many people prefer not to talk about their Parkinson's, but those who are able to discuss it openly seem to find it less burdensome. Plus, a Parkinson's diagnosis rarely affects just one person. The condition can be difficult for immediate family and friends. It is important for those who have the condition to recognize that while the physical symptoms may be ours and ours alone, the emotional repercussions can be much more widespread. Communication ensures that misunderstandings are kept to the minimum. Sharing the burden of Parkinson's is therapeutic for all concerned.

### **Why do people think I am unhappy or angry when I am not?**

The average person associates PD with tremor, but the disease is commonly referred to by health professionals as a disease characterized by "poverty of movement." Many

PWPs have stiffness and rigidity in their muscles, including facial muscles. Muscles tend to move with difficulty, lacking subtlety and fluidity. Referred to as “facial masking,” these symptoms may give a PWP’s face a grim or set look, because smiling and other facial nuances are difficult to convey.

Many people do not realize just how much they rely on visual clues to relate to you, or to interpret what you say. Tell people who may incorrectly think you are unhappy or upset that it is just symptoms of your PD and that your body language “lies.” It’s a good opener for talking about the disease in general. Meanwhile, intentionally exaggerate your facial expression to correspond to how you are feeling. Practice facial exercises and move your facial muscles frequently to help relieve the stiffness.

### **Why are my friends acting so strange?**

First ask yourself if every conversation you have had with friends recently started with, ended with or was filled like a jelly doughnut with PD. Your friends, most of them, want to be there for you, but sometimes they want to talk about the latest movie or the vacation they just took. Having PD is not a license to ignore or dismiss the needs of those around you.

A diagnosis of PD is a big deal. A serious illness calls to everyone’s mind their own vulnerability and mortality. Some of your friends will handle this better than others. And you may be surprised by their different reactions. Friends who have had PD in their family might be very supportive of you or might run in the opposite direction.

Support groups, both on- and offline, are perfect places to go on and on about your PD and help prevent it from endangering your personal relationships.

### **What do I say to friends and acquaintances who don’t take my PD seriously because I “look so good”?**

PD is a disease that often hides from the public. If you do not have significant tremor or if your medications mask your symptoms, it may not even be apparent to a medical professional. This can contribute to the difficulty, for those not so close to us, of understanding our condition.

People make comments about how good you look for several reasons. First, they are often simply stating what they see, and they hope the comment will make you feel good. At other times, your appearance may mistakenly reassure people that you are not seriously ill. Such a statement can also be a way of dismissing the seriousness of your illness because acknowledging serious illness makes others uncomfortably aware of their own vulnerability.

Also, remember that for your friends and acquaintances, discussing your Parkinson’s disease can seem like one of those “nothing I say is going to sound right” situations that we all have experienced from time to time. Most people don’t want to say anything for

fear of embarrassing you. If you don't look good, they generally (and probably correctly) assume you don't want them to tell you so. So, for many people, "you look so good" seems the safest and least awkward comment they can make.

The perception that a "you look so good" comment minimizes the seriousness of your illness is just that — a perception, which could be incorrect. Putting yourself in the shoes of the person making the comment can make a great difference in the way you react to what is said. Again, communication is the key to understanding.

**Sometimes I get angry or irritated because people just don't seem to "get it" — to understand PD and how I need to deal with it. Am I the only one who feels this way?**

We have heard many PWPs voice frustrations in trying to get others to understand and respond "appropriately" to their PD. To a great extent, that is because PD can be such a confusing and unpredictable disease. This is probably part of the reason that those who deal with their Parkinson's well are often hailed as inspirational to others.

There is more than a little truth in a saying frequently repeated in the Parkinson's community: No one really understands PD unless they have PD. But by the same token, how can we expect others to "get it" when they don't have it? Even our best-intentioned friends and acquaintances are likely to respond, at times, in ways that we find insensitive. Our frustration with others often goes down when we consciously increase our compassion for the problems they face in dealing with our disease.

It is also important to remember that having PD is not an excuse to be less than civil to our friends and loved ones when they don't respond "correctly" or anticipate our needs as PWPs, including letting us do things for ourselves. Having PD does not give us a license to take our frustrations out on others.

Finally, don't discount the role of your own actions in creating certain barriers that prevent others from "getting it." After the initial diagnosis, we all have a tendency to erect psychological walls — both to protect our own feelings and to shelter friends and family from worrying about us. By peeling back these instinctive protective layers, and communicating our fears, feelings and physical symptoms, we can not only help others understand us better, but also experience something of a personality revival.

**■ Intimacy and PD**

**Will PD affect my sex life?**

Talk to your doctor about this issue. Many folks find that PD and meds do affect their sex life. Some PWPs anecdotally report a heightened libido, but a lack of interest or physical pleasure is sometimes attributed to the agonists. While these medications may have very positive effects, there's been some link to side effects such as obsessive behavior — including sexual obsession.

Some antidepressants commonly prescribed for PWPs are known to inhibit sexual feelings. However, newer antidepressants have few such side effects. As with any other side effects, you must decide for yourself (in consultation with your physician) what you are willing to put up with in exchange for the benefits of the medication.

PD can make it difficult to move and turn in bed. Some possible solutions: use satin sheets, wear silky pajamas or a nightgown, or abandon the bed altogether for more unusual pastures. And remember: the single most important thing about PD and sex is to keep your sense of humor.

### ■ Out and About with PD

#### **What can I say or do when strangers notice or make comments about my symptoms?**

Chances are that people will notice your symptoms and comment on them. Children may stare. It can be hard to adjust to that, but most comments will be friendly. The more at ease you are with the fact that you have PD — that is, the more time and effort you have put in to understand and accept your disease — the easier it will be to take these moments in stride. You can also bring concerns like this one to a support group meeting or an online chat to get the benefit of other people's experiences.

#### **How do I deal with people who try to do things for me that I would rather do myself?**

Accepting and rejecting assistance are both something of an art. The first thing to remember is that most people won't know whether you want help or not until they ask, you ask or they try to do it for you. They can't read minds. Your response will depend on a realistic assessment of your need at the moment and your feelings about the offer of help. Try out responses (yes / no / thanks, but I've got it) and see which works best for you. One of our favorites came from a PWP who, when asked if she wanted help opening a pack of mints, said, "Thanks, but I'm taking this one as a personal challenge."

#### **How can I minimize embarrassing dexterity problems such as fumbling for bills, change and credit cards at checkout counters?**

Staying at home is a great temptation when your symptoms are showing, but it only deprives you and your spouse or friends the pleasure of each other's company. And it isolates you. The truth is that few people will even notice your symptoms. A bad tremor while making change is taken for a momentary rattling. Knocking over a glass at dinner? Spilled soup? It happens to everyone.

Some PWPs go on an endless search for the perfect wallet, but the issue is not limited to money. Car keys, theater programs, church bulletins, a glass of wine or a plate of food at a buffet — worse yet, both a glass and a plate. Everyone drops things. It just happens more frequently with us — plus, we carry around this baggage of "disease" that seems to get a little heavier with each mishap.

Compensatory strategies can be helpful: a big wallet for easy access, counting change ahead of time, not using change, asking a friend to hold your drink while you steady a plate, etc. When you encounter a new problem, think about the best way to handle it the next time. And remember, dropping change is a symptom of your disease, not a reflection on your character. The more we are out and about, the more people will see us, and visibility means more acceptance on the one hand and, on the other, more confidence. PD doesn't have to be a prison.

### **Can I drive with PD?**

Several issues are involved: physical ability, legal permission, safety and the importance of independence. You will likely be able to drive safely and legally for several years, depending on your age and general physical condition. However, PD eventually affects reaction time, ability to handle multiple tasks, vision and judgment.

A good way to gauge whether you should be behind the wheel is to ask yourself: If a loved one were my passenger, would I be risking that person's safety because of my PD? Also, be aware of others' reactions. If your spouse or child has commented negatively on your driving ability or is visibly reluctant to be your passenger, check your ego at the door and carefully consider their concerns.

### **■ PD and Employment**

#### **Will PD affect my ability to work?**

Like every other activity in your life, the extent to which PD may affect your ability to work depends on the type and severity of your symptoms and the extent to which those symptoms interfere with the duties of your particular job. We know PWPs who are still working 20 years after diagnosis. Others have been unable to continue in their jobs after a year or two. For example, if you are a house painter and have balance problems, climbing a ladder may be dangerous. It has been our experience that most people can expect to be able to work for several years before PD substantially interferes with work.

#### **Am I protected under the Americans with Disabilities Act?**

Job protection under the Americans with Disabilities Act (ADA) is only available if you are "disabled," inform your employer of your disability, and request a "reasonable accommodation" to allow you to continue to do your job at a satisfactory level. At the same time, many people understandably prefer to keep their personal and professional lives separate, for fear that if they tell their employer they will be eventually be terminated on some pretext that disguises the employer's real reason — the employee's PD.

PD in its more advanced stages is recognized by the federal government as a disability, allowing those affected to secure the protections of the ADA. The actual determination of disability is made by the individual states according to federal standards. However,

because the ADA requires an individual to be impaired in some material way affecting his daily life, not every PWP will meet the standards set. If one seeks a determination at an early stage of the disease, it is unlikely that the claim will meet the standards of an accepted disability.

### **Should I tell my employer, and if so, when?**

Each situation is different and much depends on your relationship with your boss or employer. But spend some time thinking this through before you make up your mind. You can be fired for any reason except for discrimination of race, age, gender or disability under some very narrow circumstances. Being disabled doesn't protect your job. You can be fired if you can no longer perform your job satisfactorily. Even the nicest boss in the world has an obligation to keep the business running. You may not want to "come out" at work until you are ready to ask for accommodation, as outlined in the ADA (see above).

In general, the decision on whether to inform your employer is dependent on individual factors to such an extent that one-size-fits-all advice is not possible. Many PWPs find that they get far more support than they thought they would, but that depends on the individual's reputation before PD, the quality of the company they work for, and the ability to make meaningful contributions going forward. We believe it is best to make your decision based on these highly individual circumstances. Where conflict with your employer is unavoidable, however, you should consult with an attorney who practices in this area.

One other note about PD in the workplace: If you have a personal preference not to tell your employer or co-workers about your PD, and your symptoms are not apparent, then it may well be OK to keep it to yourself. However, it has been our experience that most PWPs are surprised to find that co-workers have guessed at their condition long before the PWP thought his or her symptoms were noticeable. They may not have surmised that you have PD, but they've noticed something is not right. The symptoms of PD can appear as drunkenness, for example. You may consider telling only your close co-workers, but in thinking of who to tell and who not to tell, remember, if you have told anyone at work, you may find that you have told everyone at work.

### **What happens financially if I can no longer work?**

That depends on your situation when you stop working because you are disabled. If you are already of retirement age, and are fully vested in your pension, you probably will retire much as if you would if you did not have PD. Some pension plans include medical benefits that may even cover prescription medications. In some cases you may be eligible for early retirement, which generally reduces the amount of your benefits by a percentage that depends on how many years away from full retirement you are when you stop working.

You may also have a 401(k) or other retirement savings plan that you've been contributing to while working. Under certain circumstances a disabled person may draw down the assets in such funds before age 59, but there may be penalties or taxation consequences that make this undesirable.

If you leave work because of a disability before retirement age, there are several possible sources of income or government assistance that you may be eligible for, including SSDI, SSI and Medicare.

## **■ Insurance and PD: Medical, Life, and Long Term Care**

### **What can I do to make sure I have adequate health insurance?**

Maintaining adequate and affordable health insurance is challenging for just about anybody; for people with disabilities, it can even be more difficult. However, there are government programs that can help if you are eligible.

### **What is long-term care insurance and can I get it?**

Long-term care insurance covers costs of in-home or nursing facility assistance to persons qualifying for such care under the terms of the policy. If you have already been diagnosed with PD it is unlikely that you would then be able to purchase a private long-term care policy. However, some companies offer such policies on a group basis to employees — in such cases, federal law requires the policies to be offered to all employees without regard to pre-existing conditions for period of 30 days. If such a policy is available to you at work, seriously consider taking advantage of this opportunity.

### **Can I get life insurance?**

Generally, life insurance other than that offered through an employer is not offered to a PWP. See long-term care insurance question above.

## AUTHORS

**Carey Christensen** was diagnosed with Parkinson's disease in 1999 at age 41. She is Washington State Coordinator for the Parkinson's Action Network and serves on the People with Parkinson's Advisory Council for the Parkinson's Disease Foundation. Raising awareness of the mental health aspects of PD motivates her advocacy as a writer and speaker. Retired on SSDI after an administrative career at the University of Washington, Carey lives near Seattle with her teenage daughter, Elizabeth, Harvey the Cat, and Truly the Wonder Dog.

**Cindy Exton** was diagnosed with Parkinson's in 1999 at age 42. She has become active in the local Parkinson's Society of Southern Alberta, as a volunteer on various fundraising committees, and was elected to the Board of Directors in 2004. She is a founding member of their Young-Onset Support Group, initiated and developed a Corporate Sponsorship Package, and has written various articles on living with PD that have been published nationally and abroad. Cindy continues to work at raising awareness at a local level, and resides with her two teenage children in Calgary, Alberta, Canada.

**Tom Isaacs** is a co-founder of The Cure Parkinson's Trust and Managing Director of its fundraising arm, "Movers and Shakers." Within two years these two organizations have raised and allocated about \$2 million toward a cure for Parkinson's. Tom was elected to the Board of the European Parkinson's Disease Association (EPDA) in 2005. Tom has had PD since he was diagnosed at age 27 in 1995, and he speaks regularly about the condition, promoting hope and raising funds. In 2003, he completed a continuous walk of 4,500 miles around the coastline of Britain, raising \$600,000 for research. He was UK Charity Personality of the Year in 2005.

**Dan Stark** was a lawyer for 27 years before retiring as a Vice President from AT&T in August 2004. He now has become a writer and has chronicled his experience with PD in a series of articles that appeared in the Washington Post.

Diagnosed at age 37 in 1995, former children's book editor **Ann Wasson** left New York City for California in 2000. She and her husband, Greg, have been very active in PD advocacy and awareness, through newspapers, radio and television interviews, and public speaking engagements. They have testified before numerous governmental committees in California in favor of legalizing human embryonic stem cell research and the passage of Proposition 71. Ann is the author of five children's books and the subject of a video made by Northwestern University on living with Parkinson's disease.

**Greg Wasson** was diagnosed with PD in 1995 at age 43, which forced his retirement from the practice of law in 2000. He has been active in PD advocacy since 1998 and has worked with PAN, PDF, APDA, and the Fox Foundation. In 2002 he received the first Millicent Kondracke Award for Outstanding Advocacy. He and his wife, Ann, were the National Field Representatives for PAN in 2002-2003. They travel and speak frequently on PD issues. In 2003 Greg testified before the US Senate Judiciary Committee as a patient advocate in hearings on the subject of regenerative medicine.