

Pamela Quinn Never Stops Dancing p.12

+ Q&A with a Neurologist ▶ Dyskinesia & Dystonia ▶ PD Myths & Facts



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Parkinson's Disease

**6 Tips for
Parkinson's
Caregivers** p.16

WELCOME to HealthCentral's Guide to Parkinson's Disease. In these pages, you'll learn about current research and thinking, how to make the most of each and every doctor visit, the latest treatments, and much more. **For more practical tips and valuable information on Parkinson's disease and its treatment, go to healthcentral.com/parkinsonsdiseaseguide.**

Research Bulletin:



Dyskinesia refers to involuntary, purposeless movements that can be limited to one body part (e.g., the head or a limb) or involve the entire body. In people with Parkinson's, it's triggered by high doses or longer-term use of levodopa.

When mild, dyskinesia may not warrant treatment. But if it becomes severe, interfering with routine activities and causing imbalance, your doctor may decrease your dosage of levodopa or other Parkinson's medications. Amantadine (originally developed as an antiviral drug) may also be prescribed to help with the dyskinesia.

In August 2017, the FDA approved an extended-release formulation of amantadine called Gocovri to treat patients on levodopa-based therapy for Parkinson's. **The new formulation was shown in clinical trials to significantly reduce dyskinesia symptoms,** as measured by the Unified Dyskinesia Rating Scale. Previous research has shown that the effects of amantadine therapy on dyskinesia symptoms hold steady over time as well.



Don't Slow Down
Time to pump up your workout's intensity?

The best way to stay ahead of Parkinson's disease might be to outrun it. One study found that high-intensity workouts actually slowed the progression of the disease for some patients. Researchers divided study participants into three groups. One group engaged in intense exercise three days a week. The second group worked out, but not so intensely. The third group didn't exercise at all. After six months, people in the high-intensity group didn't get worse, while the others did.

To qualify as a high-intensity workout, according to this study, an activity must raise your heart rate to about 80 to 85 percent of your maximum rate (the number of beats per minute your heart reaches when working its hardest).

Good examples of high-intensity exercises are:

- Running or jogging on a treadmill
- Spinning on an exercise bike
- Dancing fast
- Jumping rope

High-intensity exercise is not recommended for everyone, so be sure to talk with your doctor before starting a new exercise program.



PD Myth & Fact

Myth: Parkinson's disease causes only movement-related symptoms, such as tremors and stiffness.

Fact: Many other symptoms can be related to Parkinson's, such as sleep disorders, constipation, depression, fatigue, pain, and cognitive problems.

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5 Lifestyle Strategies:
Yes or No?

Many people are interested in trying complementary health approaches.

Discuss with your doctor if you might benefit from adding any of these to your regimen. Meanwhile, learn what research has found out about these popular possibilities.



1 TAI CHI. This centuries-old mind and body practice combines certain postures and gentle movements with mental focus, breathing, and relaxation. The movements can be practiced while walking, standing, or sitting. There is some evidence—based on randomized controlled trials, systematic reviews, and meta-analyses—that tai chi may improve balance, stability, and mobility, and lessen the risk of falling.

large and well-controlled trials have yet to be conducted in the United States. The American Academy of Neurology concluded that there is not enough evidence to either support or refute the use of acupuncture for Parkinson's.

2 DANCE. Ready to channel your inner Fred Astaire or Ginger Rogers? Exercise is crucial for everyone, at every age and in any condition, and finding an enjoyable activity might keep you motivated to stick with it. Dance has many of the qualities that are important in Parkinson's-specific exercise: it is performed to music, it teaches useful movements, and it addresses balance, strength, gait, flexibility, and cognitive performance. And if you really swing, you can do your heart some good. Enlist a buddy and you'll double the fun.

4 MASSAGE. Many people with Parkinson's disease try massage as a way to lessen such symptoms as pain and rigidity, and it's generally safe and well-tolerated when performed by a licensed practitioner. While some studies suggest that massage therapy treatment can have a positive effect on reducing tremor and temporarily reducing rigidity, the American Academy of Neurology has so far found insufficient evidence to either support or refute such manual therapies as massage, biofeedback, or Alexander technique in the treatment of Parkinson's.

3 ACUPUNCTURE. While clinical studies in China have shown a positive benefit of acupuncture in treating symptoms of Parkinson's,

5 DIETARY SUPPLEMENTS. The research is still inconclusive, but so far, supplements—such as co-enzyme Q10 and creatine—have not been found to help control symptoms.

1.5

times as many men as women are diagnosed with Parkinson's

What to Know About Levodopa

Many people believe that levodopa, a drug commonly used to treat symptoms of Parkinson's disease, works for only about five years. In fact, levodopa can work for decades, though it does not address all symptoms and comes with side effects like dyskinesia. By taking good care of yourself, you can improve your condition at every stage of the disease.

Research Bulletin: **A new study might have found a way to diagnose Parkinson's before symptoms appear.** Japanese researchers looking into how people with Parkinson's metabolize caffeine discovered that even after drinking the same amount of coffee, those with Parkinson's have lower blood levels of caffeine than those without the disease. Researchers hope that these findings may give doctors a tool for diagnosing Parkinson's in its early stages.



For more tools to manage Parkinson's, go to healthcentral.com/parkinsonsdiseaseguide.



Knowing which symptoms to expect and taking an active role in your own care can greatly improve your quality of life.

Parkinson's 101

96

percent of people diagnosed with Parkinson's are over age 50

Parkinson's disease is a brain and movement disorder that affects about a million people in the United States. It's a progressive disease, but that does not mean that once you've been diagnosed with Parkinson's it's all downhill from there. Thanks to modern treatments, most people with Parkinson's function quite well for many years.

Some Examples

"Life expectancy for people with Parkinson's is only a few years shorter than average—and that gap is closing," says Victor Sung, M.D., a neurologist at the University of Alabama at Birmingham Medical Center. "When we aggressively address all the symptoms, patients experience a great increase in quality of life."

Actor Michael J. Fox founded the Michael J. Fox Foundation for Parkinson's Research soon after disclosing his diagnosis in 1998. Thanks to successful drug therapy, Fox was able to return to full-time acting in 2012 and has written several books, including the memoirs *Lucky Man* and *Always Looking Up*.

Sasha Meret, an artist who was diagnosed with Parkinson's in 2003, at age 47, agrees that you can live well with Parkinson's. He does not even think of it as a disease but more as a condition to be managed. "I treat it as just a discomfort, a condition that forces me to take more control over my life so I can function," he told researchers at New York University Langone Medical Center.

Parkinson's results when the brain fails to produce the right amount of

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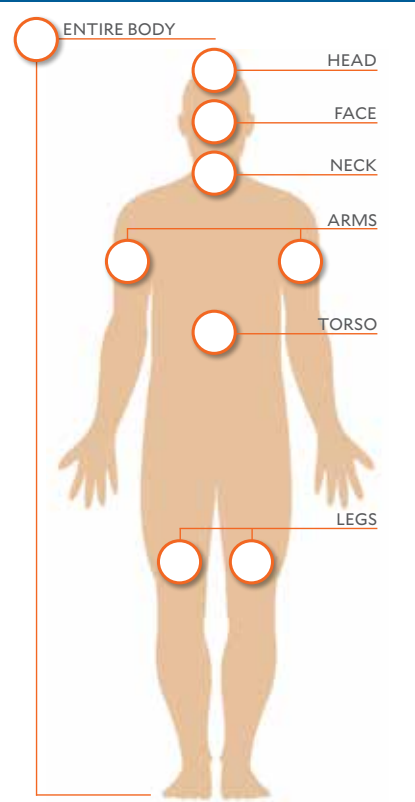
Doctor Discussion Guide:

PARKINSON'S DISEASE WITH DYSKINESIA

Is Dyskinesia impacting your life?

Parkinson's disease-related dyskinesia consists of jerky, unintentional, and uncontrollable movements. These symptoms can occur throughout your body or specifically affect your head, face, neck, torso, arms or legs. Dyskinesia has been associated with the Parkinson's disease medication levodopa. Dyskinesia can worsen due to stress, a change in your medication dosage, or the decreasing effectiveness of your medication. To better understand how dyskinesia may be affecting your quality of life, you will need to share symptom information with your doctor. Bring a friend or loved one to your appointment so they can help you communicate with your doctor. With these tools, you will be able to have a more productive conversation with your doctor, which will help him/her determine the right treatment options for you.

I am experiencing symptoms—that is, unintended, uncontrolled movements—in the following areas of my body:



This is how I would best describe my symptoms:

(Check all that apply)

- ☐ Fidgety
- ☐ Head bobbing
- ☐ Involuntary
- ☐ Writhing
- ☐ Uncontrolled
- ☐ Rocking back and forth
- ☐ Jerky
- ☐ Twisting
- ☐ Sudden

On a scale of 1 to 5, since my last visit my symptoms have:

(Circle on scale below)



I experience symptoms of dyskinesia _____ times per day/week. These are the symptoms I have most frequently:

These are the ways in which my symptoms have affected my life:

- ☐ I cannot participate in activities I used to enjoy
- ☐ I have challenges at work and home due to tremors and other symptoms
- ☐ At times I spill things while eating
- ☐ I've changed my daily routines because my symptoms make it hard for me to keep up
- ☐ It is hard to participate in social events and at times makes me feel embarrassed
- ☐ I fear I'm becoming more dependent on others
- ☐ Other: _____

On a scale of 1 to 5, my painful unintentional/uncontrolled movements have:
(Circle on scale below)



On a scale of 1 to 5, my stress level has:
(Circle on scale below)



What treatment options are available for me? What are the possible side effects of these treatments? _____

How can we track my progress on this treatment? How soon will I see benefits from this treatment? _____

How should I prepare for my next appointment? _____

Find more tools to help you prepare for upcoming doctor visits at:
healthcentral.com/parkinsonsdiseaseguide



a chemical called dopamine that is necessary for smooth and coordinated movements. That's why distinctive features of Parkinson's are types of movement symptoms. Tremor is the most well-known, but bradykinesia (slowness of movement) is more characteristic, explains Dr. Sung. Other common signs are abnormal stiffness or rigidity in a limb and problems walking.

Dystonia, or involuntary muscle contractions causing abnormal repetitive patterns at rest or with certain movements, can occur in up to 40 percent of people with Parkinson's disease. Dystonia can occur in the hands, trunk, neck, eyes, and feet (as toe curling or foot inversion). Some 40 percent of people living with Parkinson's disease may experience dystonia as an early symptom or as a side effect of treatment.

Dyskinesia is purposeless, uncontrollable movement that flows from one region of the body to another, affecting the limbs, torso, and/or head or neck. Contrary to what many people think, dyskinesia isn't the first sign of Parkinson's but occurs as a complication of levodopa treatment. Michael S. Okun, M.D., chair of neurology at the University of Florida and the medical director for the Parkinson's Foundation, advises working with your doctor to manage medications to keep dopamine at optimum levels to reduce or prevent dyskinesia.

Not Just Movement

People are usually diagnosed with Parkinson's after they experience tremors or shaking, stiffness, and slowness of movements that sends

them to the doctor. But Parkinson's also causes non-motor symptoms, many of which occur long before motor symptoms appear.

Some Facts About Symptoms

- 70 percent of people with Parkinson's have serious constipation.
- REM (rapid eye movement) sleep disorder, which affects about half of Parkinson's patients, involves acting out dreams with movements and screaming or yelling.
- A worsening sense of smell is common.
- These non-motor symptoms can also occur:
- Half or more with Parkinson's experience memory problems.
- 20 to 30 percent feel dizzy when standing up quickly or changing position suddenly, due to blood pressure fluctuations (orthostatic hypotension).
- 50 percent plus have depression.
- Up to 95 percent have fatigue or sleep disorders.
- 15 to 25 percent have hallucinations due to dopamine meds or late stage disease.
- Let your doctor know if you have any of these symptoms. "Treating non-motor symptoms can make a huge difference in your quality of life," says Dr. Sung.
- While current therapies can't slow progression of the disease, there are many medications that can make the illness much easier to live with. "I tell my patients that once treatment starts, you can expect to see improvements from where you were at your first visit," says Dr. Sung. "I fully expect them to be doing things they couldn't do before treatment."



HE SAID, SHE SAID

Women are diagnosed with Parkinson's less often than men, and there is slight gender variation in symptoms.

THE FIRST SYMPTOM in women is typically tremor. In men it is bradykinesia, or slowness of movement or rigidity.

MENTAL CHANGES seem to affect women differently from men, too. According to some research, women retain more verbal fluency, while men do better with spatial orientation.

BOTH WOMEN AND MEN have trouble expressing emotions in their faces, due to muscle rigidity. Some also find it difficult to interpret the emotions on others' faces.

BOTH WOMEN AND MEN can have trouble interpreting anger and surprise, but men are more likely to lose the ability to recognize fear in another's face.

WOMEN WITH PARKINSON'S are more likely to suffer from depression, while men are more likely to have behavioral problems and aggression.

DYS AND THAT

It can be difficult to keep straight the differences between **DYSTONIA** and **DYSKINESIA**. Here are some basics to help.

DYSTONIA

- Involuntary muscle contractions
- Muscle spasms
- Contortion of feet, hands, neck, or torso
- Pain

DYSKINESIA

- Often manifests as involuntary writhing movements that are mild
- Can cause larger movements such as swaying of the body or head

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Working with Your Doctor

How to prepare for tests and discussions when you see your doctor.

If you've been diagnosed with Parkinson's disease, you'll probably see your neurologist every 3 to 12 months, depending on how you're doing and what your needs are. You may want to bring a family member with you to the appointment to take notes, ask questions, and provide support; having another set of eyes and ears in the room can help you recall key details later. Also, says Michal T. Gostkowski, D.O., a movement disorder neurologist at the Cleveland Clinic, "Give yourself plenty of time to get there because when you're stressed, Parkinson's symptoms can be worse."

"Come prepared with notes and questions so you don't leave the appointment wishing you had asked something," advises Cindy Zadikoff, M.D., an associate professor of neurology at Northwestern Memorial

Hospital in Chicago. During the visit, you'll discuss how you're feeling and functioning overall and how well your meds are working. Be sure to tell your doctor about all your symptoms—ongoing or new—as well as any specific concerns. "We will ask a lot of questions that don't seem related to Parkinson's—about your bowels, bladder, mood, and sleep—because those issues can affect your quality of life, and they often come with Parkinson's," Dr. Zadikoff adds.

Bring a list of all the prescription and over-the-counter medications and supplements you take, including when and how you take them (with food, for example). Some physicians prefer that patients bring the actual pill containers—along with any eye or ear drops or skin ointments you use—so they can get the full picture of what's going on and be alert to



“We stress the importance of exercise—including cardio, flexibility and stretching, and developing core strength,” says Dr. Zadikoff.

potential interactions, says David Charles, M.D., professor and vice chairman of neurology at Vanderbilt University Medical Center in Nashville, TN. Some medications, such as eye drops used for glaucoma and some drugs used to treat high blood pressure associated with Parkinson’s, can have problematic interactions.

More Questions

When it comes to drugs for Parkinson’s, “the doctor will want to know how well the medication is working for you. Are you able to do all the activities of daily living with minimal disability? If not, is the medication not lasting long enough?” Dr. Zadikoff says. For example, if you’re experiencing dyskinesia (involuntary movements) despite taking medication for it, your doctor may adjust the dose or the timing of when you

take it. If dystonia (cramping of muscles) doesn’t resolve with medication, botulinum toxin injections may be an option.

Think ahead of time about how long the meds take to kick in, how you feel and function when they are working at their best, and any side effects you’re experiencing. Some medications (such as the dopamine agonists; see chart page 11) can cause uncomfortable side effects like impulsive behavior. “It’s hard for a patient

to come in and say, ‘Hey, doc, I can’t stop gambling,’ but we want to know if they’re experiencing side effects like those,” says Dr. Zadikoff.

Tests and Suggestions

At each office visit, your neurologist will perform a physical and neurological exam to check your balance, muscle tone, and gait, and to look for tremors, stiffness in your muscles, and bradykinesia (slow movement). Your doctor will also discuss lifestyle measures that can improve your symptoms and ability to function. Sticking with a healthy diet that includes plenty of fruit, fiber, and water can help with constipation; if you’re experiencing lightheadedness, your doctor may advise you to up your salt and fluid intake, as long as it’s safe for you to do so.

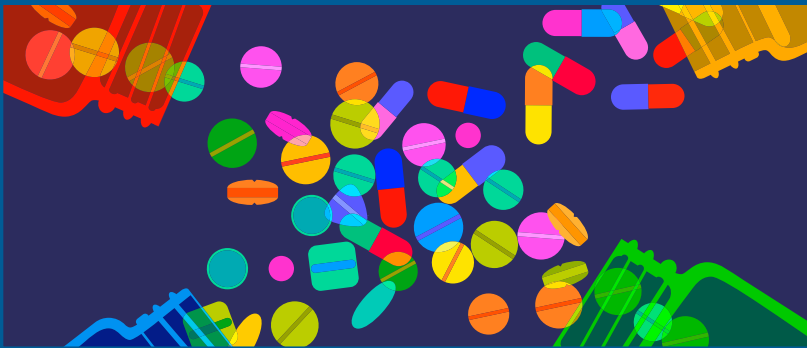
With everyone who has Parkinson’s, “we stress the importance of exercise—including cardio, flexibility and stretching, and developing core strength,” Dr. Zadikoff says. “Exercise may also have disease-modifying effects for Parkinson’s.” Aerobic exercise can improve collateral symptoms such as depression, anxiety, and constipation. Your doctor may be able to recommend

an exercise program geared toward people with Parkinson’s, such as indoor cycling, boxing, or yoga.

Your doctor may prescribe speech therapy if your voice is too soft or you’re having problems with clarity or swallowing, physical therapy if your muscle tone and strength are low, or occupational therapy if it’s hard for you to perform activities like bathing or dressing. If you’re having significant depression or anxiety, your doctor may suggest seeing a psychologist or psychiatrist or prescribe medication.

For those with moderate to advanced Parkinson’s who have motor fluctuations (meaning a return of symptoms between doses of medication), troublesome dyskinesia, or medication-resistant tremor, surgery may be an option. “Levodopa doesn’t help tremor all the time,” says Dr. Gostkowski, “and the meds may wear off in two to three hours.” But your symptoms need to have responded to levodopa for at least a few years for surgery to help. The surgical approach is deep brain stimulation (see page 10). Other options are treatment with extended-release amantadine (Gocovri) or a specific carbidopa/levodopa therapy called Duopa. The latter involves insertion of an infusion pump, which delivers the combination medication into the small intestine over 16 hours per day.

The best way you can help your doctor is to be as specific about your symptoms as possible. “Our goal is a functional one,” Dr. Zadikoff says. “We are not curing the disease—we are managing it and trying to help people live their best lives possible.” ■



MEDS FOR PARKINSON’S

“Parkinson’s is a condition where there are multiple issues, so the medication regimen has to be tailored to the person’s needs and goals,” Dr. Gostkowski says. “The goals are to improve the symptoms they have today, and plan for the future.” To make that happen, here are some of the drugs you may want to discuss with your doctor:

MEDICATION: Carbidopa/levodopa (Sinemet, Duopa, Sinemet CR, Rytary)
WHAT IT DOES: Gets converted into dopamine in the brain; reduces muscle rigidity, improves speed and coordination of movement, and in some cases lessens tremor

MEDICATION: Dopamine agonists: pramipexole (Mirapex), ropinirole (Requip), apomorphine (Apokyn), rotigotine (Neupro)
WHAT THEY DO: Mimic the effect of dopamine in the brain; treat motor symptoms in early Parkinson’s, and in combination with levodopa can improve “on” time

MEDICATION: Amantadine ER (Gocovri)
WHAT IT DOES: Helps with dyskinesia that results from levodopa treatment in more advanced Parkinson’s, and in combination with levodopa can improve “on” time

MEDICATION: MAO-B inhibitors: rasagiline (Azilect), selegiline (Eldepryl, Zelapar), safinamide (Xadago)
WHAT THEY DO: Treat mild symptoms as monotherapy or can help extend levodopa’s effects

MEDICATION: Trihexyphenidyl
WHAT IT DOES: An anticholinergic drug that treats resting tremor

MEDICATION: COMT inhibitors: entacapone (Comtan), tolcapone (Tasmar)
WHAT THEY DO: Help prolong the effects of levodopa

Deep Brain Stimulation

With deep brain stimulation (DBS) surgery, electrodes are inserted into very specific structures in the brain associated with movement and a pulse generator (similar to a pacemaker) is placed under the skin below the collarbone to provide an electrical impulse, or stimulus. You have a controller to adjust the device or turn it off if needed. While there’s a risk that injury or bleeding in the brain can occur during the procedure, it’s quite small, Dr. Charles says. “DBS helps at least 80 percent of properly selected patients,” he says. Even after undergoing DBS, most people still need to take medication—but less, adds Dr. Gostkowski.

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Action Items

■ **Keep track of symptoms** that have improved or appeared, and challenges you’re experiencing. “When patients are asked how they’re doing, the response sometimes reflects only how they’re feeling that day or what happened the night before,” Dr. Charles says.

■ **Tell your doctor about any other conditions.** Many Parkinson’s medications can interact with other drugs, so it’s crucial for your neurologist to know what else you’re being treated for. “We may need to talk to your other doctors,” says Dr. Zadikoff.

■ **’Fess up about any problems you’re having,** such as with speech, balance, dressing, or walking. Problems with thinking and memory count too. You might well benefit from speech, physical, or occupational therapy. Ask your doctor for any necessary referrals.

■ **Monitor your mood.** Some changes in mood that may occur can be treated. In particular, leaving depression untreated robs the person of quality of life, Dr. Charles says. “We now have great medications for depression and many work well with Parkinson’s meds.”

■ **Ask about virtual visits.** Some doctors now offer virtual house calls to people with Parkinson’s. In a 2013 study, researchers from Johns Hopkins Medicine found that each telemedicine visit saved patients, on average, 100 miles of travel and three hours of time.



Living Her Best Life

Professional dancer Pamela Quinn teaches others with Parkinson's how to manage the disease through movement.

Pamela Quinn was reading the newspaper one day and noticed that it was fluttering a little. First she looked to see if the window was open and then traced the movement back to her hand, which was shaking slightly. "I thought, 'Wow. That's weird,'" she says.

Soon the 42-year-old professional dancer in New York City began having problems walking.

Now 63, Quinn would eventually learn that she was experiencing the beginning of Parkinson's disease. While the news was devastating, it also brought relief. "I knew something was really wrong, but I had no idea what it was," she says. "Being diagnosed was frightening, but it was at least something that I could read about and figure out how I was going to handle."

At first Quinn was reluctant to

discuss her diagnosis with others and she tried to hide it and her symptoms. "I had to have time to process it myself before I let other people in on it," she says. "Those early years were very difficult because I was very alone with this diagnosis."

Quinn also stopped going to dance class and performing. "I thought 'I'm the best I'll ever be and I'll just decline from here,'" she says. "I retreated from my world, which defined me both in terms of who I was and what I did. I had to figure out what I was going to do. Who would want a dancer with Parkinson's?"

Coming to Grips

In her effort to hide the disease, Quinn began to use the analytical skills that her dance training had provided. "How can I make my walk

normal?" she wondered. "What can I do to take my limp away? How can I make my arms swing?" She ended up developing a toolkit of coping strategies.

Ultimately, the stress of hiding her illness became counterproductive, Quinn says, and she decided to go public with her diagnosis. She began to think about sharing her ideas for managing Parkinson's symptoms. "I've developed these techniques," she thought. "They work for me. I wonder if they'll work for other people?"

She began to investigate the possibility of teaching other people with Parkinson's. That led her to become part of a community of people with the disease, which she found very useful emotionally and psychologically because she became connected to others with the same plight, challenges, and questions.

Thinking About Meds

At first Quinn shied away from taking medication for Parkinson's disease. "I put it off for as long as I possibly could," she says. The reason she put it off, and the reason most people put it off, is that with medication use over time people develop dyskinesia, which is what causes Michael J. Fox's writhing movements. The idea in delaying taking medication, she adds, "is that you're elongating the time period before which you'll become dyskinetic. But the problem with that is that exercise is the only preventive measure we have—and you need to be medicated in order to move. It's sort of a catch-22."

Quinn now takes several Parkinson's disease medications, with the prescriptions and dosages varying over time. In retrospect, she wishes she had started taking medication when her first son, who was three years old at the time of her diagnosis, was growing up. "I didn't want to embarrass my kid by not being able to move or by looking weird, so I wouldn't go on school field trips,"



Teaching has made an enormous difference in Quinn's life and her outlook.

she recalls. "I wish I could have been a more active parent."

Moving and Teaching

Quinn's primary approach to treatment is exercise, dancing, and walking. "At the time I was diagnosed, there was very little knowledge about the benefits of exercise," she says. "In fact, I was told not to move, because my doctors were afraid I would fall and break a hip. I knew that was wrong. As a dancer I knew that movement was essential."

Music has been important too. "One of the things I discovered was that music was a fabulous facilitator of movement," she says. "I wouldn't be able to walk, and I'd turn on some music and I'd have no problem. Music is definitely one of my 'drugs.' It is as important as the medications I take, with none of the side effects. It still plays a role for me today."

Teaching has also made an enormous difference in Quinn's life and her outlook. Her class for people with Parkinson's (pdmovementlab.com) offers dance-oriented movement combined with functional training, such as learning how to get up out of a chair, sit back down, walk across the floor, and open doors

without compromising balance.

"I didn't realize at first that my own state of mind was really affected by helping others," Quinn says. "That gives me total pleasure and a sense of being able to contribute something to the world. Parkinson's is a disease that takes away. It continually robs you of your faculties. To be able to make something, or do something, or be of value is an essential part of mental and physical health. Teaching gave me a purpose."

Her advice to other people with Parkinson's? "Live your life. Don't give up what you love to do. Just figure out how to adapt," she says.

"I like to play tennis, and I once broke my wrist horribly," she continues. "People said, 'Oh, well that's the end of tennis.' And I said, 'No, it's not. It's the end of me running backwards and trying to get a ball and taking chances like I did before, but it doesn't mean I have to give up tennis.'"

For the newly diagnosed, Quinn adds, "You need to know that your life is not over. You can live a really fabulous, meaningful, and long life. The disease is really quite manageable for many years." ■



For more on Parkinson's, visit [healthcentral.com/parkinsonsdiseaseguide](https://www.healthcentral.com/parkinsonsdiseaseguide).



DYSKINESIA: KNOW THE FACTS

50,000

people in the U.S. are diagnosed with Parkinson's each year



1 million

Americans are living with Parkinson's

Of these, **96%** are diagnosed with Parkinson's after age 50

About four to five years after starting levodopa treatment, about **50% of PD patients** will experience levodopa-induced dyskinesia (LID).

LID

has been associated with the use of levodopa over extended periods.



Dyskinesias

consist of uncontrolled, abnormal and involuntary movements occurring in response to the replacement of dopamine.

Peak-dose dyskinesias

occur in response to high concentrations of levodopa in the blood. They typically take place between one to two hours after consumption; this time range is when medications work best to control motor symptoms.



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LIVE BOLD LIVE NOW

SPOT THE DIFFERENCE: TREMORS AND DYSKINESIA

After having taken dopamine-replacement medication, i.e. levodopa, for an extended time, you may begin to experience involuntary muscle movements. The majority of these movements fall into two categories: tremors and dyskinesias.

TREMORS

Occur when the body is at rest, are fairly slow, and occur five times per second—typically beginning in one body part and spreading to the other side of the body

- Usually begin in the hands and feet but can spread to the rest of the body
- Usually dissipate when the limb is used in a 'purposeful' way
- Are not functionally limiting
- Respond somewhat well to medication



DYSKINESIAS

Are irregular, involuntary, writhing, twisting movements

- Fluid and 'dance-like' or rapid and jerking
- Functionally limiting and can interfere with daily tasks
- Can occur throughout the body or specifically affect the head, face, neck, torso, arms or legs

Speak with your doctor and caregiver about possible medications that may alleviate these symptoms.

Get more info on PD at
healthcentral.com/parkinsonsdiseaseguide

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Q&A

People have trouble hearing me when I speak. Is this common? What can I do to make this better? I've tried singing, or just talking louder, but nothing seems to work.

One of the most common symptoms of Parkinson's is hypophonia, a type of dystonia. This can result in very soft speech. The interesting thing is that the person perceives that he or she is speaking at a normal volume. A type of speech therapy called the LSVT LOUD program can be effective in training you to speak louder. A few sessions with a speech-language pathologist may also be useful—talk to your doctor about a referral.

■ **Are there exercises I can do to help with balance problems?**

Balance problems are very difficult to address. Physical therapy and medications can sometimes help, but as the disease progresses, balance issues usually get worse. You need to remain vigilant about how your condition is changing, and may need to use assistive devices such as a walker to prevent falls.

■ **I've heard that Botox injections can help with my dystonia. Should I give them a try?**

Medications can often help with dystonia, and botulinum toxin (commonly called Botox) can be very useful as well. It can improve toe-curling, and when injected in the neck can help with cervical dystonia and also reduce the pain caused by



unusual posture and muscle tightness. It also can be helpful for excessive drooling—though you need to be careful not to let your mouth get too dry, because that can result in cavities.

■ **My handwriting has changed because of my tremors, and I'm worried that my bank won't accept my signature as legal. Do you have a suggestion for me?**

Many Parkinson's patients have what's called micrographia—their handwriting gets smaller and smaller as time goes on. Signatures often trail off or become illegible. You can see this, for example, in the autograph of Muhammad Ali, who suffered from Parkinson's. Occupational therapy can be helpful in learning to write larger. Also, you might go to your bank and explain that you have Parkinson's. They have several ways, other than handwriting, to accept official signatures.

■ **It seems to me that my symptoms are worse when I'm under stress. I've tried anti-anxiety medications and talk therapy, but they haven't solved the problem. Can you suggest anything else?**

Anxiety, stress, and sleep deprivation all can make Parkinson's worse. Talk to your doctor if you are not sleeping well; you may have an underlying sleep disorder that should be addressed. As for anxiety and stress, I tell my patients to live a life of Zen: Do your best to avoid people and experiences that make you feel anxious or stressed. ■



MICHAEL S. OKUN, M.D., is professor and chair of neurology at the Fixel Center for Neurological Diseases at the University of Florida, and the national medical director for the Parkinson's Foundation.

■ **Trust But Verify** It's always a good idea to verify anything you learn—*especially if it sounds too good to be true*—with a credible organization such as the Parkinson's Foundation (parkinson.org). The Foundation also has a free helpline staffed by nurses, social workers, and therapists; call 1-800-4PD-INFO (1-800-473-4636).

■ **Now Hear This** DAF (Delayed Auditory Feedback) is a speech therapy app (iOS, Android) that helps people with Parkinson's slow their rate of speech, making it clearer to others. It works by enabling you to hear your own speech in an altered manner, which causes you to slow down.

Get \$mart

Financial planning is essential.

■ Having a chronic condition makes it imperative that you set up (or revisit) financial and investment plans. Fortunately, financial planning info and tools are widely available, both online and through an accountant or financial planner (the National Association of Personal Financial Advisors, napfa.org, can help you find one in your area). The government's longtermcare.acl.gov site has loads of information as you consider financial options for your future care.



Find more info at healthcentral.com/parkinsonsdiseaseguide.



6 Tips for Caregivers

- 1 BE AVAILABLE** to help with day-to-day tasks but let the person you are caring for decide when and how much help they need. Encourage their independence and try to keep life as normal as possible for them.
- 2 ADD EXPERTS TO YOUR TEAM**, suggests the Michael J. Fox Foundation. Speech and physical therapists can be invaluable early on. A neurologist with training in Parkinson's and other movement disorders can help you and your loved one build a good treatment plan.
- 3 GET ORGANIZED.** A calendar just for noting appointments and symptoms is very handy. Keep it in a folder, along with insurance information, doctors' phone numbers, and medication information and side effects.
- 4 REACH OUT.** A support group—which you can join on your own or with your partner—offers education, hope, social opportunities, a rest, advice from others who are going through similar experiences, and more. Your doctor or parkinson.org can help you find one.
- 5 THINK OF YOURSELF.** Eat healthily, get enough sleep, find time for physical activity, and take time off every now and then to hang out with friends or catch a movie. Make sure to see your own health-care provider if you're feeling tired or down. You can't help others if you don't take care of yourself.
- 6 KNOW YOUR RIGHTS.** You may be entitled to benefits if you miss work for caregiving. Learn more at caregiver.org.

MEDICAL EDITOR: **Ritesh Ramdhani, M.D.**, assistant professor of neurology, Fresco Institute for Parkinson's and Movement Disorders, NYU Langone Health. HEALTHCENTRAL GUIDE MEDICAL EXPERTS: **David Charles, M.D.**, professor and vice chairman of neurology, Vanderbilt University Medical Center, Nashville; **Michal T. Gostkowski, D.O.**, movement disorder neurologist, the Cleveland Clinic; **Michael S. Okun, M.D.**, chair of neurology at the University of Florida and the medical director for the Parkinson's Foundation; **Victor Sung, M.D.**, a neurologist at the University of Alabama at Birmingham Medical Center; **Cindy Zadikoff, M.D.**, associate professor of neurology, Northwestern Memorial Hospital, Chicago. Some material in this guide is used with permission of the Regents of the University of California.

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