

Visiting with Family Members Who Have Parkinson's

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Visiting family members who live with Parkinson's disease (PD), especially those you don't see often, can be stressful. You may notice a change and be uncertain whether it's a normal part of Parkinson's or what to do about it. Even when you do know what to expect or have a plan to manage changes in your loved one's disease, it's often still tough.



Kate Connor, whose father lived with Parkinson’s for over a decade, felt this firsthand. She says, “Seeing your hero decline in any way is upsetting. You really feel deeply for them.” Kate and her dad lived in different states, but they saw each other frequently. During her visits, Kate accompanied her dad to the doctor, took him on regular outings — “making sure there was always some fun and not just a focus on Parkinson’s” — and even built him a wheelchair ramp. When they weren’t together, Kate researched his care and the latest science so she could stay on top of his Parkinson’s and help him “remain in the driver’s seat of his life.” Change wasn’t easy, but Kate feels her proactivity and engagement helped her and her dad.

This guide, written by movement disorder experts Rachel Dolhun, MD, and Natalie Hellmers, MSN, RN, ACNP-BC, offers practical tips and general guidelines to help you be ready to navigate change and keep you from feeling caught off guard when visiting your loved one with Parkinson’s.

Practical Tip #1: — Learn about your loved one’s Parkinson’s



It is worthwhile to familiarize yourself with the basics of Parkinson’s and how your loved one experiences the disease. You don’t have to learn every detail about PD, but having a general understanding will give you greater ability to anticipate change and interpret what you see.* Most people associate Parkinson’s with its well-known movement symptoms (tremor, slowness, stiffness, and walking and balance problems) but fewer are aware that the disease also can affect mood, memory and sleep.

Parkinson’s disease varies tremendously among individuals, so having a working understanding of your loved one’s particular array of challenges can help you prepare as well as assess how symptoms are changing over time. Think about how things appeared at your last visit and the time before that.

Parkinson’s changes gradually, but every person’s rate of progression is different. A person’s age (getting older changes us all, PD or not) and other medical conditions, as well as the length of time since your last visit, also will affect how much change you’re likely to see.



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+ Do expect symptoms you’ve previously seen to be more prominent.

After a six-month hiatus, your mom’s tremor may be more noticeable or your grandpa may be using a walker because his walking became more unsteady and he had a few falls.

+ Don’t expect extreme or drastic shifts in a short period.

Barring health events such as an illness, hospitalization or surgery, or even major life events such as the loss of a spouse, Parkinson’s symptoms don’t worsen overnight. Your brother wouldn’t suddenly need help showering and dressing, for example, when he was working full-time six months ago.

Practical Tip #2: — Call your loved one before the visit



When chatting beforehand, you can plan the best time(s) to spend together, particularly if your family member’s symptoms fluctuate and they feel better at a specific time of day. You also can get a general sense of the situation, especially if you use video. (FaceTime and Skype are good options.) Still, your family member may not share much about their PD — they may prefer to keep their disease experience private or they may not want to worry you. And sometimes people unintentionally paint a picture different from reality because they, themselves, aren’t aware of certain symptoms such as memory or mood changes.

Practical Tip #3: — Plan for the unexpected



Many families report a “disconnect” between what they hear before a visit, and what they see when they arrive. If you have the flexibility, extend your stay a day or two and don’t pack your itinerary too full. Having extra time as well as downtime may allow you to focus on your loved one after other out-of-town guests depart and holiday stress calms down. You can even plan to visit the doctor together (book an appointment in advance as this is a busy time for many offices) or observe your loved one after treatment changes are made.



Practical Tip #4: ———→ **Settle in and observe**



Your first impressions may be concerning, especially if they aren't what you anticipated. Remember that Parkinson's symptoms can fluctuate from day to day and sometimes even hour to hour. Some people have "wearing off" of medication between doses, which can make Parkinson's look significantly worse until their next dose kicks in.

Symptoms also can increase with nervousness. Your sister could be anxious, for example, about getting everything perfect for her dinner party. Or, your dad may be nervous about how he looks to you, wanting to appear well and at his best, which paradoxically can increase symptoms.

Take a few hours or days to look for what's similar or different from your last visit. See how your loved one does in their own home and with daily activities such as preparing and eating meals, doing laundry and light cleaning, and driving to familiar places. Worry may fade as you realize symptoms fluctuate and are, in general, mostly unchanged from your last interaction. Or, you may pick up more subtle or concerning symptoms. A few that may signal the need for additional support or treatment include:



+ ***Tripping, stumbling, freezing (sudden, temporary inability to walk) or falling***

Walking and balance problems can increase risk for falls. Because Parkinson's medications often don't adequately treat these symptoms, treatment involves regular exercise and, for some, a cane or walker. A physical therapist can help develop a safe exercise program. You also may consider a home safety evaluation, where a professional consultant can recommend adaptations or equipment to make the home safer and easier to navigate. Modifications could include clearing clutter, adding lighting, and fixing loose stairs or floorboards that could contribute to falls.

+ ***Uncontrolled, involuntary movement***

In some people, dyskinesia can come on after many years of living with Parkinson's and taking levodopa, the most commonly prescribed PD drug. Stress, anxiety or even talking about something exciting can magnify dyskinesia. For this reason, you may see fluctuations in dyskinesia — an increase during a lively family gathering and a decrease when your loved one is relaxed, for example.

People with dyskinesia may not feel or notice it. And if they do, they may not be bothered by it. If dyskinesia is bothersome or interferes with walking or balance, medications may be adjusted. Many times, there is a delicate balance between taking enough medication to control symptoms such as tremor and stiffness but not so much that it causes dyskinesia. Some people prefer mild dyskinesia to Parkinson's symptoms such as slowness or stiffness.

+ ***Mood changes***

Depression and anxiety are common in Parkinson's. They may show up as sadness and worry, but in some people, they may manifest as decreased energy and appetite, which leads to weight loss. Medications and therapy can be highly effective.

+ ***Memory or thinking changes***

Parkinson's can affect memory and thinking to different degrees. For some, changes are mild and don't disrupt daily life. For others, they're significant and affect everyday activities. As with Parkinson's motor symptoms, these changes, if they do occur, come on gradually. People with PD may have



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difficulty multitasking or paying attention. Sometimes, especially in those who are older and have lived with PD for many years, there may be trouble finding words or finishing sentences. It may take longer to do simple tasks such as turning on the television or getting dressed. If you notice a difference in your loved one's ability to understand and remember information, it's important to ensure these changes are evaluated.

+ ***Seeing things that aren't there***

In some people who have lived with Parkinson's for many years, hallucinations can be a side effect of PD (and other) medications. They also can be part of significant memory and thinking changes (dementia) in some people. Often hallucinations are of people, children or animals that aren't there. Sometimes these aren't bothersome and a person's attention can be redirected away from hallucinations. Other times, hallucinations may require medication adjustment or additional medication to alleviate them.

+ ***Care partner burnout***

When visiting family, check in with the care partner. Spouses, other family or friends who are the sole care provider for a person with Parkinson's may need a break or extra support. Providing around-the-clock care for someone who has limited mobility and memory/thinking changes, for example, can be physically and emotionally demanding. Care partners can experience fatigue, depression, irritability and other symptoms. They may not recognize or admit burnout unless you ask.





Practical Tip #5: ——— Ask questions and listen



Asking questions can help you understand your loved one’s experience with and feelings about their symptoms. Dyskinesia, for example, may look bothersome to you, but your grandma may prefer the extra movements to feeling stiff and slow. Polite and gentle inquiry also can help you probe symptoms, such as apathy or mood changes, that you spot even before the person experiencing them.

Just as important as asking questions is listening to the answers, which allows you to make a connection and opens the door to further conversation.

Consider these general topics for questions:

+ Symptoms

Ask about new or concerning symptoms. If you observe weight loss, you may want to inquire about changes in appetite, diet and mood. If you see tripping, ask if there have been falls. Start with “I” rather than “you” statements. For example, “I noticed your tremor seems a little worse. I wonder if it bothers



you or gets in the way of your eating (or other daily activity or hobby) and if your medication helps?”

+ **Care**

Find out when they last visited the Parkinson’s doctor and if they have a movement disorder specialist (a neurologist with additional training in PD). Also ask if they have seen a physical, occupational or speech therapist and if any instructions were provided.

+ **Medication**

Try to learn if the doctor has recently changed medications, and ask if your family member is taking drugs as prescribed. (Some people have difficulty affording medications or picking them up from the pharmacy. Others may even have physical challenges, such as trouble swallowing large pills.) You also may want to determine whether they have a system — a pillbox or alarm, for example — to remind them to take medication.

+ **Health**

Inquire about any recent changes in health such as a new diagnosis, illness, hospitalization or surgery. Not every change that occurs in people with Parkinson’s is related to PD.

+ **Deep brain stimulator (if applicable)**

Ask whether the device has recently been adjusted and if they can program it. If symptoms seem particularly different, you may want to make sure it’s on. (The devices can be accidentally switched off.)

Practical Tip #6: ——— Talk about what you see



Families have differing comfort levels when it comes to talking about Parkinson’s (and health in general). For some, there is an open dialogue around the disease and nothing is off limits. In others, a discussion about symptoms and care may feel awkward or even taboo.

Wherever you and your family fall on this continuum, you might start by talking to family members who live with or near your loved one. Especially if change looks drastic to you, this is a good way to gain perspective. Those who see your



loved one more regularly may have witnessed a more gradual decline over a longer period. Others who've been away as long as you may corroborate your observations (or dissent). In these talks, aim to balance viewpoints and agree on what support your loved one or their care partner needs.

Then talk to your loved one. Try to do it in a kind and gentle, but matter-of-fact, way. Express concern but don't scare them. It may be helpful to give examples and ask for their input. For instance, "I noticed you seem to be having trouble with your walking, especially on stairs. How do you feel with walking?"

A few tips for talks:

+ ***Find the right time***

Don't try to have these conversations in the middle of a celebration. During Thanksgiving dinner or while opening Christmas presents, for example, is not an ideal time. Look for at least 15 to 30 minutes before or after a group activity when you won't have distractions or interruptions.

+ ***Set the tone***

These discussions can be informal but still thoughtful and productive. Decide ahead of time what success would look like (for example, simply hearing from your loved one or agreeing on what support is necessary in the home) and set the stage to make that happen.

+ ***Acknowledge emotion***

It's natural to feel sad, upset or even guilty. This is especially true for adult children who live far from aging parents. As emotions arise, recognize they are part of being human and these are often difficult situations.

+ ***Focus on your loved one***

Respect your family member and their wishes. Don't talk about them (in the third person) in front of them. Always look to them for their opinion and put them in the center of the conversation. This also is important for practical purposes. In some people, Parkinson's softens the voice, making large, loud family conversations challenging and potentially isolating. Seat your loved one close and pause regularly to give them a chance to chime in. (Same advice goes for holiday gatherings.)



Before your visit ends, decide what you need to do and how to do it.

+ Broach tough topics

When necessary (earlier than necessary, if possible), have the conversations no one likes to have. There may come a time when it's no longer safe for your dad to live alone at home because of falls or memory/thinking problems. Or you may be concerned about your grandfather driving because he's gotten lost several times or had a minor accident (or near miss). And at some point, Parkinson's or not, we all should tell our loved ones our wishes around the end of life (whether we'd want to be put on a breathing machine or be resuscitated if our hearts stopped, for example). These are difficult things to discuss. Some scenarios — a potential move, no longer driving — could even lead to conflict. But ignoring them may eventually lead to bigger dilemmas. Your loved one's doctor and a social worker can be helpful resources.

+ Have more than one conversation

Don't feel pressured to fit everything in one talk. Especially as things change over time, you'll need to have additional conversations. Your first conversation is likely one of many. And depending on your family size, structure and dynamic, you may have conversations with different members at different times.

Practical Tip #7: ———> Make a plan



Before your visit ends, decide what you need to do and how to do it. That could be anything from talking to your brother's doctor about his falls or getting your mom help to care for your dad in the home. (You don't have to complete your plan during your visit, but do create action steps to accomplish it.)

If other family members can help, divide responsibilities. Can you help with advance directives while your brother coordinates medical care? One of you may want to gather information and resources related to your loved one's needs. A social worker (often available through the doctor's office) can help, but based on needs, you may want to investigate local driving evaluations;



physical, occupational or speech therapists; or movement disorder specialists (if your loved one isn't seeing one or might benefit from a second opinion).**

Decide who will make doctor appointments, attend visits and keep others updated. If your loved one has several doctors, it may be helpful to split them up so that the same person always goes to the same doctor's visits. For example, you might go to the neurologist, while your sister goes to the primary care provider. This consistency gives the care team a chance to get to know your family over time. Choose one person to lead communication for follow-up questions (you for neurology and your sister for primary care, for example) to avoid multiple people calling the doctor's office, which is less efficient.

In light of HIPAA (Health Insurance Portability and Accountability Act) laws that protect an individual's medical information, many wonder whether they can talk to a family member's doctor outside of scheduled appointments. (During a visit in which your loved one invites you to accompany them into the examining room, you can talk openly and ask questions.) You always are allowed to call and state concerns, but your family member must give permission for the doctor to discuss care with you. Every patient completes a HIPAA form at the doctor's office to name third parties (spouse, family members, friends) they permit their doctor to speak with. If you aren't on this list, the doctor may ask to speak to someone who is or, in special circumstances (such as an urgent situation around dementia), give limited information. If your family member denies permission (maybe they don't want you to mention driving concerns to the doctor, for example), you still can contact the doctor and relay your concerns. The provider will not be able to disclose details, but you can voice your observations, which may help the doctor gain a fuller understanding of the needs around a holistic treatment plan.

Now also is a good time to evaluate whether you need or want to visit more often and get more involved in your loved one's care. This may be challenging given your own family and work obligations, but you can call into doctor's visits (have your loved one put you on speakerphone or FaceTime after alerting the doctor), check in after appointments and research their condition from afar. You also may consider visiting between holidays, when there is less family around and you have more one-on-one time.



It can feel overwhelming to visit a loved one who doesn't seem like themselves or sometimes even look or act the same way you remember. Take time to process what you are seeing and feeling. And know you aren't alone. There are many care partner and family support groups (both in-person and online) that serve as platforms for learning about Parkinson's as well as new and creative ways to adapt to and manage life with the disease. (Ask a social worker or search online for groups in your area.)

Resources

*Many online resources, including www.michaeljfox.org and Parkinson's 360 (multimedia materials for patients and families navigating Parkinson's), are available.

**Consider these resources for specific needs:

- + **Driving:** A driving rehabilitation specialist (often an occupational therapist) can evaluate driving and make objective recommendations. Organizations such as AAA and AARP offer similar programs.
- + **Physical and occupational therapy:** Look for therapists with special training in PD, such as those certified in Lee Silverman Voice Treatment (LSVT) BIG.
- + **Speech therapy:** Search for therapists who practice PD-specific programs, such as LSVT LOUD or the Parkinson Voice Project SPEAK OUT!
- + **Movement disorder specialist:** Check the movement disorder specialist finder for a physician in your area.

These resources can help you get started, but discuss the plan with your loved one's doctor to ensure they agree. The doctor may have additional or different recommendations (perhaps they know a great therapist, for example) and also will want to follow up on treatment plans.

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