

Top Questions and Answers from NPF's "Ask the Doctor" Forum

November is National Family Caregivers Month. Having a supportive spouse or caregiver is integral to living better with Parkinson's disease (PD). In this issue, we will focus on commonly asked questions from caregivers. Questions are drawn from our free "Ask the Doctor" forum, but did you know that NPF also offers a "Caregiving" forum? We invite all people living with PD, their families and friends to take advantage of this free online resource at www.parkinson.org/forums.

Q My wife was diagnosed with Parkinson's at the age of 45. That was four years ago. She experiences anxiety about everything and has major break downs. She doesn't want to help herself. I feel helpless seeing her like this. I am stressed and not sure how I can help. What can I do?

A In many cases anxiety is a symptom of PD caused by the underlying disease process. Some people experience anxiety years before diagnosis. Others get anxious when each dose of Sinemet begins to wear off. Taking Sinemet more frequently may reduce your wife's anxiety. Many people benefit when Sinemet intervals are brought closer together (every two to three hours). In some cases, raising the dose can also help. If this approach doesn't work for your wife, she might benefit from seeing a psychiatrist or counselor. Taking anti-anxiety medication can also be effective.

At NPF Centers of Excellence, we have been following thousands of caregivers for years. We have found that the majority of caregivers, especially young spouses (ages 40 to 55), need help too. The long term strain of caring for someone with PD can adversely affect your health. If you think you might be experiencing symptoms of depression or anxiety, or just find



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it difficult to deal with the day-to-day trials of PD, seek help from a counselor. Here are some ways to combat caregiver stress:

- Join a caregivers support group
- Seek support from family, friends and health professionals on a regular basis
- Learn as much as you can about PD
- Take care of your health: eat healthy, exercise regularly and get enough sleep

Importantly, keep the lines of communication open with your wife. Over time, you will want to be responsive to your wife's changing needs and be patient with yourself. This approach can help in reducing some of the stress of living with PD.

Q Does the pneumonia vaccine protect people with PD from aspiration pneumonia, which some say is the leading cause of death in Parkinson's? What can I do to help my father minimize pneumonia risk? Do you recommend the pneumonia vaccine for people with PD? Should people with PD get annual swallow studies?

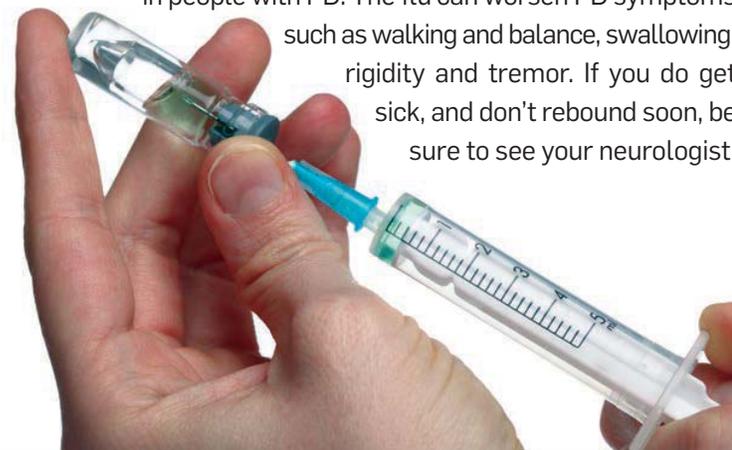
A It's true that aspiration pneumonia is the leading cause of death in PD, but the pneumonia vaccine only protects against bacterial pneumonia, not aspiration pneumonia. Pneumonia prevention measures can save lives and may have a positive impact on preventing aspiration as well. Regular swallowing evaluations can be useful for people who have difficulty swallowing or cough while eating. Food can get into the lungs, which can lead to aspiration pneumonia. If your father is having difficulty swallowing, seeing a speech language pathologist once a year may be a good preventive measure.

Q One of the things my husband misses the most is riding his bike, but his balance makes it unsafe. I would like to get a tandem bike. Do you recommend we get one? My husband had deep brain stimulation (DBS) surgery and needs to protect his head. Do you have a bike helmet suggestion? How often should people with Parkinson's exercise to delay further symptoms?

A The tandem bike and recumbent tricycle (trike) are popular forms of exercise for people with PD. Riding a tandem bike with your husband will allow you to take the lead. Some research has shown that riding a tandem bike helps improve overall motor function in people with PD. A trike is another option, it's like sitting in an easy chair, which means the rider can relax at will. Since a trike is low to the ground, it reduces balance issues. At the same time, it would allow your husband to get a good cardiovascular workout. It has been proven that exercise eases PD symptoms. We recommend 30 to 60 minutes a day. A comfortable helmet that does not push on the DBS wire or device will be the best choice. Your husband can and should maintain an active lifestyle. Riding a bike is good for the mind and body and may improve more than your husband's mobility.

Q Is there any interaction or problem with getting a flu shot while taking Sinemet and Azilect? Does it take longer for people with PD to recover from the flu?

A There is no adverse interaction between a flu shot and PD medications. In fact, we recommended that people with PD get a flu shot. Illness from infection can be more severe and prolonged in people with PD. The flu can worsen PD symptoms such as walking and balance, swallowing, rigidity and tremor. If you do get sick, and don't rebound soon, be sure to see your neurologist.



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Caregiver Tips for Daily Living



Juggling the dual roles of caring for a loved one with Parkinson's disease (PD) and working full-time can be overwhelming. The good news is that some employers now offer special benefits to caregivers. Here's what you can do:

-  **Check your company's policies.** Talk to someone in the human resources department or read your employee handbook to see if your employer offers any programs, special assistance or flexible work arrangements for caregivers.
-  **Talk to your boss.** Tell your boss about the demands you face as a caregiver. If you need specific accommodations, such as flexible working hours two days a week, explain the reason why. Emphasize your willingness to work together to find the right solution.
-  **Show appreciation.** When you meet with your supervisor, highlight your strengths and contributions to the company. Make it clear that you are willing help co-workers when needed.
-  **Get the agreement in writing.** Send an email to your supervisor or human resources representative spelling out the agreed-upon conditions.
-  **Consider other options.** Think about other ways you might be able to work, such as part-time or as a consultant.