

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

From the National Parkinson Foundation's Parkinson Report Fall/Winter 2015

*November is National Family Caregivers Month. Most people with Parkinson's disease (PD) agree that having a supportive spouse or caregiver is very important for living better with Parkinson's.*

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In this issue, we will focus on commonly asked questions from caregivers. Questions are drawn from our free "Ask the Doctor" forum. 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.forum.parkinson.org](http://www.forum.parkinson.org).

**Q** Recently my mom, who has PD, has been experiencing muscle aches right after consuming vegetable protein (tofu, beans, etc). The aches are usually in her legs. Is there an explanation for this? How should she go about addressing it?

**A** There are a few possibilities. It could be the constituents in a particular food your mother is eating. She may try avoiding these foods or even changing brands. For some people, eating protein-rich foods limits the effectiveness of levodopa. Most people who experience difficulty with Parkinson's disease related to a diet high in protein report that their medications are not working. If this is the case for your mom, she should consult with her doctor about changing her daily protein intake. The issue may also be caused by the timing of her pills. Levodopa works best when taken on an empty stomach. Waiting an hour before or after meals may help. If these strategies don't work, your mom may need to see a gastroenterologist.

**Q** My husband has had PD for 25 years. So far, he's managed well. But two weeks ago he started seeing bugs and worms that weren't there. I thought the hallucinations could be from his medications. What can I do to help him?

**A** Psychosis in PD generally comes in two forms: hallucinations (when patients see, hear or feel things that aren't really there) or delusions (which are fixed false beliefs). When hallucinations occur, they are mostly visual. Usually they are non-threatening, and people with PD mostly see small people or animals, or loved ones.

Psychosis occurs in up to 40 percent of people with Parkinson's. It initially occurs most frequently in the early evening and then carries deeper into the evening. For your husband, the urgency of treatment will depend on the type and characteristics of the hallucinations. When they are mild and benign, and insight is retained, it's best to maintain the Parkinson's medication regimen. However, when the person starts experiencing more threatening paranoid delusions, more aggressive treatment is usually warranted. Here's what the doctor can do:

Rule out the possibility of reversible causes, such as infections (urinary is most common), metabolic and electrolyte imbalances and sleep disorders.

Decrease or discontinue adjunctive antiparkinsonian drugs. Typically, when a patient is on several anti-parkinsonian medications, we "peel off" one drug at a time, until the psychosis resolves or further "peeling" is no longer practical because of worsening motor symptoms.

Simplify your husband's overall Parkinson's medication regimen; some patients may retreat to a regimen of levodopa (Sinemet or Madopar) only.

Add a new or second generation antipsychotic. Clozapine and quetiapine are antipsychotic drugs that can help suppress hallucinations without worsening PD symptoms. A new hallucination drug called Pimavanserin may soon be available for PD patients with psychosis. All other typical and atypical antipsychotics should be avoided.

**Q** My dad is 79 and has had Parkinson's for almost 20 years. Initially, he was able to function well with medication. However, these last few years his condition has grown much worse despite his medications. Is deep brain stimulation a worthwhile procedure for him?

**A** Since your father is over 70, he may or may not be a good candidate for deep brain stimulation (DBS) surgery. We have operated on people over 80, and we consider patients on the merits of their case, not solely on their age. For example, older people with multiple medical conditions and a poor response to dopamine would probably be deemed ineligible for surgery. To determine if your father is a candidate for DBS, he will need to be evaluated by an interdisciplinary team that includes a neurologist, a neurosurgeon, a neuropsychologist and a psychiatrist. Many centers also use rehabilitation specialists. Once this team meets they can assess the risk/benefit ratio of DBS surgery and recommend the most appropriate course of action for your father. It's very important to understand that only levodopa-responsive symptoms—tremor, rigidity, bradykinesia and motor fluctuations—are likely to improve with DBS. DBS also helps suppress dyskinesia. Gait and balance issues are less likely to improve in someone his age.

**Q** My father has had Parkinson's for 22 years. For the last three years he has become more confused. Is there a link between late stage Parkinson's and dementia? If so, is there anything that can be done to help my wonderful dad?

**A** As PD progresses, problems with memory loss and cognitive skills can worsen. First, your father should be evaluated by a neurologist for reversible causes of thinking problems such as drug side effects, vitamin levels and thyroid function. When medications such as agonists are removed, there can occasionally be a dramatic improvement in the symptoms you describe. Sometimes, doctors will simplify the drug regimen to more frequent Sinemet dosing and add Seroquel or Clozaril to block hallucinations and drug-induced behavioral problems. Finally, neuropsychological testing can also be beneficial. Many people with PD could possibly develop Alzheimer's. Currently, there are several useful drugs for treatment of memory problems including cholinesterase inhibitors.

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