

Understanding Parkinson's Seeking Out A Specialist



Managing Parkinson's disease (PD) is a challenge for anyone who is touched by it and doing it well may require you and your loved ones to take on a variety of important tasks, from adjusting work or retirement lifestyles to committing to an appropriate exercise regimen. But none of these tasks is more important than finding the right doctor. When symptoms first appear, it is natural to begin by talking to your family doctor or internist. If that doctor suspects Parkinson's, he or she may refer you to a general neurologist or a movement disorders specialist. The Parkinson's Disease Foundation (PDF) strongly advises people with Parkinson's to seek out a movement disorders specialist as the quarterback of their health care team. In some cases, for example, if you live far from an academic medical center or a specialist in private practice, PDF recommends receiving most of your care with a knowledgeable general neurologist nearby, and then traveling a longer distance to see a specialist two to three times a year. In this article, we explain what you have to gain by working with a specialist and guide you step-by-step through the process of finding one.

Which Doctors are PD Specialists?

Both general neurologists and movement disorders specialists care for people living with Parkinson's. General neurologists are doctors who work with conditions of the brain and central nervous system. Becoming a neurologist in the United States requires a four-year college degree; graduation from an accredited medical school; and an additional three or four years of specialized training in a neurology residency. General neurologists typically work in a private or group practice, or in a hospital. Some neurologists treat many people with Parkinson's and may be quite knowledgeable about the disease. But most neurologists have diverse practices, of which Parkinson's disease represents only a small percent.

Most movement disorders specialists are neurologists who have completed an additional one or two years of training (a fellowship) in movement disorders, a sub-specialty of neurology. They may see patients in a private practice or at university medical centers. Often they perform clinical or basic science research in addition to caring for patients. They may also teach young doctors who are on their way to becoming specialists. People with Parkinson's may constitute 50 percent

or more of a specialist's practice. With this level of experience, a movement disorders specialist will be more familiar with the range of available Parkinson's medications, how they work, and their possible side effects. A specialist is also more likely to discuss the role of clinical trials.

Finally, a movement disorders specialist is more likely than a general practitioner or a general neurologist to be aware of which health care professionals may be able to help you tackle the day-to-day challenges of PD. These may include physical therapists or nutritionists. He or she may also be well-informed about local resources.

What a Specialist Can Do For You

Both general neurologists and specialists have a lot more experience diagnosing and treating Parkinson's than does a general practitioner. Recent research underscores this point. One study reported that people newly diagnosed with Parkinson's who went to a neurologist lived longer than those who saw a primary care provider — in fact, they were 20 percent less likely to have died after six years. In addition, they were 20 percent less likely to need placement in a skilled nursing facility (nursing home). And after one year of follow-up, they seemed less likely to have experienced

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injuries from falls — they were 14 percent less likely to have broken a hip (Willis, et. al., Neurology, 2011).

Another report concluded that people whose PD was diagnosed by a neurologist were more likely to receive a prescription for an anti-PD medication immediately upon diagnosis — the standard of care recommended by the American Academy of Neurology — than those who were diagnosed by a non-neurologist (Lage et. al., reported at the Annual Meeting of the American Academy of Neurology, 2011).

How to Find a Specialist

Try several of these routes to find a qualified movement disorders specialist:

- Ask your primary care provider for a referral.
- Ask family, friends and colleagues for a recommendation.
- Contact a local support group for referrals.
- Call PDF's toll-free National HelpLine at (800) 457- 6676 to find movement disorders specialists and support groups in your area.
- Contact your health insurance provider for a list of neurologists (they may not specify who is a specialist) in your network.
- If you live in an area that is far from an academic medical center or a specialist in private practice, you may want to seek out a referral for a general neurologist, a gerontologist or an internist. You may decide to receive most of your care from a general doctor who is close to home and then travel a longer distance to visit a specialist two or three times a year.

How to Choose a Doctor

Once you have located a few qualified specialists, the next step is to find one who is right for you. Consider the recommendations you have received; check your insurance policy to make sure that it will cover all or most of the services; factor in your own convenience (travel, etc.), and come up with a short list. Browse online to learn about the doctors' training, expertise and research interests. Then schedule an appointment with your first choice.

What to expect from the doctor. At your first visit, a PD specialist will take a thorough medical

history, and ask about your family medical history and your symptoms. He or she will conduct physical and neurological exams. Among other things, you will be asked to sit, stand and walk, so that the doctor can observe your balance and coordination. A brain imaging test may be ordered to rule out other conditions.

Prepare a list of questions that will help you better understand the doctor's expertise and your treatment options. Most likely, you won't be able to discuss all of them in one visit. Once you have a treatment plan, you may have more specific questions. Here are some questions you may want to start with:

- How many people with Parkinson's do you treat?
- How do my other health conditions and medications affect my PD and how I treat it?
- Do you know of any clinical studies?
- Are you aware of new research and treatments?
- Are there lifestyle changes that can help my PD?
- If you are not available between visits, who may I communicate with, and how?
- Should I get a second opinion? This is common practice and a reputable doctor will not be offended by the question.

Making a choice. Beyond getting good medical advice, it is important for you to be comfortable talking to your doctor. Choose a doctor who answers your questions, puts you at ease and treats you with respect. Consider whether the doctor takes your opinions and questions seriously.

Decisions about your treatment will be a collaboration between you and your doctor. Your symptoms and medications may change frequently. You should feel confident that the doctor you choose is prepared to work with you and your family over a long period of time. Having a positive relationship is ultimately good for your health.

Conclusions

PDF strongly advises people with Parkinson's to seek out a movement disorders specialist to serve as the quarterback of his or her health care team. Such specialists provide the best care for people with Parkinson's disease.

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice. This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.

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