

Parkinson's Disease and the Family

A NEW GUIDE

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HARVARD UNIVERSITY PRESS

Cambridge, Massachusetts

London, England

2005



Communicating with Your Treatment Team

Now that you or your loved one has been diagnosed with Parkinson's disease, you will need to select a medical doctor to treat the condition and to help navigate the days, months, and years ahead. It is very important to choose a doctor with whom you feel comfortable because, in all likelihood, you will be getting to know that person and his or her medical staff very well.

You will have many new questions that only an experienced and trained professional can answer. If you worry about sounding petty, naïve, or even silly, we highly recommend that you abandon that fear. Select a doctor who truly believes that there is no such thing as a stupid question. Only then will you feel free to ask for the help you need.

You can begin the process of selecting a doctor by asking for recommendations from people and resources you respect. Here are some ideas:

- *Family physician.* Physicians know about the training and skill of their colleagues in the community.
- *Member of the clergy.* Most clergy members have knowledge based on their experience with other members of the congregation.
- *Local hospital.* Most hospitals have a physician on staff who treats patients with Parkinson's disease. Find out who that doctor is and be prepared to research the person's skills by _____

making inquiries to the state medical society, asking around, and interviewing the doctor in person. See below for important questions to ask of any potential doctor.

- *Parkinson's disease organization.* The National Parkinson Foundation (NPF), for example, provides an extensive list of physicians with special interest and skill in treating patients with Parkinson's disease. The list—complete with addresses, contact names, and phone numbers—is available on the NPF website (<http://www.parkinson.org/index.htm>) or by calling the organization toll free, at 1-800-327-4545.
- *Community meetings.* Many communities have disease-oriented patient and family groups that sponsor educational sessions and support groups. They are often organized by family members. There may be a Parkinson's disease support group in your community that meets on a regular basis. Most likely there will be many people in attendance willing to share their opinions about selecting a doctor.

Selecting the Right Doctor for You

Research shows that the better the relationship between the patient, family, and doctor, the better the outcome for the patient. Many people are embarrassed to “interview” a doctor and staff, but we suggest it. The interview is not just about asking questions; it is also about observing and quietly evaluating what you have seen and heard.

True or false?

- It is important that I like the doctor.
- All members of the medical staff should be knowledgeable and understanding.
- My questions should be answered thoroughly and compassionately. _____

- The doctor should describe his or her philosophy concerning medical care of patients with Parkinson's disease.
- The doctor's waiting room should be accessible and comfortable.
- Even if I call frequently with pressing concerns, I should be treated with respect. My calls should be returned within a reasonable amount of time.

The answer to all these questions is *true*. It is important that you like and respect your doctor and that you feel at ease when you are in the office or discussing your concerns on the telephone. Ask yourself if this doctor is someone with whom you can work.

A Specialist or a Primary Care Provider?

Depending on where you live, you may not have a choice about whether the doctor you select is a specialist in movement disorders (a neurologist with additional training in movement disorders) or a general neurologist. Both movement disorder neurologists and general neurologists have completed 3 years of intensive training in all neurological diseases. Movement disorder specialists have completed an additional 1–2 years of training specifically in movement disorders, and thus are highly skilled at the medical treatment of Parkinson's disease—though they probably have less daily experience in treating common neurological problems, such as headache! When you have a choice, it usually makes the most sense to see an expert in Parkinson's disease. Because of the varied symptoms and numerous medications used to treat Parkinson's disease, most people benefit by seeing a doctor who treats similar patients day in and day out.



Here's what many people do about their medical care, and successfully: They depend on their primary care physician and a local, general neurologist for regular care, and then see a movement disorder neurologist about every six months. The specialist maintains contact with the local physicians through mail and phone correspondence. This way, patients have the benefit of a local doctor who is readily available and knowledgeable about the patient's overall medical condition plus an expert in Parkinson's disease who can fine-tune medications and serve as a consultant to both the primary care physician and the primary neurologist.

Interviewing the Doctor and Office Staff

Remember that you have a right to ask questions about a doctor's skills, training, and style of work. You are entitled to obtain information about the medical practice that will provide your care. If the doctor were in your position, he or she would surely do the same.

Not everything has to be phrased as a question when you conduct the interview. Curiosity can sometimes be satisfied just by looking around. Obvious things to look for would be whether the office is clean, if phone calls are answered promptly, if the waiting room is comfortable and reading material is up-to-date, and if the wait to see the doctor is acceptable.

You will want to chat with the staff, too. Notice whether they are helpful and knowledgeable. Do they look happy? You might want to ask a question about Parkinson's disease on the basis of what you have read or heard. If you are answered respectfully and thoroughly, consider it a good sign. Mention that you are new to the practice and are wondering what to expect. You might be surprised by what you hear.



When it's time to see the doctor, look for a few niceties, such as a handshake and a comfortable chair for everyone. Notice whether the doctor is listening carefully and asking questions in a compassionate manner. Does he or she seem observant and attentive? If you are a family member, is the doctor including you in the conversation?

Doctors want their patients to be involved in their own care. That means asking questions in order to be well informed. The first meeting is a good place to begin. Here are some questions you can ask, to find out the doctor's experience with Parkinson's disease and its treatment:

- What percentage of your practice consists of people with Parkinson's disease?
- Have patients with Parkinson's disease always been part of your practice?
- What have you found is the best form of treatment for most patients?
- What would the treatment options be in our case?
- What is your availability at night and on weekends?
- Do your patients ever enroll in clinical trials?
- Could you tell us about laboratory or clinical research programs with which you are involved?
- Will your office be able to recommend a physical therapist, occupational therapist, speech therapist, or psychologist experienced in working with people with Parkinson's disease, if the need arises?

These questions should give you a good introduction to the doctor. Discuss your feelings about the visit with your loved one who has Parkinson's disease, of course, and with other friends and family members, if doing so would help you make a _____

Always Be Prepared

Once you've chosen your doctor, be prepared to get the most out of every visit. If you see the doctor once every six months, you will surely have several observations to report and questions to ask. Unless they are written down, some are likely to be missed. Paradoxically, the things we forget are often the most important.

Keep a running list of questions and concerns. Before going into an appointment, ask yourself what you want to get out of the visit. You might even keep an alphabetical list of headings as a reminder:

Appetite
Bowel and bladder habits
Complementary and alternative medicine
Exercise
Gait
Illnesses (other)
Medications
Mood
Over-the-counter medicines
Sex
Sleep
Socializing
Stiffness
Swallowing
Travel
Voice
Weight
Work
Other

This list covers concerns about the person with Parkinson's _____
disease. You might also include topics about family members _____

and the impact of the disease on the patient's relationship with his or her loved ones.

Most doctors are pleased when their patients come to appointments prepared to talk and ask questions. It means that the patient is involved in his or her care. It also can save time in the appointment by bringing the biggest concerns to the surface right away. If you have been reading about Parkinson's disease, and you probably will be, use time during the appointment to ask questions about topics that are not clear or about which you want more information. Be respectful of the doctor's time by having the questions ready. If you find that they are not being answered or that you are dissatisfied for any other reason, you might want to think about whether this is the right doctor for you. Some offices employ a nurse who is skilled at answering questions from patients and families.

Thank the doctor and staff after each visit. Be sure to let them know that you appreciate their time and attention. They, like you, work hard and are glad to hear that they are making a difference.

In Case of Emergency

You should ask your doctor about what to do in case of emergency, even though emergencies associated with Parkinson's disease are rare. Parkinson's disease is a chronic condition, so change does not happen suddenly and alarmingly. It occurs slowly, over months to years.

Families commonly think it's an emergency when they notice that the response to Parkinson's medications is not what it had been. Movements appear slower and more rigid. It is important to contact your doctor when this happens, but it is not an emergency. The doctor will make careful changes to the medication. _____
Unlike the use of antibiotics for a bacterial infection such as _____
