

Five Questions to Ask Your Neurologist

To thrive—not just survive—while living with a chronic condition,

you need to ask tough, smart questions.

BY ORLY AVITZUR, M.D.

ou've waited weeks to see your neurologist. When you arrive, she conducts a physical examination and asks about your symptoms since the last visit, all of which is vital. But when you or a family member has a chronic or life-threatening neurologic condition—such as Parkinson's disease (PD), Alzheimer's disease (AD), multiple sclerosis (MS), or a brain tumor—the concerns that keep you up at night might not make it into those discussions. Maybe you're concerned about your job, but you can't seem to find the right opportunity to bring it up.

In the last issue of *Neurology Now*, we discussed five tests or treatments that you might not need. (See "Choosing Wisely," http://bit.ly/Z9X2Me.) Here, neurologists choose five questions they think patients should ask to get the best possible care.

Should I Get a Second Opinion?

Bruce H. Cohen, M.D., Fellow of the American Academy of Neurology (AAN) and director of pediatric neurology Akron Children's Hospital, treats adults and children who have brain tumors. He recommends asking your neurologist if you should get a second opinion.

"Brain tumor treatment, especially if the tumor recurs, may differ depending on the medical center and the equipment available," Dr. Cohen says. "Ask your doctor if there are different ways to treat your tumor and whether technology better suited to treat it might be available elsewhere." Most medical centers can't afford all the different radiation therapy machines used to treat brain cancer, he says—nor provide all types of experimental chemo-

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therapy, including gene therapy or vaccine therapy. "For example, a proton beam accelerator, which is used in patients who require very precise treatment of their brain cancer, is found at only a few centers across the United States," Dr. Cohen notes.

When Dr. Cohen recommends a specific treatment, he informs his patients which therapy is available at his hospital and whether treatment differs elsewhere. He often offers his first and second choice of treatment options and provides patients the opportunity to get a second opinion if additional options are offered at other facilities.

That's exactly what he did in 1994 after diagnosing a young child who had what appeared to be a slow-growing malignant brain tumor. Although he had recommended chemotherapy to the mother, he also referred her to another expert whom he respected but thought might disagree with him. Indeed, that second neurologist recommended radiation therapy; later, a third neurologist recommended a watch-and-wait approach. The family returned to Dr. Cohen after opting for the third option of cautious observation. And the child, now an adult, has been returning to Dr. Cohen once a year...for the past 19 years.

Most of the time, doctors welcome questions such as this. If for some reason your doctor is offended, you can always check out the AAN's online "Find-A-Neurologist" tool at **patients.aan. com/findaneurologist** or contact a patient advocacy group (see Resource Central, page 45).

Should I Start Making Plans to Change My Home or Job?

Make it a point to let your neurologist know where you live and what you do for a living, and ask whether you should anticipate changes over the course of your illness that would require adjustments. Caregivers should be involved in these discussions as well; in the case of many neurologic conditions, the patient may not have the insight to recognize when he or she is having cognitive difficulties.

"Often, we get so caught up responding to what patients are dealing with in the present that we forget to help them anticipate and plan for the future," says Janis Miyasaki, M.D., associate professor and associate clinical director of the Movement Disorders Centre at the University of Toronto.

"Young doctors whom I train are often baffled when I ask them, 'Does this person live in a one- or two-story home, and does their main floor have a bathroom?" Dr. Miyasaki says. She recommends that patients, caregivers, and family members bring up subjects such as living space or work conditions.

For example, for many people living with PD, climbing

stairs may become difficult over time. These patients may benefit from advice about how to adapt their living space, such as by adding a chair lift for the stairs or a ramp. Moving to a single-level dwelling can often help them maintain independence for longer. In Dr. Miyasaki's experience, it may take a year or two for someone to accept the necessity of moving to a single-level dwelling. But after the first six months, she has found, most people say it was their wisest decision.

It's also important for family members to discuss any of their own health problems that might interfere with the caregiving role. The wife of a man with PD revealed to Dr. Miyasaki that she was about to undergo a total hysterectomy. She hadn't considered how this would affect her husband, whom she regularly assisted up the stairs. Dr. Miyasaki was able to help arrange for temporary home care so that they could both remain safe.

Dr. Miyasaki also advises people with chronic neurologic conditions to discuss their job responsibilities with their neurologist, who may be able to help if or when modifications become necessary.

"Physically, it might be easy to anticipate when you need modifications to your job—for example, changing a variable shift to a set schedule or switching to a more flexible role with built-in rest periods in case sleeping patterns are disrupted," Dr. Miyasaki says. One of her patients, a research technician, noted that he had difficulty measuring liquids when his PD medications began to wear off. She was able to support him by writing a letter requesting modification to alter his schedule accordingly. She assisted another patient, the CEO of a large investment firm, in getting long-term disability benefits. He'd developed cognitive problems as the result of his PD and couldn't properly fulfill his duties any longer.

Ronald C. Petersen, M.D., Ph.D. AAN member and director of the Mayo Clinic Alzheimer's Disease Research Center in Rochester, MN, recognizes that more testing isn't always better—especially for dementia, in which biomarkers are becoming increasingly available to help identify causes. (A biomarker is a laboratory measurement that reflects the activity of a disease.) "Nevertheless, a condition such as AD is diagnosed on the basis of a thorough history and neurologic examination, not a test," he says.

"When a doctor recommends a PET scan (an imaging test that uses a radioactive substance to look for disease), an amyloid imaging scan (a type of PET scan that detects beta-amyloid deposits characteristic of AD), or a spinal tap for tau and betaamyloid, patients should ask what each test would add to the certainty of the diagnosis. Patients should also ask if a test will

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lead to any different recommendations or help with the prognosis, and if any risks are associated with it," Dr. Petersen says. Keep in mind that testing often is not covered by insurance.

Clinical symptoms and history are often enough to diagnose AD with a reasonable degree of certainty, according to Dr. Petersen. "If an 85-year-old man with a gradual history of forgetfulness becomes unable to use his checkbook but is able to live alone, the probability of AD is high, and you don't need to do an exotic test," he says. Additional testing is typically warranted when the person has unusual symptoms—such as problems with language instead of memory—or is unusually young with no family history of AD, he says.

With This New Medication?
You may be reluctant to start taking a drug because you've heard about someone doing poorly on it. Maybe you've been warned about its side

What Side Effects Can Occur

effects. Sometimes, the side effects do outweigh the benefits of treatment. Asking your neurologist about possible side effects allows her to address your concerns and set the record straight about potential harms.

Jay E. Selman, M.D., AAN member, and chief of neurology at Blythedale Children's Hospital in Valhalla, NY—whose areas of expertise include epilepsy, autism, Tourette's syndrome, and traumatic brain injury—believes it's essential to have an open and thorough discussion about all the possible side effects of any medication you're about to start.

The parents of an 8-year-old boy evaluated by Dr. Selman declined a trial of methylphenidate (Ritalin) for severe attention deficit-hyperactivity disorder (ADHD). The reason was that the father—who'd heard methylphenidate was "just like what the street gangs were selling"—was dead set against all medications. But after Dr. Selman informed him about potential side effects and explained that the medication was not addictive when used appropriately and supervised by a physician, the father agreed to a trial. "At the next visit, the reports from teachers and family noted a significant improvement in his attention, and we were able to make further adjustments to the dose," Dr. Selman recalls.

When children are patients, the subject may require discussion with the patient as well as with parents. "All communication requires a framework based upon the child's chronological and developmental age, the seriousness of the underlying condition, and the family dynamics," Dr. Selman explains. He typically asks children and teens to notify their parents if they don't feel well, or if something is different, so that the family may contact him. He asks older adolescents to call him directly, as well. He advises all patients

to call him immediately if they observe something of concern.

Your neurologist typically discusses those side effects that he or she believes are most likely to occur or have the most serious consequences. Dr. Selman first addresses those that are potentially dangerous, such as a rash that may develop with the anticonvulsant lamotrigine (Lamictal). He then mentions those that may occur frequently, such as gastrointestinal upset with a nonsteroidal anti-inflammatory drug or appetite suppression and sleep problems with an ADHD drug. He likens the discussion to the other day-to-day decisions we all make about relative risks and benefits. "I might say to someone, 'To get to my office today, you had to decide whether to take the parkway or local streets by weighing travel time, the risk of weather and road conditions, and so forth. We do the same thing when we weight the benefits of the treatment versus the potential adverse effects."

Giving the patient and the family as active a role as possible in decision-making is important to Dr. Selman, who lets patients know he will continue to work with them, even if they decide not to follow his recommendations.

How Will This Treatment Improve My Quality of Life?
Lily Jung Henson, M.D., has been taking care of patients with MS for 23 years, currently as chief of staff at Swedish Issaquah Hospital and medical director of Swedish Issaquah Neurology, both in Issaquah, WA. "Neurologists tend to think about treatment success as it pertains to disease activity—in the case of MS, relapses or progression. But patients may care more about how they feel between the disease episodes or as a result of the side effects of the medicine," she notes.

"For example, we may be very happy because the patient is having fewer exacerbations of the disease and showing no progression. But, the patient might be miserable because she is unable to participate in activities she used to love, like going to her child's soccer game," Dr. Jung Henson says.

"In a situation like that, no matter how well the drug is doing in terms of reducing flare-ups, the side effects demand switching to a more tolerable drug," she says. In addition, Dr. Jung Henson says, she would discuss adjusting the woman's schedule to leave more energy for soccer games, consider prescribing anti-fatigue medications to give her more energy while there, and recommend that she wear a cooling vest and drink cool liquids in very warm weather.

The goal of a given treatment may not directly address quality of life, such as physical activity, social activity, personal fulfillment, mobility, and independence. Don't forget to remind your doctor that these things matter.