

Why Compassion?

By Martha Nance

The wife of a patient with Lewy body disease asks me to play the piano at his memorial service. A neighborhood lights up with sixty thousand Christmas lights each December, one for each person diagnosed with Parkinson's disease in the United States that year. A homeless man with Huntington's disease refers another homeless man to the clinic to get that new medicine for his movements.

Why compassion?

If a week of penicillin will cure the patient's infection, or a cast and time will put her arm back together again, a warm compress of compassion may be superfluous. But in the icy tundra of neurodegenerative movement disorders, where I spend most of my time, you can't get very far without it. Anyone with a license can provide the Parkinson's patient a prescription for carbidopa-levodopa pills. But it is only if the prescriber knows when the patient wakes up, works, and goes to bed, when he eats and whether he is a vegetarian, what times of day he exercises, how forgetful he is, how reticent he is about taking pills in the first place, and who else is available in the home to support this treatment effort, that the medication will be prescribed-and taken-properly.

This requires a working-with, the first component of compassion, which is even implicit in the word "com-*passion*" itself. When I meet a new patient with Parkinson's disease or Huntington's disease, I know that we will be together for the rest of that person's life (or perhaps mine). It is humbling to watch former athletes lose the ability to walk and creative geniuses become demented (and vice versa), and challenging to help them find continued meaning in life along the way. Certain tools are available to me—medications and surgery for some symptoms; rehabilitation therapists, nurses, social workers; books, classes, and support programs. And each patient brings his own resources—personal health and fitness, near and distant family, logistical and financial strength, psychological resources. We work together, combining our resources, to figure out how to enable success, maintain dignity, and relieve discomfort throughout the course of the disease.

Like other practitioners of chronic disease, I spend much of my time gazing into a somewhat hazy crystal ball, trying to anticipate what the next year or two or five have in store for a patient, to guide him as smoothly as possible through the (to me) expected changes and milestones expected along the course of his disease. For each patient and family, neurodegenerative disease is a new, discouraging, and often frightening experience. But armed with the right medications, support, and future planning, patients can experience joy and

success and novelty even after a diagnosis of Parkinson's disease or Huntington's disease. It is tremendously rewarding to see the creativity and energy that patients can summon up if they find solid footing. They write books, paint, create music; compete (successfully) in running and skiing (and pickleball and table tennis) competitions; participate in research studies, do volunteer work, and organize advocacy and fundraising events (ranging from Christmas lights to motorcycle rallies to classical music concerts, among many others); or simply find the correct focus and balance of work, exercise, hobbies, health, and family so that they can honestly say, "Life is good." The feeling I have when I see these successes must be what the schoolteacher feels when he sees a light bulb of understanding go on in a particularly challenging student's eyes!

The "-passion" part of compassion also makes a difference. I could happily describe the recent successes of gene silencing research in Huntington's disease to a hundred and one patients, or a thousand and one—the hope that shines in their faces is absolutely worth the twenty-five years of research it has taken to get there! It is easy to care about patients for whom you have passion (whether that passion is due to an interest in their disease, or some other aspect of their situation—a calling to work with homeless people or a particular ethnic group, or a love for older people or infants, for instance.) I am less animated in discussing epilepsy management, or new drugs for multiple sclerosis. Patients can tell the difference, as can families, medical students, and clinic nurses. And so can I. The perfect antidote to burnout is doing work that you are passionate about, with patients you care about.

If you share your passion with them, patients will share theirs with you. From my patients, I have learned what a vintage Shelby Cobra looks like, what happens during a Civil War reenactment, the differences between freestyle and Greco-Roman wrestling, how many different countries host ski marathons (check it out at Worldloppet.com), and how to say "Vernutsya cherez chetire metsyatsa" (return in four months) in Russian. The "com" and the "passion" of compassion both flow equally from doctor to patient and from patient to doctor.

Obviously, you can't connect with everyone. Years ago, I took care of someone whose job had been running pornography shops. I think he had been in jail for a while. He was just an old man with dementia when I met him. But he was not nice and his family was not nice and together they were not nice, and I admit that I had a hard time caring about him. And I struggle sometimes with patients from foreign cultures, especially when their understanding of health and disease and what doctors do, is very different from mine (or should I say, mine is different from theirs...) making it difficult to work together fruitfully.

A brief interlude about the homeless man with Huntington's disease. I spent the first several years trying to find him a "better" place to live. Our work together became much easier once I figured out that he was happiest when camped out under the bridge and feeding the pigeons, and that he knew how to make his way to the shelter if he needed to. Tetrabenazine, a new (at that time) drug to treat his involuntary movements, was delivered from the specialty pharmacy to our clinic, where he picked it up each month—and gradually became the sweetheart of the

clinic staff He made a point of staying in a hotel the night before each clinic appointment, so he would be clean for us. And when he recognized chorea in another homeless man who had drifted into town, he convinced that man to come to our clinic to get the new medicine. Compassion can be contagious!

Finally, compassion is all that we have left at the end. I am reminded every day of the inadequacies of our treatments, the failures of my last thirty years of research, as all my patients with Parkinson's disease and Huntington's disease die. They reach a time when one more levodopa pill or surgery or antidepressant will not forestall the inevitable. Then, all I have left to offer is my humanity. I may have known the patient and family for five years, or sometimes twenty-five years, and I need that last visit, the closure of the last goodbye, as much as they do. And it is an honor to be asked to play at a patient's memorial service, a humbling gift to receive at the end of a difficult but profoundly meaningful and human relationship.

Why compassion? Because it is the most meaningful and important thing that a doctor can give to a patient.

Martha Nance is a neurologist in Minnesota who specializes in neurodegenerative disorders such as Parkinson's disease and Huntington's disease. She has published many scientific research articles in journals with long, scary names, but is new to literary writing. She had one essay, "What it mean(s)(t) to be a doctor" published earlier this year in Dreamers Creative Writing.

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