

Staging Parkinson's Disease

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I am often asked, "What stage of PD do I have?" This is a very reasonable question although the answer may be unsatisfactory. Staging of disease is very common and particularly useful in many disorders, particularly cancer and congestive heart failure. Each stage, for each particular problem carries a well known prognosis. If you are in stage II b of some cancer, it means that the average patient has a particular likelihood of surviving the next few years, say 50% survival over the next 4 years. Similarly for heart failure and a number of other disorders. Fortunately, or unfortunately, depending on how you look at it, this is not true for PD.

The staging system for PD was developed in 1967 by Drs. Hoehn and Yahr, distinguished PD clinicians and researchers, in order to help understand the natural progression of PD. It is a very useful scheme for understanding research papers, as it provides a crude estimation for the motor severity of the disease. So, if I read a paper describing the response to medication of 100 PD patients whose severity was 3, I have a rough estimate for how severe their disease was. It means something different say, than an average severity of 4, which would mean more advanced, more disabling disease. However, this system is not useful for thinking about how severe the disease is for any particular person.

The staging system is simple. If the disorder affects only one side of the body, and does not affect balance, it is stage 1. If it affects both sides, but not balance, it is stage 2. If it affects balance, so that patients might fall when pulled backwards during routine testing, it is stage 3. If walking is significantly affected so the patient usually requires a cane or walker to safely walk, it is stage 4. Stage 5, the worst stage, means unable to walk. While this sounds reasonable, and is useful for an overview of a large population, it is not good for a single patient. Why not? Think of a person with severe one sided problems. If it is the dominant side (for example a right handed person with severe PD problems on the right), the person is disabled. But the person may only be inconvenienced if it affects the non-dominant (that is, left) side. The patients are mirror images of each other, with the same stage, yet the impact is vastly different. The staging does not consider the many other problems that occur with PD, such as speech disorders, memory impairment, fatigue, depression, constipation, etc. Someone in stage 4 who has normal memory, speech, cognition and mood may be in much better shape than someone in stage 1 or 2, who has difficulty communicating and remembering and is depressed. In addition, PD has an incredibly wide range of progressions. I have personally cared for some patients for over 20 years and each visit I wonder if I made the correct diagnosis since they seem to be aging more slowly than I am. Yet when we stop the L-Dopa as an experiment they get slower, start to tremor and resume the medication. On the other hand, there is the rare patient who has mild slowness on day 1, but three years later is in a wheel chair, despite maximal medication. The two patients may have looked the same at the initial exam, but their outcomes are worlds apart. Staging would not have been helpful in predicting their prognosis.

I explain this to my patients when they ask this question. PD is as severe as its impact on your life and the life of those around you. A slight hand tremor for an eye surgeon is disabling but not for a neurologist (I gave up giving botulinum injections to eyelids because of a tremor, but did not alter the rest of my practice. My tremor is not from PD.). As best we can determine, although PD always progresses, and progresses at different rates and causing different

problems in different people, it usually follows a fairly stable course. If things change slowly early in the disease, it usually remains slow in its progression. If the changes can be seen every few months, then the decline will be more rapid. Each person is unique. What stage you are now means little. How you cope with your problems is much more important.