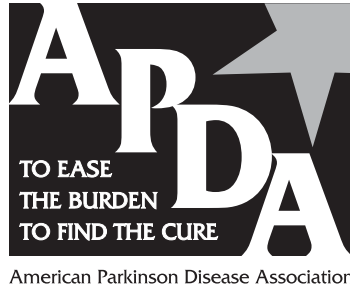


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Educational Supplement #20



FATIGUE IN PARKINSON'S DISEASE

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Fatigue is a common problem for people with Parkinson's disease (PD). For unclear reasons it has not attracted the attention that it should. It's not "sexy".

Depression has attracted a lot more attention even though it is not more common or more of a problem for PD patients. In fact, it's much better understood and much easier to treat. I believe that the debate about depression, was it "part of", or intrinsic to the disease, or was it "reactive," that is, a response to having a progressive, incurable and potentially disabling disorder, fueled the development of the discipline of "neuropsychiatry" over the last 20 years.

As a result of this discussion, neurologists and psychiatrists paid a lot more attention to depression. Depression is something doctors think they know some-

thing about. It is described in the Diagnostic and Statistical Manual (DSM), the text that defines all psychiatric illnesses, as a disorder caused by the loss of neurons in a particular location in the brain. Fatigue, on the other hand, is much less easy to grasp, hence harder to study.

What is fatigue? Although we know what it is when we feel it, it's not easy to define. People who develop fatigue as part of a new illness, following radiation therapy for cancer for example, often report that this new fatigue is quite different than the fatigue they had experienced before. When PD patients are asked about fatigue, they use descriptions like, "tired, run down, out of energy, unable to do anything, feeling like my feet are cement, out of gas, unable to get started, like I want to lay down all the time, can't get motivated, useless." Fatigue in PD is not a pleasant feeling. It

is not the same as the feeling normal people get at the end of a hard day's work. It is not necessarily something that will go away with a bit of rest.

Fatigue in PD can be defined as an unpleasant sensation of lacking energy, making the performance of routine activities, physical or mental, a strain. Several studies in the U.S. and Europe show reliably consistent results. About one-third of patients consider fatigue their single most bothersome symptom, even including the motor symptoms of PD like tremor, slowness, and problems with walking, freezing, balance and speech. In addition, about one half of patients rate fatigue as one of their three most bothersome symptoms. This means that fatigue is clearly one of the most common problems for the PD patient.

In all studies of quality of life, fatigue figures prominently as a major problem. As common sense would indicate, people with fatigue do not enjoy life nearly as much as patients who do not suffer from fatigue. This is, of course, obvious. If you don't have the energy to do routine chores, how can you enjoy doing the occasional fun outing, seeing friends and family, seeing the grandchildren, going to the movies? And even if you muster the energy to do these things, the tiredness from the effort detracts you from the enjoyment.

In most studies in PD, people with fatigue are more likely to be depressed and people who are depressed are more likely to be fatigued, but there is a large group

of PD patients who are fatigued but not depressed. The two are often related, but not always.

Interestingly, fatigue is not related to the severity of PD.

I first got interested in the topic of fatigue in PD because one of my younger patients (then in his forties) kept complaining about his fatigue. His PD was very mild and hardly interfered with his ability to do anything, but the fatigue made his work a real challenge. He kept working full time for years, but needed to rest on returning home every night and couldn't do anything but eat dinner and fall asleep watching TV, a marked change from his earlier habits. This disconnect between physical disability and fatigue was quite startling. It is true, by the way, in other neurological disorders as well. Multiple Sclerosis (MS) patients with severe fatigue may look completely normal, and sometimes are diagnosed based only on the symptom of fatigue. Another interesting facet of fatigue is that it tends to occur early in the disorder, sometimes actually developing before there is evidence of slowness or tremor, but tends to remain a problem. While this hasn't been well studied, it does appear that fatigue doesn't usually develop late in the illness. It appears early, tends not to go away, and usually doesn't develop once the disease has been present for a few years.

There is a large overlap between fatigue and other problems. Sleep disorders are common in PD and even the term "tired" connotes either fatigue or sleepi-

ness. Fatigued patients may also be sleepy, but sleepiness is different than fatigue. Sleepiness is improved by sleep whereas fatigue may or may not be improved by rest, whether the person sleeps during rest or simply relaxes while seated or lying down. Depression is associated with fatigue and many PD patients are depressed. This type of fatigue should improve with treatment of the depression, whereas the fatigue of PD does not. We do not know what role the medications for PD play in the development of fatigue. Some patients think the medications help and some report that they actually cause or worsen it.

We have no idea what causes fatigue in PD. One study examined the energy use of fatigued and non-fatigued PD patients to determine if the fatigued person simply used more energy to perform certain activities. If true, this would explain why they are more tired. There were no differences, other than the fatigued patients were more “out of shape” than the non-fatigued.

In the current rating scale, the UPDRS (Unified Parkinson’s Disease Rating Scale), a short battery of tests used in almost every study of PD in the world, no questions are asked about fatigue. An updated version is being prepared. I don’t know if fatigue will be assessed. It is important to consider because doctors are frequently not sensitive to it. One published study reported that PD specialists at a world famous PD center, routinely failed to detect fatigue in the vast majority of their PD patients who suffered from it.

Patients with PD should understand that their fatigue may be part of their PD and that it is playing a major role. Some aspects of fatigue may be treatable, either by improving sleep, altering PD medications, treating depression or through exercise programs. Patients should routinely mention their fatigue, just as they report how severe their tremors are, or how often they freeze or fall when at home. It is time for fatigue to be recognized as the serious problem it is.

The information contained in this supplement is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient’s own physician.

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