Information for patients from JNNP

Jerky movements from levodopa often not as bad as Parkinson's patients expect

Many people with Parkinson's disease delay starting treatment with levodopa, because they're worried about the jerky movements (dyskinesia) that this drug can cause with long-term use. However, a new study suggests that many people who take levodopa actually prefer their dyskinesia to the Parkinson's symptoms they would get if they didn't take the drug. This suggests that earlier levodopa treatment may be preferable for some patients.

What do we know already?

Parkinson's disease affects how you move. An early sign is a slight trembling in one hand. Over time, you start doing things more and more slowly as your muscles become stiff. You may lose your balance more easily.

Treating Parkinson's disease is complicated. Levodopa is the main drug for the disease, and can work well at first. You may even forget you have Parkinson's when you start taking it. But after taking levodopa for two to five years, you may get problems from the drug, including dyskinesia. These involuntary movements can happen just before or after you take your dose of levodopa, or midway between two doses. You may nod your head over and over again. Or you may jerk your leg, smack your lips, or make a strange face.

Concern over dyskinesia often influences when people start taking levodopa. Many patients opt first to take drugs called dopamine agonists. However, these drugs don't work as well as levodopa and also cause their own side effects, including sleepiness, leg swelling (oedema), and hallucinations. So what's the best approach for most people? There's debate about this, as it's unclear how severely dyskinesia affects people's quality of life, compared with the problems they would get from Parkinson's if they weren't taking the drug.

Researchers have now done a study to find out whether concerns over dyskinesia are borne out once people develop these movement problems. The study included 259 people with Parkinson's. Some were not taking levodopa, others were taking the drug but did not yet have dyskinesia, and others had developed dyskinesia.
The researchers asked participants about their prior knowledge of dyskinesia and their perceptions of these movement problems. People with dyskinesia were also asked whether their perceptions had changed once they started getting these involuntary movements.

**What does the new study say?**

People who didn't yet take levodopa or had not yet got dyskinesia from the drug were much more concerned about these movement problems than people who had them. Slightly more than half said they would rather tolerate worsened Parkinson's symptoms than have dyskinesia. In contrast, 83 percent of people with dyskinesia preferred these movement problems to their Parkinson's symptoms. Among people with dyskinesia, 47 percent said these involuntary movements were not as bad as they'd expected, 28 percent said they were on par with their expectations, and 25 percent said they were worse than they expected.

**How reliable are the findings?**

This was a well-designed study that provides valuable insight into perceptions of dyskinesia among Parkinson's patients, both before and after the onset of these problems. However, the study would have been even stronger if it had followed patients over several years and assessed their changing perceptions over time.

**Where does the study come from?**

The study was done by Canadian and US researchers based in Toronto and Milwaukee, Wisconsin. Most of the participants were recruited from a large movement disorders clinic in Canada.

**What does this mean for me?**

Deciding when to start levodopa treatment can be difficult. There are many variables to consider, including your age, the severity of your symptoms, and how the disease is affecting your life. You may also be concerned about the drug's side effects, and that it may not work so well with long-term use. If one of your chief concerns is getting dyskinesia, this study shows that these movement problems often aren't as bad as people expect and that many people would choose this side effect over their Parkinson's symptoms. This suggests, say the researchers, that dyskinesia may play a less important role in shaping a person's quality of life than other factors relating to their Parkinson's disease. As a result, earlier levodopa treatment may be a good option for some people.
What should I do now?

If you and your doctor are weighing up the benefits and risks of starting levodopa treatment, you might mention this study as part of your discussion. Your doctor can help put its findings into perspective for you. It might help to talk to someone who has been in the same position. You could contact the Parkinson’s Disease Society (http://www.parkinsons.org.uk) for advice.


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