

From Sandie's Desk

Dystonia

One of the questions that people living with Parkinson's often ask us is "is there pain associated with Parkinson's?" Pain is a common symptom and it is our bodies' way of telling us that something isn't right and other causes need to be investigated - we should not jump to the conclusion that any and all pain is due to Parkinson's disease. We all can get different kinds of aches and pains for various reasons, so it is important to talk to your doctor to sort out what the cause of these aches and pains are.

That said, pain is common among those living with Parkinson's but does not get much publicity. Just as with everything else related to Parkinson's, everyone is different and not everyone will experience this problem but for some people, pain can be the main symptom of their condition.

For some people, it may be discomfort brought on by stiff muscles, which have a harder time moving. Hard muscles may bring on some cramps, but this can usually be "worked out" by gently stretching the muscle. For some people, there may be a much more difficult type of cramping pain, which is referred to as dystonia.

Dystonia can be confusing to understand, and when people try to get information about it especially online, they end up more confused. In general, dystonia can be described as involuntary muscle contractions, which can cause twisting, jerking and tighten different parts of your body, for a SUSTAINED period of time. Muscles that should be relaxed are tensed and tight.

Dystonia typically twists, turns or contorts some part of your body and often results in spasmodic and repetitive movements or abnormal involuntary postures. People who have dystonia often refer to it as a painful cramp, which lasts a long time. Unlike typical cramps however that usually resolve when we stretch the muscle, dystonia muscle contractions are sustained - like a "Charlie horse" that doesn't go away.

If you were to just look up 'dystonia' online, or in a medical book, you might read that dystonia, like Parkinson's, is a movement disorder and is the most common movement disorder after PD and essential tremor. This does not mean that you now have two different movement disorders! Some kinds of dystonia happen independently for different reasons, but with a diagnosis of Parkinson's, it is usually just another secondary symptom that your specialist will have to treat.

Dystonia is more common in young-onset Parkinson's, but it can affect anyone with PD. The most common forms of dystonia related to Parkinson's happen in the lower legs, for a SUSTAINED (lasting a long time) and can include:



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Sandie Jones trained as a registered nurse, specializing in psychiatry. In 1998, she joined Parkinson Canada, and is now an integral part of the Information & Referral team. In this role she has provided information on support, education, medical aspects, coping strategies, community services, and other information about Parkinson's disease and its management, not only to people living with Parkinson's disease and their families, but to professionals working with these people as well. This role has given her a comprehensive insight into the problems of people living with Parkinson's disease, as well as their carepartners.



- curling or arching of the toes
- spasms in your muscles may make toes curl into a claw-like position
- in-turning of the foot – your foot may turn in at your ankle and your big toe may extend cramping in the calves

The symptoms mentioned above typically reflect an untreated or under-treated state and often develop several hours after a dose of levodopa when the beneficial effect of the medication has worn off. Thus they often occur during the night or early in the morning, many hours after the last levodopa has been taken. Dystonia can also occur during the day and may be present continuously if the person living with PD is underdosed or under-treated.

I have been talking about dystonia affecting the lower limbs, especially toes, feet or calves. But Dystonia can also involve the head and neck, with the head turning, the face contracting, the eyes blinking or the tongue thrusting outwards. There is also a type of dystonia called blepharospasm which is involuntary eye closure where the eyes tend to close unintentionally. As with the other types of dystonia, all of the above symptoms most often occur during the levodopa off-state.

In summary:

1. Dystonia is a sustained (lasts a long time), involuntary, usually painful, muscle contraction that can affect different parts of the body.
2. Dystonia happens most often when levodopa treatment is “wearing off” –when the drug becomes less effective before the next dose is due.
3. It is most likely going to happen when you wake up, because it has been some time since your last dose of medication, and is most likely going to affect your feet and legs.
4. More common in young-onset Parkinson’s but can affect anyone.
5. Often mistaken for muscle cramps caused by rigid muscles but rigid muscles are hard because they are less elastic or flexible, whereas the hardness in dystonia comes from muscles contracting without relaxing.
6. The first step is to identify the cause of your dystonia. Keep a diary that will show how your dystonia relates to your medications. Speak to your doctor about changing the type and timing of your medications.
7. For dystonia that does not respond to changes in PD meds, discuss other drug treatment options with your doctor e.g. Botox (botulinum toxin) - a nerve toxin that is sometimes injected in small doses into the affected muscles.

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This article does not substitute for medical advice specific to an individual, but is for general information purposes. Please speak to your doctor(s) for all diagnostic and therapeutic information.