

Understanding Parkinson's Pain in Parkinson's Disease



If you live with Parkinson's disease (PD) and experience pain, you are not alone. Chronic pain is twice as common among people with PD as it is in people who don't live with PD. In fact, more than 80 percent of people with PD report experiencing pain and many say it's their most troubling non-motor symptom.

Fortunately, there are many ways to manage pain in PD. As with other aspects of PD, there's no one-size-fits-all approach. The first step is to work with your health care team to understand what's causing the pain and then work together to find the best treatment plan for you.

What Is Pain?

At its simplest, pain means the body hurts. When a person feels pain, nerves in the skin, joints and organs alert the brain to the location of an injury. Researchers have found that in early PD, there are already changes in the way that the body detects and regulates pain. Pain is complex, and can take many forms. In PD, pain tends to affect the side of the body where motor symptoms first appeared. If your PD started with a tremor in the right hand, you're more likely to develop pain in the right shoulder, wrist or fingers. Here are a few common types.

Musculoskeletal pain. Musculoskeletal pain is experienced by up to 75 percent of people with PD and includes pain in the muscles, bones or skeleton. It is related to rigidity and decreased movement, and to arthritis. Many people with PD experience muscle cramps and tightness in the neck, spine and arms. Cramps in the toes or calf muscles, particularly at night or in early morning, are common. Muscles may feel sore. Joint pain, especially in one shoulder, is also common. It's not uncommon for people with PD to be diagnosed with frozen shoulder or rotator cuff problems, and even undergo surgery.

Dystonic pain. Do you have painful curling of your foot, toes or hands? This is dystonia, a painful muscle spasm. Up to 50 percent of people with PD experience dystonia at some stage of the disease. Foot dystonia is one of the most common sources of dystonic pain in early PD. Severe, painful spasms also can occur in the neck, face or

throat muscles. Dystonia may occur spontaneously or may be triggered by certain movements, but is very often experienced in the early morning. It can also be related to fluctuations in PD medications.

Neuropathic pain. Also called radicular pain, neuropathic pain occurs when a nerve is crushed or inflamed. Between five and 20 percent of people with PD experience neuropathic pain. It feels sharp, electric, tingling or like coolness or numbness. In people with PD, changes in posture, as well as dystonia, can cause nerves to be crushed. A common type is sciatica — lower back pain that extends down one leg. People with PD may also experience peripheral neuropathy — injury to nerve endings that begins with numbness in the toes or fingertips.

Central pain. Central pain affects about 10 percent of people with PD at some point. It can be difficult to describe but may include a vague, constant boring sensation; abdominal pain, reflux, shortness of breath or feeling flushed; painful sensations around the mouth, genital or rectal areas or simply "pain all over."

Treating Pain

How can you make a specialized plan for your PD pain? Build a team that includes a PD doctor, nurse, physical therapist, occupational therapist, pain management specialist and in some cases, an orthopedic specialist.

Optimize PD medications. First, it's critical to ensure your PD medications are working as well as possible. Talk with your doctor. He or she may want to examine you immediately before and after

(over please)



you take PD medications. He or she may increase, decrease or change your medication to extend its effectiveness.

Exercise and physical therapy. Exercise is beneficial, particularly for musculoskeletal pain, but it can be a catch-22. It may be difficult to exercise when you're in pain, but if you're in pain and you stop moving, it gets worse! A physical therapist can recommend exercises to target the source of your pain. For example, if you experience neuropathic pain, a physical therapist can help you to improve your posture, which may alleviate pain.

Other medications. Your doctor can prescribe medications that target specific sources of pain. For example, muscle relaxants can help dystonia, as can deep brain stimulation (DBS) and botulinum toxin (Botox®). Medications for epilepsy and depression, such as gabapentin (Neurontin®) or nortriptyline (Pamelor®) may be helpful for neuropathic and central pain. Anti-inflammatory medications like ibuprofen may ease musculoskeletal pain.

Treat depression and other health conditions. Chronic pain and depression are intertwined. If a person experiences depression, it may worsen pain and other PD symptoms. In addition, people who are depressed have a hard time taking medications properly, and this sets a vicious cycle in motion: with missed doses, medications don't work well, and a person feels worse. Getting treatment for depression is essential for managing pain. It's also important to treat other health conditions — for example, osteoporosis or diabetes — that impact pain.

Alternative Treatments & Practical Tips

In seeking relief from pain, many people with PD try alternative treatments. Most of them have not been studied in clinical trials so we don't clearly understand the benefits and risks, and those that have been studied have been found equal to placebo treatments. Two that have been studied are acupuncture and marijuana.

Acupuncture. One small study suggested that acupuncture might improve sleep, but not pain, in PD. But we need larger rigorous studies to tell us more.

Medical marijuana. There have been several studies looking at the effectiveness of marijuana

What Kind of Pain Is It?

The better you can describe your pain, the more your doctor can help. Remember "OLD CARTS":

- O - Onset:** when did the pain start? Suddenly? Gradually? Yesterday? Last year?
- L - Location:** where does it hurt?
- D - Duration:** how long does it last?
- C - Character:** is the pain achy, sharp, electric, nauseating?
- A - Aggravating and Alleviating factors:** what makes the pain worse or better?
- R - Radiation:** does the pain start in one place and spread elsewhere?
- T - Timing:** how does the pain relate to when you take PD medications?
- S - Severity:** on a scale of 1 (no pain) to 10 (hit by a truck), how much does it hurt?

in treating PD. So far, the research tells us that it's probably ineffective and may exacerbate PD symptoms such as low blood pressure, dizziness, hallucinations, sleepiness and confusion. But it's important to remember that marijuana has 60 active ingredients, compared to aspirin, which has one! It is possible that future rigorous study of specific formulations for specific symptoms may show otherwise. We don't know enough yet. Always talk with your doctor before trying any new treatments, alternative or mainstream.

Road to Recovery

Pain in PD is often overlooked, and can have a significant impact on quality of life. The good news is that it can be managed. Tell your doctor about your pain, so you can figure out what kind it is and find the right solutions for that type of pain. Once a cause is determined, you and your health care team can choose therapies that best fit your individual needs so you can feel your best.

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If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice. This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.

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