

# From Sandie's Desk

## A Painless Discussion

By the time you read this article, I will be celebrating the beginning of my 17th year working with Parkinson Society Central & Northern Ontario. Many changes have taken place during my tenure here including changes to the name of our organization, the number of staff, and the number of support groups. Our support group network is over 50 groups across our vast region. When I started there were just three staff, and now there are fifteen of us!

Just as there have been changes and progress here, so too has there been a great deal of progression in the understanding of Parkinson's disease (PD). Not that long ago, PD was regarded as a painless condition, but I know many of you would dispute that!

Many of you are only too aware of the fact that other than problems with movement (tremor, slowness and stiffness) there may be non-motor symptoms that have an ever greater impact on your quality of life. Pain is one such non-motor symptom that has garnered some attention in recent years by researchers and health care professionals. Although there are still a lot of unanswered questions about pain, I will share with you what we do know.

The scientific literature varies greatly regarding the prevalence of pain but somewhere between 33% and 85% of people living with PD report pain as a troubling symptom. That's a lot of people! Pain is also not a normal part of aging, but the belief that it is normal is one reason many people suffer needlessly.

People living with PD can experience many different types of pain, but there are three main causes I will focus on today: progression related; wearing-off related; and non-PD related pain.

### Progression related

As PD progresses, the muscles become more rigid which may produce a deep, nagging pain. This type of pain usually relieved with an adjustment in medication. If muscle stiffness was one of your initial symptoms, this symptom may be familiar to you, as is the benefit from medication. Talk to your specialist.

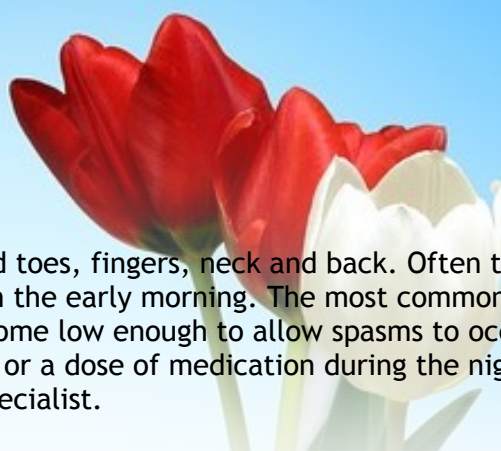
### Wearing-off related

Increase in muscle tone - overactive muscles - or partial contraction of the muscles that result in spasms or dystonia cause a different sort of pain. These muscle contractions are involuntary, meaning they are not under your



### Sandie Jones

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.



control. Most often these spasms affect the feet and toes, fingers, neck and back. Often these spasms occur as medications are wearing off, particularly in the early morning. The most common solution is to ensure that the level of medication does not become low enough to allow spasms to occur. Sometimes, taking a time-release medication at bedtime or a dose of medication during the night can help with this, so again, it is important to talk to your specialist.

When someone is in an 'off' state (when medication wears off before the next dose is due) or when PD is inadequately treated, pain from any source seems to be magnified. If a person has fluctuations during the day (when meds work well and when they don't), the degree of pain fluctuates too. Therefore, when motor symptoms - tremor, stiffness, slowness - are well controlled, pain due to other causes may be well controlled too.

### **Non-PD related**

Of course, you can also have other conditions, such as arthritis, bursitis, or tendonitis which can also be painful! The treatments for these problems include pain relievers and are different from PD treatment, so it is important for you to partner with your doctor to try and figure out which disorder is causing the difficulty. Sometimes, just to confuse things, the problem is mixed: for example, stooped posture related to PD may impact on sciatica, which is a pinched nerve in the back. One thing is for sure: pain from any other disorder clearly gets worse when your antiparkinson medications wear off.

It is very important to address pain, as it may interfere with your daily activities; your mood; your sleep and your overall quality of life. Chronic pain can result in sleep disturbance, malnutrition, social withdrawal, depression, anxiety and even impair cognition.

### **In conclusion:**

1. Pain that is attributed to PD can often be alleviated by starting antiparkinson medications, or adjusting the dosage you are currently on.
2. Causes of pain can be tricky, and PD might get blamed for everything you experience. Though PD may worsen pain you have, the cause may be another source.
3. Keep a diary of painful symptoms, including time of day and the location in your body affected. Use descriptive words: e.g. sharp, constant, dull, occasional, throbbing etc. This will help the doctor to narrow down the cause, and suggest treatment options.
4. Physical therapy and mild exercise, massage therapy and warm baths can be helpful as non-medical approaches.

There are no cut and dried answers about why pain occurs in PD, but research is happening right now. There are already good strategies in place for managing pain so don't suffer needlessly, and please talk to your doctor!

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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.