

Apathy and Parkinson's disease

Apathy is a feeling of low motivation that is common among people with Parkinson's disease (PD). About 50% of people with PD will experience apathy, which is believed to be due to problems with the brain networks responsible for mood and thinking.

Introduction

Apathy is more common in men than women and is related to worsening of PD. This means that people with PD who have more apathy tend to have more PD-related problems. Apathy has also been reported after surgery for deep brain stimulation but the reasons are not fully understood.

People who experience apathy are generally less interested in taking part in activities that help maintain their level of functioning. This can be extremely frustrating for carepartners. Research shows that apathy worsens caregiver stress.

Greater understanding of apathy and Parkinson's is very important for individuals with PD and their carepartners. The purpose of this information sheet is to give an overview of how apathy can differ from other Parkinson's related symptoms and to provide ideas for self-care and coping.

What are the Symptoms of Apathy?

Apathy relates to behavioural changes including but not limited to:

- reduced interest and curiosity in people and activities
- reduced spontaneous interactions with others or with pets, including showing affection
- lack of motivation and decreased initiation of activities
- flat affect (an inability to express emotions) or emotional indifference
- changes in mood and thinking, and difficulty participating in cognitively demanding situations
- little or no goal-directed behaviour

Apathy and Depression

An individual who is experiencing apathy may have symptoms that are similar to those associated with depression, such as low energy and lack of interest. Apathy and depression are separate problems and can be present at the same time. The symptoms of depression are different than those of apathy. People who are depressed may feel sadness, hopelessness, irritability, anxiety and thoughts of suicide, which are not typical of apathy.

Apathy and Fatigue

Fatigue is an extremely common symptom of Parkinson's. Fatigue has many similarities to apathy such as low energy, lack of interest in activities and low motivation. Bradykinesia (slowness of movement), dyskinesia and medication on/off periods can be unpredictable and exhausting. Improved medication management can provide some relief from these symptoms, and thereby reduce fatigue. If the symptoms of low energy, lack of interest in activities and low motivation are not resolved with improved medication management, they may also be symptoms of apathy.

Apathy and Motor Symptoms of PD

It is common for people with PD to have decreased facial expression which can make a person appear sad or disinterested when, in fact, they are not. The "Parkinson's mask" is often misunderstood by care partners and medical staff because the person appears apathetic.

Compounding this problem is the soft voice common to PD. Lack of facial expression and a soft voice can lead to incorrect assumptions on the part of others that the person with PD is apathetic and/or depressed. It is possible that the person with Parkinson's is not apathetic but, rather, is having difficulty expressing himself or herself.

So what can you do?

Start talking to your doctor as soon as symptoms of apathy appear, as it is important to discuss potential causes in order to assess what is going on.

Apathy and Self-Care

Here are some things you can do to identify and cope with apathy:

- **Activity:** Regular physical activity and exercise are important for enhancing energy levels and for social interaction. A pre-arranged schedule, involving other people or an exercise class, can help.
- **Support:** Participate in a support group for people with PD and for carepartners.

Talk to Your Doctor

Start talking about apathy shortly after a diagnosis of Parkinson's or as soon as symptoms of apathy appear. It is well understood that people with a positive attitude who are involved in their care have greater success coping with Parkinson's and with life in general. **Be sure that potential causes of apathy are assessed on a regular basis**, including:

- **Screening for depression:** Investigate causes and treatment of depression and other conditions.
- **Identify causes of fatigue:** Uncover the causes of fatigue and discuss treatment.
- **Review of medication:** Ensure medication is providing the best possible symptom relief.

The Impact on Carepartners

Apathy is a symptom that typically has a greater negative impact on carepartners than on a person with Parkinson's. Many carepartners report feeling frustrated with the person they care for and it is not uncommon for a carepartner to feel they are working harder than the person with Parkinson's. Without an understanding of the nature of apathy in PD, a carepartner may start to see the person they care for as lazy, defiant, bored, difficult to motivate and generally unwilling to help themselves. This can become a highly stressful situation resulting in significant strain on the relationship.

Apathy presents challenges to everyone in the family. While it can be a potential source of stress, it is also an opportunity to enrich relationships and build stronger bonds.

Self-Care and Apathy

Here are some things you can do to identify and cope with apathy:

- **Ask:** Ask the person with Parkinson's how they are feeling. What looks like apathy may be a symptom of another condition that could benefit from medical attention, or it may be related to Parkinson's.
- **Patience:** After being gently encouraged to take part in an activity, a person experiencing apathy may say afterwards that they were glad they did participate. Getting started is often the hardest part!

The contents of this document are provided for information purposes only, and do not represent advice, an endorsement or a recommendation, with respect to any product, service or enterprise, and/or the claims and properties thereof, by Parkinson Canada.

© Parkinson Canada 2017