

From Sandie's Desk

When Your “Get-up-and-go” Leaves You Behind: Apathy

One of the most common complaints from spouses of people living with Parkinson's sounds something like: “if he/she doesn't get up off the couch and do something instead of sitting all day watching TV, I'm going to scream”. Carepartners may start to see the person living with Parkinson's as lazy, disinterested, and unwilling to help themselves out, by doing their exercise and speech therapy, without being constantly reminded. This in turn is construed as nagging by the person' living with Parkinson's. This type of stress often puts significant strain on a relationship. Sound familiar?

Well, in defense of individuals living with Parkinson's, they may be experiencing something called APATHY (or sometimes 'amotivational syndrome') that may occur at any time - even early in the disease process, before the motor symptoms show up. Apathy occurs in approximately 50% of people living with Parkinson's, and yet remains one of the most misunderstood symptoms.

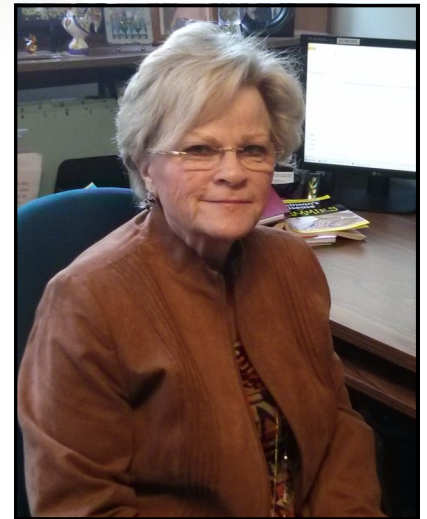
The symptoms of apathy include:

- Reduced interest in people and activities
- Reduced spontaneous interactions with others
- Lack of motivation (not starting things on their own)
- Inability to express emotions
- Changes in mood and thinking
- Loss of motivation to pursue old activities they used to enjoy, such as hobbies
- Not speaking for long periods of time

People may mistake apathy for depression or anxiety. It is important to understand that apathy is seen as a separate symptom. These symptoms may happen separately or at the same time. While we do have effective treatment options for depression and anxiety now, research is still under way for apathy. This makes it important to have your doctor help sort out which symptom(s) you have, so that options can be tried.

Fatigue is another common symptom of PD. Like apathy, fatigue has such symptoms as low energy, low motivation and lack of interest in activities. Unlike apathy, fatigue often relates to medication management of the physical issues, whether symptoms like stiffness or dyskinesia, which can be exhausting. In other words, if the symptoms of low energy, lack of interest in activities, and low motivation are not resolved with improved medication management, they may be symptoms of apathy.

As if that is not enough, lack of facial expression and soft voice - two very common symptoms of PD - can lead to erroneous assumptions on the part of others that the person with PD is apathetic, depressed or even rude and disinterested: all of which can lead to the person living with Parkinson's being left out and isolated.



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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.



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. Things such as:

1. Screening for depression - investigate causes and treatment of depression
2. Investigate possible causes of fatigue and discuss treatment
3. Ensure your antiparkinson medication is providing the best possible physical symptom relief

Things that you can do for yourself would include:

1. Getting involved with an exercise group to enhance energy levels, as well as social interaction. You may not always feel like going, but it is important to push yourself, as the end result will be beneficial.
2. Participate in a support group. It is comforting to know that you aren't the only person dealing with apathy!

Carepartners, will hopefully now have a better understanding that their loved one's apathy results from physiological changes in the brain; specifically disruption in brain pathways as well as decreased levels of dopamine. It is not the case that your loved one is lazy and doesn't care about doing those speech and physical therapy exercises at home. Rather, he or she simply doesn't think to do them, even when a simple reminder brings the need to do something to mind. Demanding, arguing, begging, wheedling or haranguing is likely to produce a minimal effort at best.

The situation calls for flexibility, ingenuity and PATIENCE! When apathy is truly the reason your loved one struggles with meeting the demands of the day, it may become necessary to be gently directive, but not overly reactive. Don't let your frustration get the better of you, and start doing things for your loved one as things will only build up a sense of helplessness on their part.

Tips:

1. Negotiate a schedule for regular daily activities.
2. Mutually establish a list of household chores the PlWPD can reasonably manage.
3. Make it clear that diminished motivation is *not* the same as diminished responsibility.
4. Get timers, post reminders and cue with clear statements e.g. "the trash needs to go out".
5. If the negotiated activity is not done, it is reasonable to hold the person accountable and make it clear it is their own responsibility.

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.

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