DYSKINESIA

A Double-Edged Sword

Written By Charlene Heavener

Do you find you have extra movement, involuntary movement you cannot seem to stop? Do you feel you switch between stiffness and too much movement? Then you might be experiencing dyskinesia. You may have heard the words dyskinesia or diphasic/biphasic dyskinesia. You might be thinking these are hard words to pronounce and even harder to describe.

So, what is dyskinesia? In basic terms it is abnormal, involuntary, purposeless movement. It can involve your limbs, trunk, head, neck, facial muscles, mouth or even tongue. This movement is different from a tremor which is described as a rhythmic type of movement. Dyskinesia can be related to both disease progression and medication, or a combination of both. As Parkinson's progresses, motor fluctuations increase and are a result of the brain's declining ability to store and release dopamine consistently. Parkinson's medications like levodopa carbidopa help replace dopamine, however, over time the brain's lack of dopamine leads to more inconsistent symptom management, leading to peaks and valleys in symptom control and dyskinesia. For some people, especially those diagnosed at a younger age, years of levodopa use can also increase the likelihood of developing dyskinesia.

Peak dose dyskinesia is the most common type. These typically occur when medications are working at their peak or best to control motor symptoms. This time frame of when medications are working is often referred to as the ON period. These movements have been described as twisty, bouncy and writhing movements. If one was to plot this on a graph it would look like a roller coaster: going up represents the medications starting to work and the dyskinesia occurring and then coming down represents when the medications are starting to wear off and the dyskinesia subsiding.

Diphasic or biphasic dyskinesias are more rare than peak dose dyskinesia and can occur as the "ON" starts and AGAIN as the "OFF" starts. These movements have been described as jerky like movements.

They can be more difficult to describe, and this form of dyskinesia is often harder to manage.

Diphasic/biphasic dyskinesia often appears when levodopa levels are changing rather than when they are at their highest, which is one reason it can be tricky to recognize. As these are more uncommon and movement is similar yet different from peak dose dyskinesia it can sometimes help to record videos of these movements to show health care professionals. Taking a series of videos at specific times when the movements are happening with the mention of the time in relation to when was the last dose of medication can be very helpful. This can help in diagnosis and help differentiate the movements from peak dose dyskinesia.

Dyskinesia is different for everyone; it can range from mild and unbothersome to severe where it has an impact on everyday life. This includes making some activities more challenging when someone is unable to control the movements. Activities like getting dressed, putting on make-up, brushing teeth, shaving, eating. It can also affect other leisure activities like going to a movie, out to eat, reading a book. For some it impacts them during times when moving is not ideal such as at the dentist, getting a haircut, or having an x-ray just to name a few. Dyskinesia can also have social impact. It can feel embarrassing when people are staring or pointing or worse when one must explain why they are moving around in "that way." Dyskinesia can also cause pain and discomfort from the additional movement. This might feel like tightness, burning or joint pain.

Another important consideration is unintentional weight loss. Movement burns calories and some people with dyskinesia find they start to lose weight and struggle maintaining or gaining back weight due to this additional movement. Maintaining a healthy weight is important and when this weight loss is occurring in an uncontrolled way where weight is getting low the intake of additional calories or healthy higher calories foods may be considered to help with management. A registered dietitian or your health care provider can help explore options for maintaining weight in a safe and healthy way.

Dyskinesia can be a double-edged sword, where there is a fine line of balance between stiffness and rigidity and too much movement. For many people with Parkinson's, they would prefer to be able to move even if it is dyskinetic type of movement, rather than be stuck or frozen or unable to move.

Management of dyskinesia will depend on the type of dyskinesia and how dyskinesia impacts daily life. As individuals experience with dyskinesia varies and management can be challenging the goal is to maintain good movement and mobility while reducing or limiting dyskinesia. If this abnormal movement is impacting your everyday life, then it needs to be discussed with your health care provider. Sometimes it may mean adjusting Parkinson's medications, sometimes it may mean adding a medication like amantadine to help control some of these extra movements, sometimes it may be a discussion about other potential options for symptom control like Duodopa or Deep Brain Stimulation. Both of which may be able to reduce dyskinesia for some individuals. Alongside medication adjustments, some people also find that certain lifestyle approaches can help reduce the impact of dyskinesia. These may include gentle, rhythmic exercise such as walking or stretching to help settle excess movement, planning activities during more predictable ON times, reducing stress where possible (as stress can sometimes amplify movement), and pacing daily tasks to avoid fatigue. Staying hydrated, maintaining regular meals, and keeping a consistent medication schedule can also support steadier motor control. While these strategies do not eliminate dyskinesia, they can help make daily life feel more manageable. In many cases, a combination of medication changes, advanced therapies, and lifestyle strategies (such as timing activities around ON periods) can offer the best balance.

Dyskinesias can be challenging to treat but often more difficult to live with. It is not as simple as "just stop moving!" ■