



Wearing off and involuntary movements (dyskinesia)

If you have been taking a Parkinson's medication that contains levodopa for some time, for example Sinemet, you may develop some side effects that can affect your movement. This factsheet describes the different movement problems that can happen after using levodopa for several years. It explains what might cause them and how they can be controlled.

WHAT ARE THE MOVEMENT PROBLEMS SOMETIMES ASSOCIATED WITH LONG TERM LEVODOPA USE?

If you go from having good control of your symptoms to having less control, you may be experiencing motor fluctuations.

Motor fluctuations may come on slowly or quickly. They typically happen when levodopa is wearing off, but they may occur at other times too. If the fluctuation is caused by your levodopa based medication wearing off this is called "end of dose wearing off" or just "wearing off".

In the early stages of Parkinson's, you may not notice when a dose of levodopa begins to wear off. But as Parkinson's progresses, you may find that it doesn't last as long as it used to. These fluctuations can become more unpredictable in the later stages of Parkinson's when people have been taking Parkinson's medications for several years.

A lot of people with Parkinson's experience motor fluctuations or involuntary movements after five to 10 years of levodopa treatment. Some people may develop them earlier, especially if they are on a high dose of levodopa. People who develop Parkinson's before the age of 40 are also at a high risk of developing motor fluctuations and involuntary movements.

"ON" AND "OFF" VERSUS "FREEZING"

Being "on" is when your symptoms are controlled and when you feel you can do the most. Being "off" is when Parkinson's symptoms come back and affect you the most.

Being "on or "off" is different from freezing. There are different ways of managing the swings due to freezing and "on/off" swings. During "off" periods you are hardly able to move at all, so walking,

especially up stairs or reaching for a cup will be impossible. But when you freeze, it affects certain movements and not others. You may not be able to walk, for example, but you're still able to reach for a cup.

For more information, see our Parkinson's and Freezing factsheet.

MOOD AND EMOTIONS

In addition to motor (movement) symptoms related to wearing off you may also experience feelings of anxiety, sleepiness, low mood or pain as your medication wears off. You are advised to talk to your Parkinson's Community Educator or family doctor regarding any such issues.

DYSKINESIA (INVOLUNTARY MOVEMENTS)

Dyskinesia is uncontrollable muscle movements. They include jerks, twitches, twisting or writhing movements, or restlessness. Involuntary movements can affect various parts of the body such as your arms, legs and the upper half of your body. The side of your body most affected by Parkinson's is where they often start and they usually occur in the legs before the arms.

There are different types of involuntary movements, and when and how often they appear differs from person to person. Some people experience involuntary movements for most of the day, while others may have them just prior to their next dose of medication.

"Peak dose", when levodopa is at its highest level in the bloodstream and in your brain, is another time when you are more likely to experience this side effect.

Because dyskinesia causes people to move around so much it can cause substantial weight loss. If you are worried about this, speak to your family doctor or Parkinson's Community Educator.

HOW CAN I MANAGE MOTOR FLUCTUATIONS AND INVOLUNTARY MOVEMENTS?

MEDICATION

Treating motor fluctuations and involuntary movements can be complex. Reducing your dose of levodopa to reduce involuntary movements, means your Parkinson's symptoms may be less controlled and you may have more wearing off or "on/off".

You will need to discuss any problems you have with your Community Educator, family doctor or specialist. If your symptoms suddenly become worse, make sure to speak to them as soon as possible. Your health professional can advise you on what changes you can make to your medication regimen to balance treating motor problems and keeping your other Parkinson's symptoms under control.

Options include avoiding peaks and troughs in doses of levodopa. The strategy might be taking smaller and more frequent doses of levodopa but keeping the overall amount the same.

You may also be advised to change to a different type of levodopa that helps even out levels in your bloodstream. You could also take it in another format, for example by intestinal gel. Additionally, there are other Parkinson's medications such as amantadine that can help levodopa to work better. Unfortunately, amantadine can have serious side effects of its own and does not work for all who experience dyskinesia.

If you take dopamine agonists from early on after your diagnosis of Parkinson's, for example lisuride or ropinirole, there is some evidence to suggest that you may be less prone to motor fluctuations. However this may mean your symptoms are less well controlled and dopamine agonists can cause dyskinesia as well.

DIET

For some people eating protein (such as in fish, meat, eggs, cheese and beans) can cause problems by reducing or slowing down the amount of levodopa that is absorbed into the bloodstream. Protein is essential for your health, so it's vital you retain it as part of your diet. However, you may find it helpful to take your medication at least 30 minutes before you eat to allow the medication time to start working. Talk to your Parkinson's Community Educator, family doctor or specialist about when to take your medication.

SURGERY

Surgery may be the best option for people who do not respond well to medication. It may also be used for people who are experiencing particularly troublesome involuntary movements.

A type of surgery called deep brain stimulation can help increase the amount of time you are in the "on" state. This can mean that you're able to reduce your Parkinson's medication and help reduce side effects such as involuntary movements.

Like any surgery, there are potential risks to having deep brain stimulation. Talk to your Parkinson's Community Educator or specialist to find out more.

For more information see our Deep Brain Stimulation factsheet.

MANAGE YOUR STRESS

Stress may contribute to motor fluctuations and involuntary movements, therefore finding ways to stay relaxed is highly recommended. You could try complementary therapies such as massage or exercises such as Tai Chi or yoga.

For more information see our Parkinson's and Complementary Therapies factsheet.

If you are frequently highly stressed or anxious, it's recommended you ask your Parkinson's Community Educator or family doctor for advice on managing these conditions.

You may find dealing with people's reactions to your involuntary movements annoying, stressful or embarrassing. It may be worth explaining to those around you that the symptoms are part of your condition and they shouldn't be alarmed or concerned if they happen.

MAKE THE MOST OF "ON" TIME

If you start to experience your medication wearing-off, it is important that your medication regimen is managed so you get the most of your "on" time.

This becomes more complicated if you also begin to have involuntary movements. You might then have to decide on a compromise between more "on" time with involuntary movements, or more "off" time with other Parkinson's symptoms. Many people tend to prefer more "on" time, even with involuntary movements, but everyone is different and you should discuss your options with your Parkinson's Community Educator, family doctor or specialist.

KEEP A DIARY

To make the most of your "on" time with the least possible involuntary movements, it can be helpful for you or the people who care about you to keep a 24-hour diary.

This will show when your symptoms and fluctuations happen, and for how long. Record this along with the times you take your medications, and the medication dosages.

Some women with Parkinson's find their motor symptoms fluctuate in line with their menstrual cycle. This link has not been proven, but keeping a diary will help you see whether your monthly cycle is having an effect on your movement symptoms.

Recording your progress, issues you encounter and similar can help you and your healthcare professional understand how your medication affects you, and how often you're experiencing difficulties. It can also give a better idea of what strategies to use to smooth out fluctuations.

For more information see our Preparing for a Medical Appointment and Keeping a Diary: for carers factsheets.

Sources: Parkinson's UK