

Fatigue and Parkinson's Disease

What is fatigue?

The feeling of fatigue has been described as an overwhelming sense of tiredness, a lack of energy and a feeling of exhaustion. This sense can apply to physical, intellectual or emotional feelings. Anybody can feel fatigued when they are working too hard, causing their muscles to be overactive, or when pressures at work or at home cause stress or overwork.

Is fatigue common in Parkinson's?

Fatigue is a subjective feeling with many different interpretations, which can make it difficult to measure accurately. For people with Parkinson's disease, however, fatigue is particularly common. In a study carried out in 1991 and followed up ten years later, one-third of people with Parkinson's interviewed rated fatigue as their most disabling symptom, and more than half of those interviewed rated it as one of the three most disabling [1]. Studies suggest that fatigue can affect over half of people with Parkinson's.

Fatigue in Parkinson's is not specific to any stage of the condition, and can occur at any time.

People who are newly diagnosed appear to be just as likely to experience fatigue as those who have had the condition for some time – in fact, for some people, it can be their first symptom. Also, the fatigue experienced by newly diagnosed people is not likely to be any more or less severe.

Often, fatigue can arise from the day-to-day variability characteristic of Parkinson's, which means that after feeling quite fit and able one day, people can feel too tired to do much the following day. It may be related to the fact that, for people with Parkinson's, many activities that were previously automatic may now require conscious effort. For those who are still in employment, a day's work can leave them exhausted in the evening, with little desire for other activities.

What causes fatigue in Parkinson's?

There is little agreement as to the specific cause of fatigue in Parkinson's, but it is possible that at least some of it is related to other symptoms. Fluctuations in a person's mobility can occur

throughout the day and are often related to the timing and dosage of medication. A person may feel more energetic and able to handle certain tasks at specific times of the day.

Also, the slowness of movement (bradykinesia) that people experience can mean that they find they are trying to complete tasks within too short a space of time, and fatigue, like other symptoms such as tremor, is aggravated by stress.

Tremor, stiffness or the dyskinesias (involuntary movements) that some people can experience after having Parkinson's for some time can put considerable stress on the muscles, which have to work harder, often against each other, in order to initiate movement or complete a task. In this instance, the muscles can become fatigued very quickly and easily.

Many people also find that it is difficult to concentrate for long periods without a break. Mental fatigue can often be as difficult a symptom as physical fatigue and, depending on the nature of a person's job, can be a limiting factor.

If fatigue can be related to Parkinson's symptoms, it may be treatable with normal anti-Parkinson's medication. Improved management of symptoms may mean that a person is better able to carry out tasks that might otherwise be difficult, and may have more energy to expend on them.

However, it is important to realise that fatigue in Parkinson's may not be related simply to tremor, stiffness or slowness. It can often be related to more complex difficulties such as sleep disturbance or depression, in which case treatment with anti-Parkinson's drugs will not help. It is very important if you are often feeling fatigued that you identify the primary reason for this and treat it accordingly.

Sleep and Night-time Problems

Up to 90% of people with Parkinson's can experience problems with sleeping at night [2], which can often leave them feeling tired and lethargic during the day. A person may be waking

through the night due to tremor or stiffness, or may find that they have difficulty turning over in bed. They may also be waking up in the night with the need to go to the toilet.

The range of sleep and night-time problems experienced in Parkinson's will mean that a person may not feel well rested in the morning, and a poorly rested person will under perform during the day. Night-time problems will also contribute to daytime sleepiness (called excessive daytime sleepiness), but frequent napping during the day can make sleeping at night-time more difficult. It is important to check the reasons for sleep disturbance, as many of these can be treated and may help the person to perform better during the day. For more information, see the Parkinson's Association's Information Sheet on Problems with Sleep in Parkinson's Disease.

Depression

Even if not formally diagnosed as 'depressed', as many as 30–40% of people with Parkinson's may experience significant feelings of depression at some point during the course of the condition [3]. Depression is a recognised clinical condition that involves more than just feeling 'down' for a short while.

A person who is depressed can exhibit a range of symptoms as well as low mood, including fatigue, which is presented as tiredness and difficulty with sleeping, and a lack of interest in or pleasure from a person's usual activities and interests. However, the presence of such symptoms does not necessarily mean that a person is depressed. This is particularly true in Parkinson's where many symptoms can be found in the absence of depression. Depression and fatigue therefore may be separate entities.

If fatigue is experienced as a symptom of depression, it should be alleviated by proper treatment. If you are diagnosed with depression, treatment may involve a combination of medication, psychological treatment, counselling and support. For more information, see the Parkinson's Association's Information Sheet on Depression and Parkinson's Disease.

Fatigue may also mimic a condition known as apathy, which is being increasingly recognised in Parkinson's and which can lead to a loss of interest in activities that the person previously engaged in actively. Apathy, like depression, needs to be diagnosed and treated with input from a psychological specialist.

Can Fatigue Be Treated?

Treatment of fatigue can be attempted with certain drugs, but this has not proven successful in all cases. For example, the drugs amantadine (Symmetrel) and selegiline (Eldepryl) both have a mild stimulant effect and may be helpful at low doses given during

daytime. Rasagiline (Azilect) may also be effective for fatigue, but is unproven. Other drugs that promote wakefulness may also be useful. However, it is not known what the long-term effects of drug treatment in Parkinson's may be. You should discuss this option carefully with your GP or Parkinson's specialist, as other non-drug treatments may be more appropriate.

Possibly the most important factor in treating fatigue in Parkinson's is identifying its source. The causes discussed above are not the only reasons why someone may feel fatigued; it may be due to other causes not related to Parkinson's. For this reason, it is important to discuss fatigue with your GP, hospital doctor, or Parkinson's Disease Nurse Specialist (PDNS) if you have one. While fatigue is common in Parkinson's, it can often be overlooked by doctors, but it is important that it is managed and treated properly.

Fatigue can often trigger a cycle in which the person becomes less and less active – if they are easily exhausted by some activities, they may become less likely to initiate them. This can, paradoxically, result in a further loss of stamina, as the muscles become weakened through inactivity.

It should also be remembered that fatigue is not just physical, but can impact on a person's intellectual and emotional lives as well.

If a person becomes less inclined to engage in activities, their interest will decline and they may increasingly choose to stay at home rather than go out. The person may then find that they get bored easily, may have few topics of conversation with family and friends, and can be more liable to depression.

Because of this, it is important to keep active, both physically and mentally. Initially, this increased activity may not seem worth the effort and the exhaustion, but as it develops, the long-term benefits will become apparent.

What can I do myself?

Although some of the primary causes of fatigue, such as sleep disturbance, depression or Parkinson's symptoms, can be treated medically, there are a number of strategies that a person can employ in order to avoid fatigue or keep it to a minimum, as outlined below.

Keep track of the times of day when your symptoms are better, and if you are on medication, the times when it is most effective. It may be useful to arrange the more difficult daily tasks for times when movement is easier.

If you are in employment, this may not be easy to arrange. In this case, regular short breaks may help

you to work more efficiently and to avoid fatigue building up. This can be something simple such as a cup of tea, a chat with a colleague, or sitting back for a few moments with your eyes closed.

If you are working around the house, it may be useful to consider a rearrangement of the usual household tasks; someone else may feel capable of taking on a job you have previously done and you may be able to take on one of theirs in return. It may also be useful to remember that household appliances can save you a lot of time and effort – microwaves and remote controls, for example. Make sure you put these to use rather than expending energy unnecessarily.

Try to get some regular exercise. This may seem difficult at first, but your stamina will build up over time.

Mental exercise is also important – try to keep an active involvement in your hobbies and interests, as boredom can also lead to fatigue.

Diet is important and you should make sure you are eating the right foods. Some people find that a small snack every couple of hours provides them with a constant supply of glucose, which is used for energy. It is also important to try to avoid constipation, as this can make you feel sluggish. For more information on diet, see the Parkinson's Association's Information Sheet on "Diet and Nutrition in Parkinson's Disease".

Try to develop good sleeping habits by establishing a regular bedtime and sleeping hours. Increase your daytime activity where possible and try to avoid daytime napping. Relaxation before bedtime, such as a warm bath, can also help. Alcohol, tobacco and caffeine should be avoided in the evenings. Occasionally, a sense of fatigue becomes obvious after a large midday meal. A short nap may be particularly helpful at this time and may reduce the sense of fatigue.

Above all, it is important to realise your capabilities and to know your limitations. Pace yourself – you should not try to ignore your fatigue, as this is only more likely to make it worse. Try to perform as much of your daily routine as you can by yourself, but take a rest or seek assistance when you think you need it. If you are feeling fatigued, it does not help to try to force too much into one time period.

You may also find that even after a good night's rest you are feeling more tired and less energetic than usual. This may be due to you having overworked the day before, or it may be simply due to the day-to-day variability of Parkinson's itself. Whatever the cause, you should be aware that days like these may occur, as will days when you are feeling better than usual.

With time and consideration, most people with Parkinson's and their relatives can come to recognise their own limits and to plan their lives so that these episodes of fatigue are minimised or managed. Achieving a good balance between rest and activity can help to combat fatigue and to improve your quality of life generally.

How can fatigue in Parkinson's Disease be measured?

The Parkinson's Disease Non-Motor Symptoms Scale (NMSS) addresses fatigue among other symptoms [4]. The Non-Motor Symptoms Questionnaire, available from the Parkinson's Association, allows you to complete a questionnaire that includes fatigue, while waiting to see the doctor or nurse. There is also an assessment scale to measure the clinical features and impact of fatigue in Parkinson's, and it has been validated (PFS-16) [5].

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Other Relevant Information Sheets:

G8: Diet and Nutrition in Parkinson's Disease

NM8: Problems with Sleep in Parkinson's Disease

EX2: Exercises for People With Parkinson's Disease

References:

1. Chaudhuri KR et al (2006) 'Non-motor symptoms of Parkinson's disease: Diagnosis and management' *Lancet Neurology*; 5:235–245
2. Chaudhuri KR (2003) 'Nocturnal symptom complex in PD and its management' *Neurology*; 61 (suppl 3): S17–S23
3. Global Parkinson's Disease Steering Committee (2002) 'Factors impacting on quality of life in Parkinson's disease: Results from an international survey' *Mov Disord*; 17: 60–67
4. Chaudhuri KR et al (2005) 'The non-motor symptom complex of Parkinson's disease: Time for a comprehensive assessment' *Current Neurol Neurosci Reports*; 5:275–283
5. R Brown et al (2005). 'Qualitative and quantitative assessment of subjective fatigue in Parkinson's. The Parkinson fatigue scale.' *Parkinsonism Relat Disord*; 11(1):49–55

DISCLAIMER – The information on these pages is not intended to be taken as advice. No changes to your treatment should be made without prior consultation with your doctor or allied health professional.

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