

Fatigue and sleep



Fatigue

Many people living with PSP experience fatigue. Fatigue is an overwhelming feeling of tiredness, lack of energy and exhaustion. It is often referred to as an invisible symptom, and can be felt physically, emotionally and mentally.

In the earlier stages of PSP, you may be affected by fatigue but still feel able to work or carry out many of the everyday activities of daily life. However, if fatigue is preventing you from doing the things you want to do then you may wish to review your activities to help maintain your energy levels and get the most out of life. Sitting down with family or friends and talking about the effects of fatigue may seem like a tiring idea in itself, but it can help you to work together to find ways of coping.

Think about how you feel during the day, and plan rest breaks that suit you. Some people benefit from several short breaks throughout the day, whereas others feel better after a longer rest. Do you feel tired about the same time each day? If so, then plan around this. For example you could let visitors know to avoid those times of the day where you really need to rest. If you are going out on a trip, plan around this to ensure that you are well rested before and after your excursion.

Whilst it is important to remain as active as you can, do take care not to overdo things, as this can lead to extreme fatigue. When you are feeling energised it can be tempting to fit in lots of activities. However, if this makes you feel more tired it may prevent you from doing the things you

really enjoy. Planning ahead is key to maximising your energy and getting the most out of life.

It can be really helpful to think about your daily tasks and start to prioritise them. Which tasks are urgent? Can you delegate any tasks to family or friends, so that you can conserve your energy for the things you really want to do? It can be hard to ask for or accept help, but remember that family and friends often relish the chance to help out in any way that they can. You may find it helpful to prepare a list of tasks that you are happy for other people to do.

If you are still working do speak with your occupational therapist who can advise you on how to make changes to your living or work spaces to help maximise your energy levels. This could involve small changes, such as keeping items that you use regularly in easy reach, through to various items of equipment that may help you to conserve your energy.

Taking care of your general health can also boost energy levels. Make sure that you are eating and drinking well, and if you are having any problems getting enough nutrients (perhaps due to swallowing difficulties) then your speech and language therapist and dietitian will be able to advise you on the best methods to manage this.

See section on *Swallowing, eating and drinking*.

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Sleep

As PSP progresses you may find that your sleeping pattern is affected. You may find it difficult to fall asleep or remain asleep, and you may experience changes in your body clock which cause you to be awake at night and asleep during the day. Making sure that you take regular visits outdoors for some gentle exercise and some fresh air can improve sleep cycles.

Sometimes sleep difficulties are made worse by other symptoms, such as pain, muscle spasms, restless legs, and anxiety or even as a side-effect of medication. You may find it helpful to discuss these issues with your GP or a member of your healthcare team, who can advise you on how to alleviate these symptoms.

They can also offer advice on methods of good 'sleep hygiene', which can help you to establish a regular and relaxing nighttime routine, leading to more restful sleep. In some instances, you may be invited to attend a sleep clinic.