

# Sleep Management in Parkinson's

## Booklet 1

### Introduction



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## An introduction to Sleep Management in Parkinson's

Sleep disturbances are commonly experienced by those with Parkinson's, and by the relatives and partners of those with Parkinson's. When they become chronic these disturbances are symptoms of *insomnia*. This is the first of 6 booklets designed to help people with the symptoms of insomnia improve their sleep. The booklet will cover what is called the 'structure' of sleep (how normal sleep is made up), how sleep can be influenced by Parkinson's, and then consider how insomnia symptoms can both develop **and** persist.

This booklet will also describe the background to the whole self-management programme. Altogether, there are 10 'mini-lessons' in this booklet (numbered 1-10). Try to make sure that you have grasped each mini-lesson before you read the next.

### 1 The structure of sleep

Sleep is made up of five distinct phases which change throughout the night. The five stages of sleep follow each other in sequence:

**Stage 1** is 'light sleep', a transition between being awake and being asleep.

**Stage 2** is 'true' sleep, but it isn't particularly deep. Consequently it is fairly easy to wake someone up from this stage.

**Stages 3 and 4** are known as 'deep sleep' and it is more difficult to wake someone up during these stages.

The fifth stage is called Rapid Eye Movement Sleep (REM) because during this stage the eyes dart to and fro beneath closed lids.

Each stage follows the next in sequence from Stage 1 to Stage 4 and then REM. The sequence takes about 90 minutes to complete, and then starts all over again. This means that our sleep gets deeper, then lighter, then deeper again as the night wears on. It also means that, because REM sleep is followed by very light sleep, we may momentarily wake up and remember a dream, before slipping back into sleep.

All stages of sleep are important, but we do need a balance of deep, light and REM sleep to feel at our best in the morning. However, as we shall see in the following section, the structure of sleep is strongly influenced by age and chronic health conditions, like Parkinson's.

### 2 How sleep may change in Parkinson's

As we age there is a decrease in deep sleep (Stages 3 and 4) and a corresponding increase in lighter sleep (Stages 1 and 2). This is perfectly normal, but it does mean that sleep becomes lighter with age.

In addition to this naturally changing pattern of sleep with ageing, the underlying neurochemical changes of the condition, motor difficulties and medication are some of the factors that can also interfere with the process of sleep in Parkinson's. Drugs frequently used in the treatment of Parkinson's appear to be involved in the regulation of REM sleep by inducing behavioural arousal, having a sedative effect or, more generally, disrupting the sleep-wake cycle.

Sleep disorders are among the most frequently reported non-motor symptoms in Parkinson's with common problems being: restless legs syndrome (RLS), rapid eye movement sleep behaviour disorder (RBD), sleep fragmentation and insomnia. RBD is characterised by bursts of vigorous and uncontrolled limb movements during sleep, and dreams or nightmares can become quite vivid.

### **3 What is insomnia?**

Broadly, there are four main insomnia symptoms:

- Problems getting to sleep
- Problems staying asleep
- Waking up too early in the morning (and being unable to get back to sleep)
- Feeling unrefreshed in the morning

It is important to recognise that the same person may experience one or more insomnia symptoms at any age, and stage of Parkinson's, but as we get older problems of staying asleep tend to be most common.

### **4 How can we measure the severity of insomnia?**

One of the simplest ways of assessing the quality of someone's sleep is to calculate their Sleep Efficiency. This simply means working out the percentage of time spent in bed asleep each night. If you spend 8 hours in bed, but only 4 of those hours are spent asleep, then your sleep efficiency is very low. If, on the other hand, you spend 8 hours in bed, and more than 7 of those hours are spent asleep, then your sleep efficiency is high. Sleep efficiency is based on the simple assumption that we go to bed in order to sleep. If you can keep a Sleep Diary for a week it will provide a record of your bed times and time awake giving you the numbers to work out your sleep efficiency.

Calculating sleep efficiency is easy, but you may need a calculator: simply divide the time spent asleep by the time spent in bed, and then multiply by 100 to make it a percent.

In Parkinson's, the quality of your sleep can also be measured by the Parkinson's Disease Sleep Scale (PDSS). The PDSS is a set of fifteen questions, the answers to which can be used to assess how good or bad your sleep has been over the previous week.

## 5 Who suffers from insomnia?

Severe sleep problems and insomnia are probably more common than you would think. The scientific research tells us that about 30% of the population experiences occasional sleep difficulties, and about 10% of the population suffers from insomnia. In a recent survey it was suggested that approximately 90% of individuals with Parkinson's experience some form of sleep disruption or insomnia.

## 6 How do sleep problems become chronic?

While people with insomnia are all individuals, research shows that there is a common pattern in the way insomnia develops and becomes persistent or chronic. This pattern is created by three different factors.

**First**, some people are more prone to sleep problems than others (technically, these people are described as 'predisposed' to insomnia). For example, being an anxious person could predispose someone to insomnia. These predisposing factors are very difficult to control since they are often unchangeable characteristics of the individual.

**Next**, there are events which can trigger or precipitate episodes of insomnia. These triggers can be episodes of emotional stress, environmental interference, or ill health. While these events would make most people lose some sleep, they tend to have the greatest impact on people who are already predisposed to insomnia.

**And finally**, once a sleep problem has developed, there are common habits and behaviours which people adopt in order to cope with insomnia which just make matters worse. Because these habits and behaviours have the effect of prolonging sleep problems, they are called perpetuating factors. Examples of perpetuating factors include things like; taking naps during the day; drinking tea and coffee to stay alert during the day; spending too much time in bed; and blaming insomnia for all your problems. Even if the precipitating factors (the things which triggered the insomnia in the first place) are kept under control, these perpetuating factors can still make the sleep problem worse.

The longer you have had your sleep problem, the more likely it is that perpetuating factors are helping to maintain or worsen your insomnia symptoms. The objective of this self help programme, therefore, is to help you minimise the influence perpetuating factors have on your sleep.

## 7 The vicious circle of insomnia

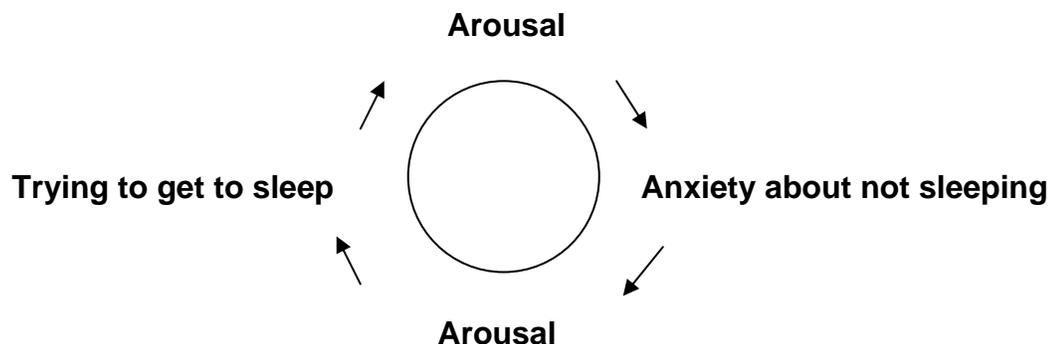
Because the goal of this self-management programme is to reduce or eliminate the factors which perpetuate or maintain insomnia, it is also important to understand how insomnia actually 'works'. Insomnia is frequently described as a 'vicious circle', a 'loop' of unhelpful events which end where they start and consequently go round and round.

In the vicious circle of insomnia, **arousal** is often the starting point of a poor night's sleep. Arousal means we are 'wide-awake'. Many things can create a state of arousal at bedtime, but the main sources are **our feelings** (like feeling sad, unhappy or anxious), **our thoughts** (for example, repetitive thoughts and concerns going round and round in your mind), and **our health**, particularly conditions like Parkinson's. All of these factors can cause arousal, which prevent you from falling asleep.

People who experience sleep problems can also become anxious about the consequences of not sleeping (for example, being concerned about feeling sleepy, or irritable, or 'below par' the next day).

All of this encourages the person with insomnia to try harder to fall asleep. This is the point where, for many people, insomnia becomes chronic, **because trying to fall asleep helps to keep you awake**. That's because trying to fall asleep creates a special type of arousal that occurs only when we attempt to control something that should be automatic.

So the vicious circle of insomnia begins with arousal, and ends with arousal:



## Habits and Sleep

If people are tired enough they will eventually fall asleep. Unfortunately people with insomnia often develop habits (like lying in later during the morning or napping during the day) which reduce sleepiness **at bedtime**. These strategies do help to compensate for lack of sleep, but they also help to maintain the insomnia since, at bedtime, the same level of unhelpful arousal will be present. For this reason, it is important to recognise that some of the habits we acquire when trying to cope with insomnia may, in the long run, contribute to the same vicious circle.

## 8 The self-management approach: take control of your sleep

People who develop sleep problems often say things like "*There is nothing that can be done for my sleep problems*" or "*I have tried everything and nothing has helped*". This self-management programme will help you to break the vicious circle by teaching you skills and methods which control insomnia. The emphasis of the approach is not on 'curing' insomnia. Rather, the self-management approach will help you to decrease your sleep problems, increasing your satisfaction with sleep, and deal effectively with sleep difficulties when they occur.

## 9 The key principles of the self-management approach to insomnia

### Motivation and effort

Even if the procedures seem simple, following all the advice in the booklets is the key to success. Completing the programme will take approximately 6 weeks, depending on the severity of your sleep problem, your health, and your level of motivation. Do not expect improvements in the first few weeks. Your sleep difficulties have probably been present for some time, so it's well worth the effort and patience to follow the advice offered in these booklets, and wait for change to happen gradually.

### Support

The changes in lifestyle and sleep habits suggested in this self-management programme will not only affect you, but may also affect other members of your family and those who care for you. It is important, therefore, to let them know what you plan to do, and to encourage them to support you. If you are living with someone who is also caring for you, your sleep problem can become their sleep problem, so getting their support to improve your sleep can ultimately benefit both of you.

### Recognising change

We have already emphasised that the aim of this self-management programme is to improve the quality of your sleep by reducing the frequency and severity of your sleep difficulties. Change will happen gradually, but it is important that you notice these changes as they happen. To help you to do this, complete the questions at the end of this booklet and calculate your own sleep efficiency. Over the course of this self-management programme you should find that your sleep efficiency improves.

## 10 Is this programme effective?

This self-management programme has been developed in scientific studies and is known to be effective when **all** the procedures are applied consistently. The scientific evidence shows that 70-80% of people who apply these procedures find that their sleep has improved after 6 weeks. And almost everyone finds that the programme helps them to understand their sleep better.

Recent studies have also been conducted specifically for patients with Parkinson's experiencing insomnia symptoms, and improvements in sleep measures were evident over a 6-week period.

**That's the end of the first booklet. All you need to do now is complete the sleep questions over the page, and calculate your sleep efficiency. In the next booklet we will consider how the 'bad habits' of sleep are learned, and how they can be changed.**

### My sleep before the self-management programme

First, select a night from the past week that was neither your best, nor your worst night's sleep.

		Answer in hours	Answer in minutes (hours X 60)
<b>Question A</b>	For your selected night, how long did you spend asleep? (add up all the periods of sleep if you had more than one).		
<b>Question B</b>	For your selected night, how much time did you spend in bed (from first getting in, to finally getting up)?		

### My typical sleep efficiency before the self-management programme

Answer to Question A \_\_\_\_\_ Divided by ( $\div$ ) Answer to Question B \_\_\_\_\_ = \_\_\_\_\_

Now multiply this answer by 100 = \_\_\_\_\_%  $\Leftarrow$  This is your sleep efficiency

- The sleep efficiency of good sleepers is generally above 85%
- A sleep efficiency of 75% - 85% indicates a sleeping problem
- A sleep efficiency of less than 75% indicates a severe sleeping problem



