

Sleep Management in Parkinson's

Booklet 6

Maintaining Progress



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Sleep Management in Parkinson's

In previous booklets we have explained how changes in your habits, thoughts and lifestyle can help to improve your sleep. Overall, our aim has been to show you how you can take control of your own sleep. We also explained that, in order to get the most out of this self-help approach, you must continue to follow the advice. In this, the final booklet, we suggest ways in which you can now 'take stock' of your sleep, and maintain your progress.

How to maintain your progress

Introduction

This is the last of 6 booklets designed to help you manage your insomnia symptoms, and it is now time to evaluate the progress you have made. The aim of this self-management approach has been to help you to feel more in control of your sleep by teaching you skills and methods which can control insomnia symptoms. The emphasis of the approach is not on 'curing' your sleep problem. Rather, this self-management approach aims to help you reduce your sleep problems, increase your satisfaction with sleep, and deal more effectively with sleep difficulties when they arise.

It is possible that you have already experienced an improvement in the quality of your sleep. However, you may need a bit more time to feel the complete effects of this programme. If you have already noticed improvements in your sleep, this booklet will help you to maintain that progress. It is also possible that, some time in the future, you will find yourself in one of those situations that can cause sleep difficulties to return (for example, a change in your health condition, a stressful event, etc). In this booklet we will also consider suitable ways of dealing with these events.

How is your sleep now?

It would now be a good time to keep a sleep diary for a week or so. Using your completed diary, compare your sleep now to how it was at the beginning of this self-help programme.

For example, compare:

- The time it takes you to fall asleep
- The number of times you wake up in the night
- Your overall satisfaction with your sleep

Remember, sleep varies from night to night even among the best sleepers, so don't worry if you notice some variability within your sleep.

Getting the most out of self-help

So, do you feel your sleep has shown signs of improvement? If the answer to this question is 'yes', then well done. We would now advise you to continue with the self-help procedures, and make them part of your routine. However, if you feel that you didn't gain much from the self-help programme, then it is important to consider why. Here are some possibilities.

- Perhaps there are some parts of the programme that you haven't completed yet? Experience shows that the self-help approach to insomnia works best when practised as a 'whole', so we would strongly advise you to work through each booklet in order to get the most out of this programme
- If you have attempted all the components, and you still cannot see an improvement in your sleep, then it is possible that the programme may simply not be suitable for you. For example, it could be that the advice was not relevant to your particular problem, or perhaps you had to leave out some important steps because they were not practical in your case. Either way, you may benefit from some additional support, and we would suggest that you consult a health professional (like your PDNS).
- Another possibility is that the programme requires more time to work in your case. Changing sleep habits takes more time for some people than for others. If you have put the self-help advice into practice, but you haven't yet noticed any improvement in your sleep (or you have noticed some improvement, but not as much as you would like) try giving it more time.
- It is also possible that the programme is completely suitable for you, but needs a bit more effort to work well. This tends to be the most usual reason for slow progress. Ask yourself the following questions:
 - Did I apply the programme properly?
 - Did I follow the procedures regularly or only when it was convenient or easy?
 - Did the start of the programme coincide with a worsening of my condition that would have caused almost anyone to suffer difficulty sleeping?

If you found it particularly difficult to follow the advice, it would be helpful to think about why. Perhaps you found it difficult to find the motivation, or you felt there was a lack of support from those around you. Or perhaps something else was going on that distracted you (personal or family events, for example). If this was the case, then why not wait for a more appropriate time and start the programme again from the beginning.

- Another possibility is that the programme was hard to understand or difficult to follow. Speak to your PDNS about any queries or concerns you may have regarding the programme.
- Finally, it is worth keeping in mind that you may have improved more than you think. Remember that success is a change for the better; it does not matter if it is a large change or a small change. The important thing is that **you** made it happen. So keep your expectations realistic and don't expect too much. If you are aiming to fall asleep within a few minutes, or sleep all night, your standards are too high. Changes in sleep habits are always gradual and poor nights will continue to happen. If you think this point applies to you, look again at the section 'Keep your expectations realistic' in Booklet 4.

At this point, we would encourage you to make a decision. If you think the programme may still work for you, then keep trying (or even start again from the beginning).

If, on the other hand, you feel that the programme is unlikely to help with your particular problem, then you may need to consult a professional to obtain additional help.

Maintaining your gains

If you feel the programme has benefitted your sleep, then it is now time to consider how these benefits can be maintained. Sometimes, people wonder if it is necessary to follow the procedures every day in order to get a better night's sleep. The answer is not the same for everyone. Some people will always have to pay special attention to their sleep because they are more vulnerable to sleep problems. The important thing is to accept this and learn to live with it. The self help programme will, nevertheless, help you to cope better.

It is also very important to remember that an occasional poor night's sleep is normal, and happens to everyone from time to time. During periods of stress, or change, or emotional upheavals, it is normal to experience changes in your sleep. In fact, sleep is very sensitive to these factors. So don't think that a period of poor sleep means a return of your chronic sleep problems. If you sleep poorly for even a few nights, try to identify what may have caused this. But you needn't feel that you have 'lost control' of your sleep. Everyone experiences poor sleep occasionally.

Learn to cope with these occasional poor nights by adopting a positive attitude. After a poor night, rather than worrying and making things worse, tell yourself that the worst thing that can happen is that you will feel more sleepy the next day. Train yourself to be calm after a poor night's sleep and go about your day as you normally would. Learning good sleep habits is no different from learning any other skill. With practice, it becomes easier and automatic. Just as your old sleep habits were a part of your old way of life, the good sleep habits you have acquired will become a part of your new way of life.

You have already learned that the goal of this programme is not to eliminate poor sleep completely, but rather to help you feel more in control of your sleep habits, and to develop ways of better dealing with poor nights when they occur. Better sleep doesn't necessarily mean more sleep, but it does mean more efficient sleep. In addition, the programme helps you to change the way you react to poor sleep and to change certain attitudes which only serve to worsen sleep problems.

By reading all the booklets you should also have gained a better understanding of how insomnia 'works'. Keep in mind that sleep and insomnia are very easily influenced by your attitudes and your lifestyle in general.

If you notice that your sleep starts to worsen

Do not let these events overcome you. It is possible that at times, you will find it beneficial to apply the treatment programme again. You may need to re-read certain parts of your booklets, so keep them all in a safe place.

High risk situations

Because you have a long term condition, it is likely that your health will change over time, perhaps affecting your sleep. In addition, high levels of stress caused by changes in your condition can also disturb your sleep. At these times, always remember what you have learned in the programme and try not to worry. Generally, your sleep should return to normal when your condition settles down, and when the period of stress is over (or is at least less intense). Cope with the poor nights by keeping a positive attitude and using the procedures described in this programme. That way, you will feel more in control of your life and your sleep.

In conclusion

If you have reached this part of the programme, then you have already put in a lot of time and effort. Keep your booklets safe; you may need them again in the future.

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