

I-CAN SLEEP: Cognitive-Behavioural Therapy for Individuals with Insomnia and CANcer

Chapter 1

In this chapter you will:

- ◆ Learn about the self-management approach for insomnia
- ◆ Discover the art of setting realistic goals
- ◆ Learn the about the importance of self-monitoring your sleep

Goals for the chapter:

- 1) To grasp the basic principles of how to cope with sleep problems
- 2) To set realistic goals for what you can to get out of the program
- 3) To practice using the Daily Sleep Diary

OVERVIEW OF THE PROGRAM

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A common story:

Jane is a 56 year old woman who was diagnosed with breast cancer 2 years ago. She underwent surgery to remove the entire breast and had subsequent chemotherapy and radiation. Currently she takes Tamoxifen to prevent recurrence of the cancer. Before the cancer diagnosis, Jane had little trouble with sleep, despite often waking up during the night to use the washroom. Now she finds sleep to be very frustrating. She tosses and turns all night and wakes up exhausted and irritated. Jane tries to nap during the day in order to feel better but then finds that she can't sleep at night. Her sleeping problems have not gotten any better and she worries about how they might affect her family and her employment.

Does Jane's story sound familiar to you? If so, take a minute to respond to the following questions. Check off all the questions that are true for you.

- Do you...have pain that makes it hard for you to get a good night's sleep? _____
- ...wake up several times in the middle of the night and can't get back to sleep? _____
- ...spend hours lying in bed hoping that sleep will come? _____
- ...feel fatigued during the day? _____
- ...worry that your sleep problems might impact your cancer recovery? _____
- ...feel your cancer treatments are harder because of your disturbed sleep? _____
- Does it take a long time for you to fall asleep on most nights? _____
- Are you upset and frustrated by your sleep problems? _____
- Have you tried sleeping pills and found that they just don't work as well anymore? _____
- Are you ready to try something different to manage your sleep problems? _____

If you answered yes to any of these questions, then there is probably something in this program that will help you sleep better. Chances are you answered 'yes' to at least several of the questions.

When added to the burden of cancer and its treatment, insomnia can be very distressing. You might cancel plans with friends or family because you feel tired and run down most of the time. You may also have difficulties concentrating, focusing attention or staying alert. Emotionally, the problems you have with getting a good night's sleep may have contributed to more stress in your life. You may feel overwhelmed but you are not beyond help!

Who Should Benefit from this Program?

The program described in this manual is meant for people with cancer and sleep problems for whom long-term treatment with drugs is neither a realistic nor an acceptable option. People who begin this program are generally at the point where they feel little or no control over their sleep.

The people who will benefit most from this program are those who are willing and motivated to change the ways they think and act around sleep. This means a fair amount of work and commitment on your part. In addition to reading this manual, personal projects in the form of exercises will be assigned throughout the program.

The focus is on learning how to manage your sleep disturbances. It is possible, however, that as your sleep improves, you will find some improvement in your overall sense of well-being.

What Are You Doing to Cope with Your Sleep Disturbances Right Now?

It is not uncommon for people to have suffered from disturbed sleep for a long time before starting a program like this one. You have probably tried lots of things in the past to help your sleep problem whether they be homemade or physician-prescribed methods. What are some of the things you have tried to make your sleep better? Check any of the following that apply:

- | | |
|--|--|
| <input type="checkbox"/> Sleeping pills | <input type="checkbox"/> Warm milk |
| <input type="checkbox"/> Listening to music | <input type="checkbox"/> Avoiding caffeine |
| <input type="checkbox"/> Relaxation methods | <input type="checkbox"/> Napping |
| <input type="checkbox"/> Pain medications | <input type="checkbox"/> Changing mattresses |
| <input type="checkbox"/> Over-the-counter sleep aids | <input type="checkbox"/> Other drugs |

The next question is, 'how much success have you had with these methods?' If you are like most people, you probably had limited success with some of them, but found that they didn't work on a consistent basis in the long run. Actually, most of these approaches are really valid remedies for disturbed sleep. Throughout the program, we will be discussing how you can use them with the other important strategies you will be learning.

Don't worry if you are beginning this program with a history of treatment disappointments and frustrations - that can actually work to your advantage. For starters, you are probably ready to try something new and different from the other types of treatments you have tried in the past. Second, with the mere passage of time, you have no

doubt become an expert on your own sleep problems and you are probably aware of the many psychological and physical factors that can affect your sleep.

Is this Program Effective?

The answer is yes. The program described in this manual is called Cognitive-Behavioural Therapy for Insomnia (CBT-I) and is based on several different procedures that are used in the treatment of insomnia. Each of these strategies on its own has been proven to be helpful for people with chronic sleep problems but research has shown that combining several different treatment strategies is even more effective than relying on any one method. The reason is simple: different people respond to different types of techniques. By using a variety of approaches, the chances of helping more people are increased. What's more, complex sleeping problems usually require more than one strategy. For example, you may have difficulties falling asleep and you may also wake up repeatedly through the night. There are specific strategies you can use for coping with each of these problems. This is why it is important for you to try all the strategies in this manual and find the combination that works the best for you.

Unfortunately, however, this program will not help everyone who tries it. There is no miracle cure. In general, about 75% of people suffering from chronic insomnia will experience an improvement in their sleep by using this program. How much improvement? Again, you should be aware that most people who complete this program do not necessarily become perfect sleepers. Achieving 'perfect sleep' may not be an attainable goal. However, if you use the strategies and guidelines as outlined in this manual you should experience a noticeable improvement in your sleep. In light of this, you should try to set realistic goals for yourself and remember not to get discouraged from occasional bad nights. Try to focus on improving your sleep, rather than trying to become a 'perfect sleeper'. However, success with this program does require that you take action to modify your sleep behaviour and make a commitment to this program for the next six weeks.

By continuing to use the skills you learn with this program, the improvements you make in your sleep can be maintained indefinitely. Research has shown that improvements made during the course of a self-management program for insomnia are actually better than those obtained from the long-term use of sleeping pills. In fact, the prolonged use of sleeping pills often leads to an eventual worsening of sleep.

What are the Costs of this Program?

This program doesn't involve any drugs or special diets. Furthermore, there is no special equipment or sleep aids that you are expected to buy. Time, energy and motivation

are the major human costs involved. Reading this manual is only a small percentage of the work involved. It is vitally important that you do the personal projects and other exercises provided in this manual. This cannot be emphasized enough. Just remember the saying that "you only get out what you put into it". Also remember that old habits are sometimes hard to break and it takes time to develop new skills and new ways of looking at things.

Format of the Manual

In the remaining chapters, you will be introduced to the complete self-management approach for coping with insomnia. Each chapter will begin with an outline of the goals for the chapter and a discussion of the rationale for the specific strategies to be practiced. You will then be provided with detailed step-by-step instructions on how to apply the strategies to help you improve your sleep. The second and third chapters focus on behavioural strategies--things to do with your bedtime routine. This is so that you can begin right away learning the skills that will help you modify your sleeping pattern. Many people will experience some improvement in their sleep within the first couple of weeks if they follow these behavioural strategies carefully. The fourth chapter focuses on helping us learn how to relax our minds and bodies so that sleep will become easier to initiate and maintain. The fifth and sixth chapters focus on cognitive skills--ways to change the way you think and feel about sleep-related problems. In these chapters, you will explore the various ways that your thoughts can affect your sleeping behaviour, and how various exercises can help you put your mind at rest.

Throughout the program we will discuss ways in which you can maintain the progress you achieve as a result of the program. Tips on how to incorporate the skills you learn into your daily routine will be presented. Information on how to prevent relapses will be reviewed, as will strategies that can be used to deal with "bad nights" when they occur.

INTRODUCTION TO THE SELF-MANAGEMENT APPROACH

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The Self-Management Philosophy

The philosophy of self-management is a simple one. Although we can show you a variety of techniques and teach you new skills to cope with your insomnia, it is up to you to use them on a daily basis. Reading this manual and attending the classes are only about 10% of the work involved; the main part must be done on your own time. In a sense, you are both the therapist and client, and it is up to you to motivate yourself to complete the work. This manual contains several exercises and personal projects for you to try. Of course, it is completely up to you, how many and how often you practice them. The only encouragement we can provide you is to tell you that most people who try them consistently do manage to improve their sleep.

In this way, the program is designed to help you make improvements in your sleep. Using step-by-step instructions, we will guide you through a series of skills-training exercises and personal projects designed to help you cope with your sleep problem. *Coping* is probably a word you have heard before in conjunction with cancer. To some people, coping means 'just getting by' or surviving a problem. However, this way of thinking is an example of *passive* coping. This may be a reasonable strategy to use during the initial stages of your condition, but after awhile you realize that it is not making your problem any better. Unfortunately, using passive coping strategies during the initial phases of a sleep problem often results in several bad habits being formed. It's easy to fall into a routine of doing nothing about a sleep problem, especially when you are not aware of some of the more active coping strategies you could be using.

In this program, we emphasize a more *active* approach to coping. One way to think of the difference between active and passive coping is to think of the difference between moving forward and staying in one place. When you use passive coping strategies, you stay where you are; your condition may not be getting any worse, but it is also not getting any better. Active coping may involve a little more work on your part in the beginning, but the rewards will be long-term improvement.

One example of passive coping for chronic insomnia is taking sleeping pills. Initially, they may make your sleep better but with continued use the effects start to wear off and you have to take more and more of the drug to get the same effect (this is called developing a "tolerance" to the drug). Eventually, you reach a point when you're taking the maximum dosage allowed--or worse, more than the maximum safe dosage--just to keep your sleep

disturbance at a moderate level of severity.

Take a minute to look at Table 1.1 which compares the self-management approach to chronic insomnia to treatment with sleeping pills. We have already discussed some of the points in this table. There are pros and cons of both treatment approaches. For acute or 'transient' insomnia, sleeping pills do have an advantage over a self-management or psychological approach since they work very quickly and they do not require any real effort on your part. Side-effects and the risk of addiction are the most significant dangers involved in the short-term use of sleeping pills to treat insomnia.

Table 1.1

**Comparison of Self-Management of Chronic Insomnia vs.
Treatment with Sleeping Pills**

Self-Management	Sleeping Pills
Take control of own sleeping behaviour (ACTIVE treatment)	No control; you are dependent on the pills to do all the work (PASSIVE treatment)
More effective for long-term control of sleep disturbances	Some pills lose their effectiveness after 2-3 weeks of use at constant dosage; after this time, pharmacological effect of sleeping pills is reduced—psychological effect is increased
Doesn't lead to dependence	Can become dependent (i.e., physically dependent on the drug so that your body constantly needs the drug)
No side-effects	Side-effects: daytime drowsiness, alertness and performance at psychomotor tasks (e.g., driving) impaired, memory difficulties, 'hangover'
No health risks involved	Health risks: risk to fetus if taken during pregnancy; risk of overdose if combined with alcohol or other drugs
Under right circumstances, will increase slow-wave and REM sleep	Most sleeping pills reduce slow-wave sleep and REM sleep
No risk of tolerance; actually, opposite generally occurs: your sleep gets better with continued application	Tolerance (i.e. reduced effectiveness, requiring a change in dosage to achieve the same effect) builds with prolonged use
Low risk of rebound insomnia effects	Rebound insomnia can occur with sudden discontinuation of pills
Free	Expensive (\$\$)

For the long-term treatment of chronic insomnia, the reality is that sleeping pills do more harm than good. Sleeping pills were never designed to be taken for months or years at a time and their prolonged use typically results in a continuing sleep problem rather than making it better.

What Will You Do in the Next Five Weeks?

Over the next five weeks, you will be introduced to many ways of coping with your insomnia besides the use of drugs. In essence, you are going to learn how to make use of the most powerful resource at your disposal: **yourself**. Different techniques will be presented with easy step-by-step instructions that will help you to achieve more consistent and satisfying sleep.

The Art of Setting Goals and Making Realistic Expectations

Goal-setting should reflect not only what you would like to get out of the program, but how you would like to take permanent control of your sleep. Although your goals may be expressed in numerical terms such as a '25% decrease in the time it takes to fall asleep', the underlying motivation should be one of lifestyle change. Quality sleep should be thought of as one component in an overall healthy lifestyle along with maintaining a proper diet, reducing stress, etc. Therefore, before you set your goals, you have to make a decision as to how much of a lifestyle change you are prepared to make. This is by no means a small decision. Remember that you spend almost one-third of your life in bed, so you are making a commitment to alter a substantial portion of your life. If you are ready to make this decision, then the rest of the program should proceed smoothly.

GUIDELINES FOR SETTING GOALS

Setting SMART goals is a skill that involves both creativity and logic.

CRITERIA

A goal should be specific (S).



SOMETHING TO ASK YOURSELF

Am I precise about what I exactly want to accomplish?

A goal should be measureable (M).



How will I determine if I have met my goal?

A goal should be achievable (A).



Is my goal something that I can do?

A goal should be realistic (R).



Is my goal sensible given my limitations or time-frame?

A goal should be time limited (T).



How long do I plan to be working on this specific goal?

At the end of this chapter, you will be asked to define your goals in more specific terms. In accordance with the first criterion above, your goals will be expressed in terms of actual numerical changes that can be measured by the sleep diary. Before getting into the details of your specific goals for sleeping better, take a minute to reflect on what your overall goals for this program are. Think about them using the five criteria for goal-setting.

If you are having a hard time coming up with some goals, you can try the following exercise. Long before you started this program, you probably had some ambitions for sleeping better. Maybe these were expressed as "I wish" statements that you said to yourself (e.g., "I wish I could sleep through the night without waking up so often"). Think back on some of your ambitions and wish statements and then complete the following "I wish" sentences with a statement concerning your sleep:

I wish _____.

I wish _____.

I wish _____.

Now, look at your "I wish" statements. Do they meet the goal-setting criteria? If possible, modify and rewrite the goals that don't meet all the criteria. Consider making a goal smaller as a means of making it more realistic. For one, most people can't fall asleep within 5 minutes. Rather, if it now takes you an hour to fall asleep, consider setting a goal of being able to fall asleep within 30 minutes.

Having realistic goals is very important. One of the reasons many people fail at making lifestyle changes is that they set goals for themselves that are unrealistic or in some cases completely unattainable. How many times have you made a New Year's resolution and failed to stick with it? It is probably because the resolution was made quickly with little forethought into the magnitude of the change and the actions necessary to carrying it through. Consider the case of someone trying to quit smoking. Deciding to go 'cold turkey' at 12:01 a.m. on January 1 is probably an unrealistic goal when it comes to quitting smoking. Many people who try to quit smoking in this manner don't consider how big a lifestyle change they are pledging to make. As a result, the rate of relapse for smokers is around 90%.

An important thing to keep in mind is that there is nothing wrong with occasional relapses when trying to make permanent behaviour changes. Throughout the program, we will talk about relapses in more detail and ways of dealing with them without getting discouraged. For now you should consider that coping with relapses is a little easier when your goals are realistic.

The Importance of Self-Monitoring

An integral part of this program involves monitoring your progress via the Daily Sleep Diary. This is a brief measure that you will complete every morning. On the form, you will record information about your previous night's sleep, such as how long it took you to fall asleep and the number of times you woke up during the night (“awakenings”). Careful self-monitoring of your sleep is a necessary step for determining your success in this program since it provides the primary means for evaluating changes in your sleep that occur over the course of the program.

Some other important reasons for using the Daily Sleep Diary are:

- ◆ You can document the type and severity of your sleep problems. You may be able to detect a specific pattern to your sleep problem that you were not previously aware of. Part of the treatment can be focused on changing or interrupting this pattern.
- ◆ It can be used to explore how your daytime activities, thoughts and feelings are related to your sleep.
- ◆ The diary can actually be therapeutic. For example, some people find that after self-monitoring their sleep for a period, they discover that their sleep disturbances were not as severe as they originally believed and that they actually have several nights of good sleep in the course of the week. This can reduce some of the anxiety around their sleep problem, which is helpful because anxiety about sleep problems can sometimes be as harmful as the loss of sleep itself.

Step-by-Step Instructions for Completing the Daily Sleep Diary

Step 1: All items should be completed approximately 30 minutes after rising in the morning. This is important since your memory of the previous night's events fades quickly. It may be unrealistic to expect that you feel completely alert first thing in the morning. Most people will experience some sleep inertia when they first wake up that may last anywhere from 15-60 minutes. **Sleep inertia** is the feeling of being mentally foggy and physically fatigued and represents your brain and body's transition from being asleep to being awake. This feeling typically lessens as you begin to move about and get started with your day. Try to wait until your sleep inertia has passed before completing your sleep diary.

Step 2: The sleep measures Time in Bed (TIB), Total Sleep Time (TST), and Sleep Efficiency (SE) are easily calculated from the information recorded on the sleep diary.

Time in Bed = Time got out of Bed - Time to Bed

e.g., I got out of bed at 8:00am this morning, and went to bed at 11:00pm last night. 8:00 a.m. - 11:00 p.m. = **9 hours** spent in bed (Time in Bed)

* Note: "Time got out of Bed" may be different from the time when you wake up. For example, you may wake up at 5:00 a.m. but lie in bed for another 2 hours trying to get back to sleep until you finally get out of bed at 7:00 a.m. In this case, you would record 7:00 a.m. as your time got out of bed.

Total Sleep Time = estimated number of hours actually spent sleeping

e.g., I spent 9 hours in bed but didn't fall asleep until 11:30pm, woke up at 2:00am and fell back to sleep around 3:30am, woke up at 5:00am then got out of bed at 7:00am.

9.0 hours in bed
- 0.5 hrs awake(11:00pm-11:30pm)
- 1.5 hrs awake(2:00am-3:30am)
- 2.0 hrs awake(5:00am-7:00am)
= **5.0** hours total sleep time

From Time in Bed and Total Sleep Time, we can calculate the **Sleep Efficiency** ratio:

Sleep Efficiency (%) = Total Sleep Time / Time in Bed

e.g., My total sleep time was 5.0 hours but my time spent in bed was 9.0 hours. $5/9 = 55.5\%$

This number represents the percentage of time you spend in bed actually sleeping. Sleep efficiency is one of the best indicators of a person's sleep behaviour and therefore it will be used as one of the main indicators for monitoring your progress throughout the program. *Generally, as your sleep improves your sleep efficiency ratio will increase.* Just to give you an idea, the average sleep efficiency ratio for healthy adults (i.e., people without insomnia) is between 85% and 95%. A person with a sleep efficiency ratio above 90% is considered to have very good sleep. The cut-off value for distinguishing 'good' sleepers from people with insomnia is **85%**.

Step 3: Another indicator of how well a person is sleeping is **Sleep Onset Latency (SOL)**. Put simply, this figure represents how long it takes a person to fall asleep for the first time. The average Sleep Onset Latency for healthy adults with no sleep problems is between 10 and 20 minutes. However this value can range considerably. The cut-off value for distinguishing good sleepers from poor sleepers is **30 minutes**. Someone who takes longer than 30 minutes to fall asleep at least three or more times per week is considered to have a problem falling sleep.

Step 4: Another indicator that will be used to monitor your progress is the **number of awakenings** you have during the night (NWAK). With these, we ask that you distinguish between the total number of times you wake up during the night and the number of times you wake up and have difficulty getting back to sleep. In other words, how many awakenings do you have during the night that are actually contributing to your sleep problem? You will learn in the next chapter that it is perfectly normal for someone to wake up during the night. They only have a problem if they can't get back to sleep.

Step 5: Sleep efficiency and number of awakenings tell you how much sleep you are getting. They tell nothing about the **quality** of your sleep, that is, whether you feel your sleep was refreshing and satisfying. The amount of sleep you get is not always directly related to the quality of your sleep. For example, some research with people who have cancer has shown that many of them may actually sleep as many hours per night as people without cancer, but in fragmented chunks that doesn't feel very restful.

In order to assess this aspect of your sleep, you are asked to make a rating of the quality of your sleep each morning. When making these ratings, it is important that you judge each night's sleep on the basis of the best and worst nights you have had since your sleep problem started. For example, if you feel your previous night's sleep was one of the best you have had in a long time, you should give it a rating of 3 or 4 on the scale. The same is true of the rating for how refreshed the previous night's sleep was to you.

Step 6: Once you have a grasp of what the different items on the diary are meant to measure, you should begin completing the Daily Sleep Diary form every morning from now until the end of the program. You are welcome to continue using the Daily Sleep Diary even after you are finished with the program; just make enough photocopies of the original blank form to keep you going.

Goal-Setting Form for Treatment

Once you have the basics on how to complete the daily sleep diary, you are ready to define your goals for the program. To do this, complete the goal-setting form below. First, indicate your current sleep pattern by averaging the first week of sleep diary recordings. Then, indicate your desired sleep pattern.

Current Sleep Pattern (before treatment)

- A. Based on a typical night's sleep (i.e., average for past week),
how long does it take you to fall asleep after turning the lights off? _____minutes
- B. How many times do you wake up in the middle of the night? _____times
- C. On average, how many hours can you sleep in a row before waking up? _____hours
- D. On a typical night, how many hours of sleep do you get in total? _____hours
- E. Other concerns about sleep (specify):
-

Desired Sleep Pattern (after completing treatment)

- A. After turning the lights off, I would like to fall asleep in . . . _____minutes
- B. If I still wake up in the middle of the night after treatment,
I would like to wake up no more than . . . _____times
- C. I want to be able to sleep this many hours in a row before waking up. . . _____hours
- D. I need this much sleep to feel rested and function well
during the day and would like to achieve this sleep duration: _____hours
- E. Other goals for sleeping better (specify):
-

Required Calculations from your Weekly Sleep Diary

In order to formulate an individualized sleep program, we need you to calculate the following from your weekly sleep diary: **nightly average time in bed; nightly average time spent sleeping; and sleep efficiency.** Please complete the shaded areas in the table below and bring these calculations to the second week of class.

	Time in bed	Time Sleeping
Example	10:30pm to 7:30am = 9hrs <i>(Take these numbers from questions 1 and 2 of your sleep diary)</i>	6hrs <i>(Take this number from question 6 of your sleep diary)</i>
Day 1		
Day 2		
Day 3		
Day 4		
Day 5		
Day 6		
Day 7		
Weekly Total <i>(Add all of the days together)</i>		
Nightly Average <i>(Divide the Weekly Total by 7)</i>		
Sleep Efficiency <i>(The percentage of time sleeping divided by the spent in bed)</i>	Nightly average time spent sleeping/Nightly average time in bed*100	6/9*100=67%