NHS
Cumbria, Northumberland, Tyne and Wear
NHS Foundation Trust

Sleep after Traumatic Brain Injury

With YOU in mind

Contents

Who is this booklet for?

This booklet is for people who have had a traumatic brain injury (TBI) and would like to learn more about sleep and what can be done to improve their sleep.

If you have problems with your sleep and **do not** have a traumatic brain injury, please see our 'Sleeping problems – self help guide' at www.cntw.nhs.uk/selfhelp

"I toss and turn for hours on end. No matter what I do, I just can't seem to get off to sleep".

"I'm very restless through the night, often waking and not able to get back to sleep".

"I wake up two or three hours before I need to get up and just lie there trying to drop back off to sleep".

"I never feel like I've had a proper night's sleep. I sleep very lightly and seem to drift in and out of sleep".

"I have no trouble sleeping. In fact I sleep way too much but I still feel really tired".

These are all comments made by people who have different types of sleep problem.

This booklet will be able to help you understand your sleep problem and learn some simple ways to sleep better.

There is a lot of information in this booklet, and it may be helpful to read it several times, or to read it a bit at a time, to get the most from it.

Understanding sleep and sleeping patterns

Sleep problems are very common and are often referred to as insomnia. One study in America found that only 5% of adults reported never having trouble sleeping.

Another recent study found that as many as 30% of the adult population are affected by sleep problems. Sleep difficulties are particularly common in women, children and those over 65. In fact, roughly half of the elderly population complains of insomnia. Therefore to have trouble sleeping at some point in your life is quite normal.

A recent study found that people with a traumatic brain injury (TBI) are more likely to have problems with their sleep compared to the general population. The study found that around two thirds of people with a traumatic brain injury complain of daytime sleepiness. This can often be caused by difficulties falling asleep, staying asleep or awakening too early.

As well as daytime sleepiness, there are other sleep problems that can be experienced by people with a brain injury:

- Feeling restless, or finding it hard to keep your legs still (also called Restless Leg Syndrome)
- Disordered breathing during sleep (also called Sleep Apnoea)
- Unusual behavior while you are asleep (also called Parasomnias)
- Changes to the times when you feel awake or sleepy (Sleep Rhythm disorders)
- Sleeping more than usual (also called Hypersomnia)

Changes to sleep following a traumatic brain injury

There are lots of reasons why someone might have changes to their sleep following a TBI. Some of the following may apply to you:

- **The part of your brain affected**
  You may have heard of the phrase ‘Circadian rhythms’. This is the regular pattern of changes that occur in your body over a 24 hour period including your brain activity, hormones, digestion and other functions.

  For example, most people tend to feel sleepy in the afternoon, after lunch. Specific areas of the brain organize these rhythms and depending on the part of the brain that was affected as part of your brain injury, there may have been disruption or damage to these systems that are involved in sleep and circadian rhythms.

- **Changes to routine**
  You may find that following your brain injury your average week looks very different, and your bedtimes and time of getting up have changed.

- **Recovery**
  You may find that in the early stages of your recovery, you need to sleep more as part of the healing process.

- **Pain**
  Pain can make it difficult to feel comfortable and to relax. People who are in pain may tend to wake up more during the night too.

- **Changes to activity levels**
  Daytime activity is important for sleep and after a brain injury you may find that you have reduced mobility, or perhaps there are other reasons why it is harder for you to exercise. If your activity level during the day has dropped compared to how it used to be, it might be affecting your sleep.

- **Changes to mood**
  It is not uncommon for people with a TBI to struggle with their mood. This may take the form of worrying more (anxiety), or feeling low, or even depressed. Problems with mood and worrying can both interfere with our sleep. Sometimes, nightmares can interrupt sleep too.

- **Medication**
  Some medications can impact on your sleep in different ways, for example making it harder to fall asleep, or making you feel drowsy even when you are well rested.

Summary

Sleep problems are very common in the general population and more so in people with a TBI. This is because the TBI can cause physical, psychological and social changes for the person, all of which can make it more difficult to get a good night's sleep.

Important information about sleep

Why is sleep important?

There are plenty of reasons why you should focus on your sleep as part of your rehabilitation and general wellbeing. Here are a few reasons for you to think about:

- We all know what it is like to feel sleep deprived. It is not pleasant and can affect your quality of life. For some people, they may feel irritable or more short-tempered. For others, it may have a greater impact on their mood and they may feel low, or worry more.

- Many people find that they have some changes to their thinking skills following a brain injury. The most common of these are difficulties with attention and memory. Poor sleep will likely make these difficulties worse and make it harder for you to concentrate and remember things.

- Fatigue is a very common difficulty following a traumatic brain injury. Reduced energy levels following poor sleep may make it harder for you to manage your fatigue.

- Some people find that other symptoms from their injury can be made worse by poor sleep – such as dizziness or pain.

- Poor sleep is also associated with a number of chronic health conditions, such as obesity, diabetes, heart disease and high blood pressure. Looking after your sleep can help reduce your risk of developing these conditions and can help maintain a strong immune system.

How much sleep do we need?

You may have heard that we all need between seven and eight hours of sleep every night. This is not necessarily true, as everyone is different and people can vary greatly in their need for sleep. Some people may feel fully refreshed after as a little as six hours sleep, whereas others might prefer to have closer to ten hours per night.

The amount of sleep a person needs varies throughout their life. For example, a newborn baby spends 14 to 17 hours sleeping per day. As children grow older they require less sleep, possibly 11-14 hours as a toddler, and maybe 8 to 10 hours as a teenager. Older adults, aged 65 and over, may get slightly less sleep, but sleep requirements do not change into older age.

Not only does the need for sleep vary from person to person, and with age, it also varies depending on level of activity. For example, if someone is no longer at work or has experienced a reduction in their level of activity, they may be less active and therefore require less sleep.

On the other hand, if they have a busy lifestyle and are constantly on the go, then they may require a bit more sleep. It is important to work out what is the right amount of sleep for you.

What are the signs that I might not be getting the right amount of sleep?

You may already know what the right amount of sleep is for you. However, there are some signs that you might not be having enough sleep, such as:

- Falling asleep when you didn't mean to
- Struggling to get things done
- Feeling exhausted through the day
- Waking up not feeling refreshed

These signs may indicate you might need more sleep and that it might be time to start making some changes.

There are also signs that you might be aiming for more sleep than you need. These can include:

- Taking a long time to fall asleep
- Waking through the night and struggling to get back to sleep
- Waking earlier than planned (before your alarm goes off)

The above can be signs that you are trying to get more sleep than you need. Have a think about your current activity levels, pre-injury sleep requirements and consider whether going to bed later or getting up earlier might be useful for you.

Sometimes, following a brain injury, some people find that they sleep too much. Signs to look for might be:

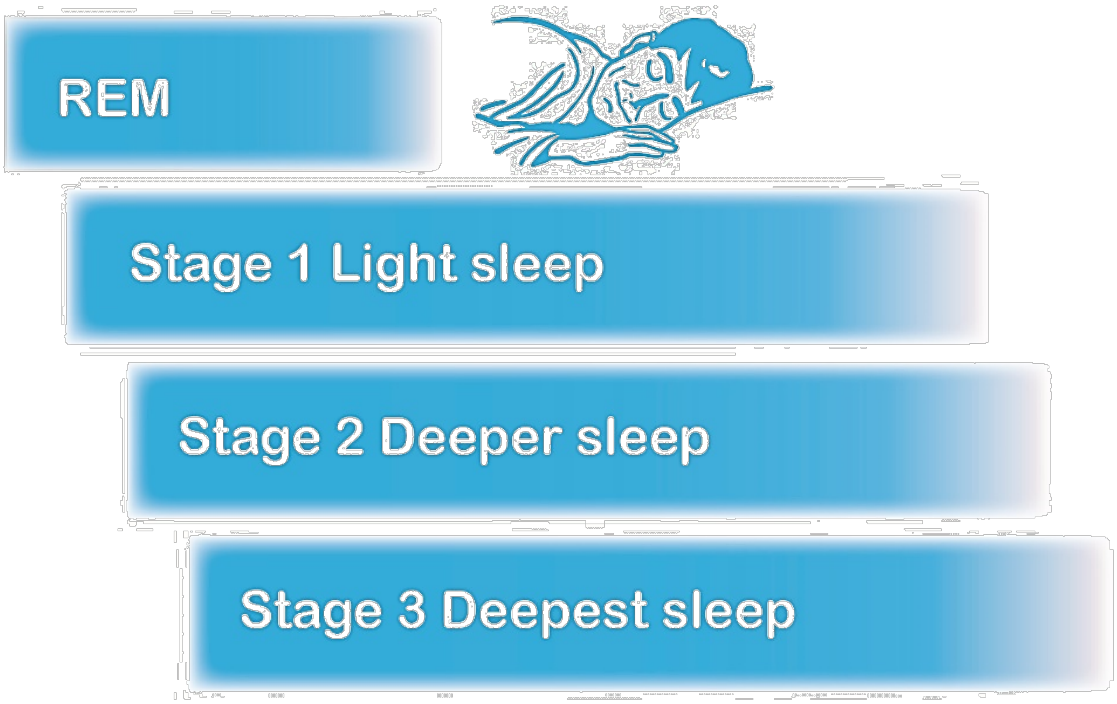
- An inability to stay awake even when you are interested
- Feeling lethargic, or slowed down
- Sleeping for much longer in a 24 hour period than pre-injury.

The rest of the leaflet is not aimed at people who sleep too much, so if you think the above describes your current sleeping pattern, we recommend that you speak to your GP who may wish to refer on to a specialist such as a neurologist.

Are there different sorts of sleep?

Sleep is not like a light bulb which is either on or off, but has different stages, varying from light to deep sleep. At least four different stages of sleep have been identified. Broadly, sleep is divided into what is called Rapid Eye Movement (REM) and non-REM (NREM) sleep.

REM sleep occurs several times during the night and is where most dreaming is thought to take place. Non-REM sleep is divided into three stages, each stage being a bit deeper, almost like a staircase of sleep.



During the night whilst asleep, people go up and down this staircase many times and in fact, most of us wake up several times.

On a typical night an adult who sleeps well will spend about 25% in REM sleep, 5% in Stage 1, 45% in Stage 2, and 25% in stage 3.

As with the amount of sleep we need, the sort of sleep we have changes as we get older. Sleep in older people tends to be lighter and more broken, with more frequent waking.

For a typical person aged 70, deep sleep takes up less than 10% of the night's sleep. Therefore, an older person may report waking more times throughout the night.

In summary, sleep in older people does tend to be shorter, more restless and more easily disturbed, but it should still be refreshing.

Summary

Sleep is vital to many aspects of our functioning. It is therefore important to pay attention to our sleep because of the consequences of not getting enough sleep, which can impact our physical and mental wellbeing.

The amount of sleep needed per person varies, and your requirements may have changed following TBI.

Improving sleep

Good sleep habits

Building healthy sleep habits is key to improving and maintain good sleep. The following are always useful to consider when you are not sleeping well:

- **Routine** - A consistent routine is the cornerstone to good sleep. Try to get a consistent timetable so that your brain and body knows what is coming. Going to bed and getting up at roughly the same time every day is much better than trying to catch up on lost sleep, or going to bed early or napping at odd times during the day. In particular, getting up at the same time in the morning is helpful. This should be maintained even at weekends.

- **Pre-sleep routine** - Try to use the hour and a half before going to bed to unwind and prepare for sleep. Dim the lights, listen to some calming music. Again, it is helpful to get into a pattern so that your body and brain know what to expect.

- **Avoid Naps** - Unless naps have been specifically recommended as part of your rehabilitation or fatigue management programme, naps are unlikely to be helpful in the long run. Although naps might seem like a good way to catch up on sleep, it will mean that you are less likely to sleep well on the next night. Sleep is a biological need that builds over time, just like hunger - so having a nap is the equivalent of having a snack before your main meal. Be aware that you can still have regular rests during the day, but that they should not be spent in bed, and sleep itself should be avoided.

- **Bed is for sleep**
  - Bed (and bedroom) is for sleep - make sure your bed is associated with sleep. For example, don't watch TV, eat, play on your phone, answer emails or work in bed. The only exception to this is sex which can help with sleep.

  - Only go to bed when you are feeling tired (yawning is a good sign).
  - Spending time in bed feeling tense, clock watching or attempting to force yourself to fall asleep is unlikely to be helpful. Instead, if you find that you have not fallen asleep within 20-30 minutes, get up and go to another room. Listen to relaxing music, read a calming book or sit quietly until you feel sleepy again. It is important to avoid the use of electronic screens (iPad, mobile phone, television) when doing this. When you feel sleepy (again, look for yawning), return to bed.
  - The same is true if you wake during the night and are unable to fall asleep within 20-30 minutes - get up, doing something quiet and relaxing and then return to bed when feeling sleepy.

- **Exercise** - When your body is tired, your mind will follow. Explore opportunities to gradually increase your daytime activity and exercise. For best impact on sleep, exercise outdoors and in the mornings. Avoid exercising close to bedtime as the increase heart rate can make it harder for your body to relax and fall asleep. You may want to consider accessing a gym or joining a local exercise group to motivate you.

- **Electronic devices** - Blue light emitting from these screens (TVs, gaming machines, tablets and smartphones) stimulates the brain and interrupts melatonin release – the hormone you need to sleep. Therefore it is best to avoid using electronic devices in the hour before bedtime. Some devices have settings that reduce the blue light, which can help - although the gaming, reading emails, texting etc are all stimulating activities which will make it harder to fall asleep. For best results, you could try turning off your devices in the early evening.

- **Time spent outside** - Daylight promotes the production of melatonin, the hormone we need for sleep. Try to spend some time outdoors every day, preferably in the morning.

Psychological factors

It's important to think about your mind as well as your body when working on your sleep. Some of your thinking habits may also be impacting on your chances of a good night's sleep.

- **Try not to worry too much about your sleep.** Although sleep is important, fixating on the number of hours, or how tired you feel can be counterproductive. The more stressed you are about sleep, the less likely you are to fall asleep. Try to remember that the amount of sleep we get is an individual thing and can change throughout our life.

- **Switching off**. Some people can find it hard to 'switch off' and that when they go to bed, they find it hard to relax as they are bothered by thoughts which can make it hard to fall asleep. The following can be useful for busy minds:
  - Mindfulness meditation is a way of distancing yourself from your thoughts and engaging with the present. You can learn to practise mindfulness through books, apps or even classes.
  - Guided imagery can be useful as a means of relaxing. It involves imagining a calming scene, and making it as vivid as possible. Popular images include beach or forest scenes. Guidance on can be found online to help you develop this skill. Generally, imagining anything pleasant, allowing your brain to be creative and adding lots of details helps your mind relax. What would you do if you won the lottery? What would your ideal holiday be?
  - Progressive muscle relaxation is a great way to relax and helps the body unwind. Instructions can also be found online
  - If you find that your mind goes over things you need to remember the next day, keep a notepad and pen by your

bed. That way you can quickly write down what you need to remember- leaving your mind free to relax!
  - You can find audio recordings of some of the above relaxation techniques at www.cntw.nhs.uk/relaxation

- **Mental Health** - It is normal to experience changes to your mood when a significant life event happens. Having a brain injury can sometimes cause people to experience increased worry (anxiety) or lower mood (depression). If you feel that you are experiencing worry or low mood that interferes with your daily functioning, consider speaking to your GP or healthcare professional about treatment options that are available to you. Successful treatment of either of these conditions will likely result in improvements to your sleep.

Environment

Your environment can affect how well you sleep and if you find yourself waking through the night, consider what you might be able to change to improve your odds of having a good night's sleep:

  - Noise. Soft, silicone earplugs may help block out noise. Some people find a small amount of white noise or the sound of a fan helps too. Some phone apps can generate background noise to help you sleep.
  - Light. An eye-mask or blackout blinds may help, especially in summer when sunset is later and sunrise is earlier.
  - Electronics. Electronic devices such as laptops, mobile phones and tablets can disturb our sleep in a number of ways. They can emit light which interrupts one of the hormones we need to sleep (melatonin). They are also stimulating and distracting which can stop us fully relaxing. Consider moving them to a different room if possible, or deactivating them at night.

- Mattress and pillows. It may be time for a new mattress and pillows if you cannot get comfy with your current ones. Try several out if possible. Choose ones that are best for your back and neck.
- Temperature. Bedrooms should ideally be a few degrees cooler than the rest of the house to encourage good sleep. Consider changing your bedding with the seasons (consider the 'tog' of your duvet) to avoid feeling too hot or cold. Wearing socks, electric blankets, hot water bottles can all be used if you are too cold.
- Your partner. Your partner may have sleep habits of their own that impact on your sleep, such as being restless or snoring. Consider using earplugs or using a spare bedroom.

Food, drink and drugs

Good sleep depends on many factors, including what we eat and drink as they can all affect the balance of systems in our body. Consider making changes to some of the following areas:

- **Caffeine**. Caffeine is a stimulant which promotes alertness and helps people feel more awake. It also reduces the quality of sleep and makes it more difficult to fall asleep. It should therefore be avoided in the evenings and if you are having trouble with your sleep then it is probably best to consider avoiding caffeinated drinks after lunchtime.
  - Caffeine is found in lots of drinks, including coffee, tea, energy drinks, hot chocolate and cola. Chocolate also contains caffeine. Caffeine-free versions of tea and coffee are available in most supermarkets.
  - Caffeine affects everyone differently and some people are more tolerant to the stimulating effects of caffeine than others. You may find that as you get older, you

feel the effects more. You may find that it affects you more following your brain injury.
  - The amount of caffeine in your body halves every 4 hours. So if you have a coffee at 6pm, there will still be half as much caffeine in your system at 10pm, when you might be going to bed!

- **Cigarettes** - Smoking last thing at night can keep you awake as nicotine is also a stimulant. If you do smoke, try to have your last cigarette at least four hours before bedtime. Nicotine patches or chewing gum can also affect sleep. Quitting smoking and nicotine withdrawal can make sleep difficult in the short term, but in the longer term your sleep will improve.

- **Medicines and other drugs** - Following your brain injury, you may have been prescribed medications for some of the symptoms, such as fatigue or low motivation (e.g. Amantadine). Some of these drugs can affect sleep because they are stimulants. Other medications can affect how deeply you sleep, such as certain drugs for asthma and for migraine. You may find it useful to speak to your GP to see if any of your new medications are known to affect sleep, and if you can adjust the timing of your medications to reduce the impact on your sleep.

- **Sleeping tablets** - These include benzodiazepines (such as diazepam and lorazepam, also known as Valium and Ativan) as well as the 'Z' drugs (Zopiclone, Zolpidem). Whilst they can help in the short term, they often cause sleep problems in the longer term as they interfere with the quality of sleep and can alter sleep patterns. Sleeping tablets should only be taken for very short periods as they can be addictive and habit-forming. Sometimes people are also prescribed anti-histamines (Nytol, Sominex) for

help with sleep, however these have various side effects and people who take them can still feel drowsy in the morning. They also have been found to be less effective within a few days of taking them. You can discuss medications for sleep with your GP.

- **Alcohol** - Although alcohol may make you feel sleepy and help you fall asleep initially, you will be more likely to wake during the night and the quality of your sleep will be affected. It is best to avoid drinking alcohol close to bedtime if you are having sleep problems. Alcohol-free versions of wine, beer and cider are available in most supermarkets. There are also other reasons you may wish to avoid alcohol post-TBI, for example the risk of falls and impact on your thinking skills.

- **Fatigue Medication** - You may also be prescribed medication for fatigue, which can sometimes impact on your sleep as well. If you feel that a medication you are prescribed for fatigue is interfering with your sleep, discuss this with your prescribing clinician to see if the timing or dose can be adjusted to minimise the impact on your sleep.

Other things to remember

- These simple guidelines really can improve your sleep but they take time, especially if you are re-building a regular routine. Please be patient, your hard work will pay off although it can take many weeks to develop new sleep habits.
- Before your brain injury, you may have never thought about your sleep much, or perhaps you have had sleep problems before. Either way, these recommendations are useful for people with and without brain injuries.

- Your sleep will never be perfect. No-one sleeps exactly the right amount every night and awakes feeling 100% refreshed every day. There will always be some factors outside your control which may interrupt your sleep from time to time. This could be changes to your mood, physical health, stress, etc. Although your sleep will likely change at these times, applying the above recommendations will help prevent you falling into bad habits.
- Although sleep is important, and no-one likes feeling tired, try not to worry too much about your sleep. Obsessively monitoring your sleep is unlikely to help you relax at night and may even be counter-productive. Your body is good at recovering from poor sleep and you will sleep deeper after a period of disturbed sleep.
- These techniques have been proven to help many people but take time and hard work. If you feel you are making little progress or the problem is getting worse then speak to your GP.

Improving sleep

Our sleep is affected by lots of different factors. When trying for better sleep it is best to aim for a regular routine, an appropriate sleeping environment, a calm mind as well as avoiding medications or substances that impact on your sleep. You may need to make changes to some or all of these areas to maximise your sleep.

Good luck and sleep well.

Useful organisations

National Sleep Helpline

If you'd like to talk about your sleep, you can call between 7pm and 9pm, Sunday to Thursday
Tel: 03303 530 541 https://thesleepcharity.org.uk/

British Association for Counselling and Psychotherapy

Tel: 01455 883 300 (Monday – Friday, 9am - 5pm)
www.bacp.co.uk
Offers an information service providing contacts for counselling in England and Wales.

Healthwatch

www.healthwatch.co.uk
Healthwatch England is the independent consumer champion for health and social care in England. Working with local Healthwatch networks, we ensure that the voices of consumers and those who use services reach the ears of the decision makers.

Mental Health Matters

Tel: 0191 516 3500
www.mentalhealthmatters.com
A national organisation which provides support and information on employment, housing, community support and psychological services.

Mind Infoline

Tel: 0300 123 3393
www.mind.org.uk
Provides information on a range of topics including types of mental distress, where to get help, drug and alternative treatments and advocacy. Also provides details of help and support for people in their own area.
Helpline available Mon - Fri, 9am - 6pm.

NHS website
www.nhs.uk
Information about conditions, treatments, local services and healthy lives.

Useful books

The Sleep Book: How to Sleep Well Every Night
Guy Meadows
Orion 2014
A five-week plan based on principles of mindfulness and Acceptance and Commitment Therapy (ACT)

Overcoming Insomnia and Sleep Problems
Colin A. Espie
Robinson London 2006
A self help guide using cognitive behavioural techniques.

Why We Sleep: Unlocking the Power of Sleep and Dreams
Matthew Walker
Penguin 2018
An in-depth look at the past twenty years of research to find out why sleep matters (Note: this is not a self-help book)

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