

# **Scottish Muscle Network**

Patient information leaflet

## **The importance of sleep**

## Introduction

Alongside a healthy, balanced, and varied diet and an active lifestyle, sleep is one of the most important factors in developing and maintaining wellness throughout our life. In recent years the healthcare community has become increasingly aware of the importance of good quality sleep on health and wellbeing and why a poor sleep pattern is not good for anyone.

Sleep is so important to our health that it is being studied globally in great depth as poor sleep is linked to dementia, Type 2 diabetes, hormonal imbalances, and poor weight control to name but a few. This leaflet gives an overview of the factors that affect sleep and potential solutions to help you get a better night's sleep. If you want to read more about this topic, Professor Matthew Walker has written an excellent book on this subject, "Why we sleep".

## What can affect our sleep?

The most common causes of poor sleep are:

- stress and anxiety (areas of our life at work, home, or school that we feel are challenging and cause us to give undue amounts of time to worry in our thoughts)
- a busy lifestyle (not having time to switch off and think about our own personal needs). Being overly busy and rushing from one thing to the next generally means we are not taking time out to rest and digest after meals or enjoy time with loved ones. Whilst many of us go through periods of this in our life, it is when the balance shifts, and we are doing this more often, that issues can develop with our health
- a poor bedtime routine (spending too much time in front of the TV, scrolling on social media or gaming for example – not having a consistent bedtime)
- lack of daylight and not getting out of doors on a regular basis
- alcohol or caffeinated drinks late in the day

There are many other areas not listed that can contribute to our lack of sleep and within this series of leaflets you will come across this exercise of "tuning in to ourselves". Giving thought to reasons why our sleep pattern may be challenging, may help identify the areas that we can bring our attention to, to help improve our sleep quality. A poor night's sleep can make your neuromuscular disorder symptoms worse. Making time to improve the quality of your sleep will help you feel better through the day and improve your overall health span i.e. the number of healthy years we have in our life.

## Why do we need sleep?

In days gone by, we believed we needed sleep so our bodies could rest but in fact, our bodies are very busy during sleep. In recent years, scientists have begun to find out more about the biological processes that happen when we sleep. For example, in mice, the brain's ability to repair itself doubles during the sleep cycle and we are aware of a similar increase in humans.

The brain has its own system of removing waste products through the glial cells. The waste management system, the glymphatic system, is a network of vessels that carry fresh fluid into the brain, mix the fresh fluid with the waste-filled fluid that surrounds the brain cells, and then flush the mix out of the brain, into the blood stream, to be disposed of. It will come as no surprise to learn that this process happens when we sleep. Through the day, our brain is too busy to allow the garbage to be taken out, so this happens through the night. If we get poor sleep night after night, the waste products build in our brain causing our thinking to become slow and "foggy", hence the term brain fog!

Scientists also know that many of the body's functions involved in repairing bone, muscle and vital organs happen when we are experiencing Rapid Eye Movement Sleep (REM sleep).

REM sleep is thought to be associated with growth in babies and infants as approximately half of sleep in newborns is REM sleep. REM sleep lessens as we get older and coincides with the ageing process. Every decade we experience less REM sleep and the amount of NON-REM (NREM) sleep increases.

As well as being good for our physical health, sleep is also necessary for our emotional health. Our physical and emotional health are one and the same. If our emotional wellbeing is poor, then our physical health can also deteriorate as we become less motivated to be active or socialise. If our physical health is poor, then lack of energy, can cause low mood, anxiety, or depression.

Whilst we all experience sleep problems during various stages of our life, it is when these sleep problems become frequent that our health can deteriorate. We can start to notice that it becomes more difficult for us to concentrate, and our memory is not so good: we can experience more negative emotions such as becoming more irritable, frustrated, or angry. We can feel our mood dropping and we become more emotional and tearful.

## What happens if we don't get enough sleep?

If we don't get enough sleep, we are said to be sleep deprived and we end up with a sleep debt, which means we owe our body some extra sleep to make up for the

sleep we have missed. Our bodies will try to recoup this lost sleep by increasing the length of time we sleep the following night. We will need to make up  $\frac{1}{3}$ <sup>rd</sup> of all NREM sleep and  $\frac{1}{2}$  of all REM sleep that we have lost. If this sleep debt continues, we will start to notice negative changes to our physical and mental health.

Lack of sleep also affects our cognitive ability i.e. our learning ability. During sleep our brain sorts through everything we have learned, all our memories from that day. It will sort these memories and experiences and will consolidate our new learning. You may have heard the term that if you have a problem, it is good to sleep on it? Well, this is true. When our brain is sorting through our experiences, it groups them together with previous similar experiences. Then, the next day, we will have retained and in many cases, improved upon new skills or memory acquisition, and our ability to solve that problem seems to be at our fingertips, whereas the day before, we were unable to find a solution. Sleep is crucial in this process and particularly important for our children who need to have good focus and attention through the day and consolidate their school and play learning through the night. Good sleep is imperative if our children are to learn good emotional resilience.

Research has shown that after 22 hours of no sleep, our alertness and reaction times are the same as those found in people over the legal limit of alcohol. People will take more risks, i.e. take a chance on going through a red light, become more emotional and have difficulty putting sentences together. Speech can become slurred.

As many of the body's cells increase reproduction during sleep, this shows the importance of our "beauty sleep". Lack of sleep tells in our physical appearance with darkness and puffiness under the eyes and our skin becomes dull. Our skin is a good reflection of what is happening on the inside. Lack of sleep and long-term sleep deprivation has an effect on our hearts and lungs and can also affect our immune system, our ability to fight infection.

## **How much sleep do we need?**

As a rule of thumb, we need 16 waking hours and 8 sleeping hours and this is what we call our Circadian rhythm. Everyone's Circadian rhythm is slightly different with some people only needing  $6\frac{1}{2}$  or 7 hours whilst others may need nine or ten. It is important to explore how much sleep we need so again, tune in to yourself in the morning. Do you feel awake and ready to start the day or is your brain foggy and you feel as though your night was not restful?

If this is the case, you will need to work backwards from the time you need to get up to find out when your bedtime should be. This may be earlier than you think, considering we need to be in bed around 30 minutes before we fall asleep. Remember, children need more sleep than adolescents and adolescents need more

sleep than adults. Gradually adjusting your bedtime may feel like you are missing out on part of the day, but you will have more energy, feel better and have much sharper attention and focus and it is highly likely this means you will get through more in a day than you previously did. It's a very worthwhile trade!

## **The sleep cycle**

Sleep is generally divided into three phases:

1. the initial sleep phase when we drift off to sleep at night
2. the intermediate sleep phase when we stay asleep through the night
3. the terminal sleep phase when sleep becomes lighter, and we start to awaken

## **Getting off to sleep (the initial sleep phase)**

### **Comfort and Posture**

If you have difficulty getting off to sleep, it could be because you are uncomfortable, or it may be because you have thoughts in your head that are keeping you awake. If you cannot get to sleep because of discomfort, you can discuss this further with a healthcare professional such as your GP, nurse or physiotherapist who can help find out why you are uncomfortable and help do something about it.

### **Anxiety**

If it is more to do with feeling that you just can't switch off, there are other methods that can help you deal with this. Sometimes when everything around us is quiet, worries and concerns can take over and prevent us from sleeping. If you have worries or concerns it is important that you work through them.

Sometimes it helps to discuss things that are troubling you with a family member, friend, or counsellor. There are many online counselling services too that can be helpful. Costs do vary and it is best if you can ensure the counsellor is properly trained in the area that you would like to discuss. Journaling and taking time to write for even as little as 5 minutes every day can be beneficial in the long term and there is a good body of evidence to support this.

There are various online tools that can also help you work through difficult thoughts and feelings and often charities such as Muscular Dystrophy UK can help point you in the right direction. Your healthcare professional may also be able to guide you towards the best area to support your needs.

### **Sleep Apps**

There are also several sleep apps and CD's that can help you relax and clear your mind to prepare you for sleep. For many people, the quietness of the bedroom can increase feelings of anxiety and your mind may need a "bridge" or somewhere to

“rest” before you can fall asleep. Sleep apps that tell you a bedtime story, something for your brain to focus on but won’t stimulate you, can be useful. Meditation apps or gentle vibrational tones have also been shown to be helpful. You will need to experiment with this and once you find a voice or app you like, stick with it. This form of sleep-inducing sound requires a bit of practice and with time, you will gently train your brain to fall asleep more quickly.

## **Sleep hygiene**

How long we take to drift off to sleep, largely depends on our bedtime routine. Another term for this is “Sleep Hygiene”. Our sleep hygiene needs to be good to get a good night’s sleep. Developing a good bedtime routine is important and forms part of the brain training practice that we discussed in the previous paragraph. If we do the same things each night, our brain remembers that we are doing this to wind down so we will start to get sleepy. Forming good habits such as a warm bath, changing into comfortable clothing like cotton pyjamas, a soothing drink and a bedtime book are all ways of telling the brain that we are preparing our body for sleep.

## **Calming the senses in a restful environment:**

Another way to look at our sleep hygiene is to think in terms of calming the senses. Traditionally we think of ourselves as having five senses that help us make sense of the world around us. Our senses help us navigate safely through our environment. For example, our sense of touch tells us if things are too hot and likely to cause harm. Our sense of smell tells us when to avoid unpleasant experiences and our sense of hearing warns us of impending danger. Taste helps us avoid foods that have gone off and our sense of sight helps us to interpret everything around us to prevent us bumping into things, falling over etc. Our senses are always working hard through the day to protect us but also play an important role in helping us enjoy our life. Taking time to turn these senses down at night can help us enter a more relaxed state that can help our sleep.

For some people who feel restless, stressed, or anxious at night, a weighted blanket can be helpful. The additional weight has been described as feeling like “pressure therapy” that calms the parasympathetic nervous system inducing the feeling of being held or hugged. Some people have found this to be very useful when trying to get to sleep and this type of pressure therapy is gaining momentum in conditions such as autism. A cautionary note to think about weighted blankets is just that; they will add weight to your bedclothes, and this may not be suitable if you have weakness in your arms and you can’t alter the blanket if you are too hot as it may be too heavy. If you overheat at nighttime, it also may not be suitable for you.

## Sight:

Calming our sense of sight is a good place to start. Low lighting in the bedroom gives the brain the impression of firelight whereas an overhead light signals it is time to get up in much the same way as the sun rising in the sky. A dark room works best particularly during summer nights and blackout curtains or curtains and blinds can give that extra dimness that you might need to fall asleep.

Turning off the TV and not using a games console or computer is important for at least one hour before bed. The blue light emitted by electronic devices disrupts the production of melatonin, our sleep hormone. The release of melatonin is triggered by the type of light reaching our eyes. Blue light is thought to slow down the release of melatonin making it difficult for us to fall asleep.

Warmer based light is natural in our environment from the afternoon onwards whereas blue light is natural in our environment in the morning to signal to our brain, through our eyes, that it is time to get up and ready. No need for melatonin in the morning. This is all part of our Circadian rhythm, so minimising blue light is important in the evening and maximising blue light in the morning is helpful.

Many experts now feel that a good night's sleep starts with a good morning and if we can expose our eyes to daylight and get out of doors in the morning, this will help our overall sleep pattern. So, getting out before breakfast or even just having your coffee or tea out of doors in the morning will be beneficial to your sleep health in the long run.

**Lighting is an important part of our bedtime routine.**

## Sound:

Trying to sleep in a noisy environment is tricky. Our brain often tunes into sounds like dripping taps and ticking clocks when we are trying to get off to sleep. However, some people find if the room is too quiet, this can also be problematic so having consistent low noise, relaxation apps and CD's can be useful. However, this is very much a personal choice, and you will know what works best for you.

## Smell:

This sense is often underestimated but smell can evoke strong memories. If for example we smell a certain perfume, it can remind us of someone, or sea air can remind us of a certain holiday. We can use smell in our sleep hygiene as certain smells such as lavender or rosemary used solely in the bedroom can help our brains remember it is time for sleep. A few drops of essential oil on or near our pillow can be useful and form part of our routine. Each time we smell it, we will associate it with

sleep. There are also some very good natural and organic sleep sprays on the market so experimenting with smells can help you decide if this will work for you.

## **Taste:**

There are certain foods associated with a good night's sleep. Warm milk or indeed any dairy product such as yoghurts (and even cheese in small amounts) can help tryptophan enter our blood stream and support our sleep cycle. Tryptophan is an amino acid that can induce sleepiness. There are many foods that contain tryptophan, but we should try and remember not to eat for around three hours prior to our bedtime. This will give our bodies time to process our food as trying to sleep when your body is busy digesting your dinner is a lot for our body to do when we are trying to wind down.

The 3-2-1 rule is useful as part of our bedtime routine:  
Stop eating 3 hours before bed  
Stop working 2 hours before bed  
Stop scrolling 1 hour before bed

## **Touch:**

A comfortable bed, our nightclothes and bed linen may not seem to be something we place much attention to, but this can make a big difference. Natural fibres such as cotton feel good next to our skin. Fabrics that are “breathable” are important to help prevent us over-heating through the night and our thermal comfort is an important consideration when calming our senses.

## **Thermal comfort**

**Temperature:** Achieving the correct temperature at night is important. If we are too hot or too cold, then we will have problems getting to sleep. Temperature is a very individual preference. We must think of our external temperature (the room and our surroundings) as well as our internal temperature (our core body temperature).

**External Environment:** Our external temperature depends on the heat in our bedroom. There is no real agreement on the best temperature for the room, but we do know it should be cooler than we expect a room to be in the daytime. Some experts recommend between 17<sup>o</sup> and 19<sup>o</sup> Celsius. However, everyone is different, and you may have to spend a bit of time experimenting to see what is best for you.

As the temperature drops through the night, you may wake up cold but adding extra covers may not be the answer as you do not want to add weight to the bedclothes. You may also have difficulty moving your blankets on and off due to your muscle weakness. Some people find using a temperature regulating undercover that can



cool you if too warm and heat up when you are cold, is helpful. Another idea might be a hot / cold fan or radiator that maintains the room at a constant temperature through the night.

**Internal Environment:** This is more difficult to maintain as our body will get warmer and cooler in cycles through the night, as it goes in and out of NREM, REM and light sleep.

Wearing natural fibre night clothes such as cotton and using cotton sheets and duvet covers on the bed (rather than poly cotton) can help prevent the build-up of heat.

Our internal temperature is also a signal for sleep. As we drift off to sleep our body naturally cools. Having a hot bath just before bed opens the superficial blood vessels and this will start the cooling cycle when you get out of the bath. Getting into a warm bed with an electric blanket will do much the same thing and when you turn off the blanket, the bed will cool down as will you.

Mattress covers made of natural fibres are also helpful. If overheating at night is problematic, try to avoid foam mattresses and memory foam toppers as these can cause heat to build, although they are useful for pressure re-distribution. If pressure is an issue during sleep, particularly if you are unable to readily change position, and you often wake up to move or turn over in bed or perhaps you need to get assistance to change your position, do speak with your physiotherapist. There are various mattress toppers and sheets with cooling features that may help you regulate the temperature of your bed.

## **Sleep posture**

Sleep is a good time for your muscles to rest but when you are relaxed in bed, you are more likely to move into asymmetrical (unbalanced) and difficult positions. If you wake up sore or uncomfortable, or you need help to turn more than two or three times per night, then you may need to think a bit more about your sleep position. You can discuss this in more detail with your physiotherapist.

If you prefer to lie on your side, it is important to make sure that you support your top arm and you can do this by laying it across your partner or by supporting it on a pillow. Support your top leg on a pillow too as this helps keep your hips, back and neck and shoulders in a good position. Use a pillow that is large enough to take up the space between your ear and the bed, ensuring your neck is in a neutral position. If your pillow is too high or too low, then your head will be in a side-flexed position, and this can cause discomfort if lying in that position for any length of time. It is not good to lie on the same side for extended periods of times, so always make sure you lie on the opposite side too.

If you only ever lie on one side, you may develop an asymmetrical thorax (rib cage) as often we do not realise that our bones are not as rigid as we think and can change shape over time.

If you have slept on the same side for many years, then it may be best to maintain lying on that side as your breathing muscles and diaphragm will have adapted and be working at their most effective in this position. Changing position and getting used to a new posture will take time and you can gradually introduce this. Your physiotherapist can further advise.

## **Beds and mattresses:**

If you wake frequently through the night with pain and discomfort, it may also be a good time to consider your bed and mattress. If you need help turning, you might want to consider a 4-section profile bed that rises and lowers, as this will help your carers support you in a more comfortable position and help you change position more easily. The four integrated sections will assist you into a more comfortable sitting position and the knee break can help you maintain the position more easily by preventing you from sliding down the bed. It will also support your carers by enabling them to adjust the bed to the correct height to work with you more easily and help them look after their own posture.

There are a variety of aids such as sliding sheets and sliding gloves and your OT or District Nurse can assess to see what would be most helpful for you and your caregivers.

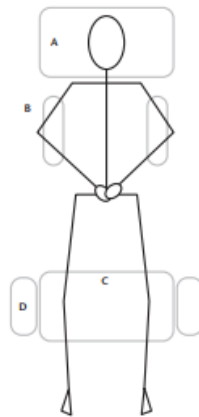
It is also important to have access to both sides of the bed to make sure you can turn easily to either side. If possible, try and organise your room so your bed is not against a wall.

The mattress selection is also important. If you can turn on your own but do so with difficulty, then a memory foam mattress may not be suitable. Although it has excellent pressure re-distribution qualities, moving around on a mattress that you sink in to, is a bit more of a challenge. It is also more difficult to sit on the edge of the bed to dress and standing from the seated position can be more of a challenge than if you had a firmer mattress. In this case a firm mattress with a memory foam topper might be better as it will give you the pressure re-distributing qualities, whilst a firmer mattress underneath supports your positional changes.

However, if moving in bed is not an option, a memory foam mattress may be beneficial, as you will be able to lie in the same position for longer. No matter if you are lying on your side or your back, it is important to be as symmetrical as possible, and in some cases, a sleep system may help.

A sleep system is a system of specifically shaped pillows, cushions and mattresses that can be selected specifically to suit your sleep posture. A sleep system is suitable for people who don't change their posture much through the night as it allows them to sleep longer in the same position without discomfort. If you think this might be helpful for you, please do further discuss with your physiotherapist.

### Good sleep posture when lying on your back



<b>A</b>	Hollow the pillow out under your head and try to support the head and neck in mid line.
<b>B</b>	Use small cushions or supports under the elbows to take the stress off the chest and support the shoulder joints.
<b>C</b>	Pillow under knees– you may need two. Make sure knees and feet are hip width apart and knee caps are facing the ceiling and not falling out to the side as this puts excessive stress on the hip joints. Pull the middle of the pillow up to hollow out two furrows to support the legs on the pillow.
<b>D</b>	Place small rolls or blankets rolled up under each side of the pillow to keep knees in mid line (if necessary) and help prevent 'frogging'.
<b>E</b>	A 30° degree turn (partial side lying) is recommended to make sure no harmful pressure goes through the head of femur (hip joint) as in a 45° degree turn (complete side lying). When in side lying, support the top leg with a pillow underneath.

## Waking through the night (the intermediate sleep phase)

If you waken through the night, it may be because you have:

- pain
- need to go to the toilet
- have had enough sleep
- feel breathless
- have anxiety or feel stressed

**Pain:** If you awaken through the night with pain, and you know your sleep position is as good as it can be and there are no problems with your mattress, it may be that your medication requires review. If you do not use pain medication, then perhaps this is something that you could discuss with your GP. Pain always feels worse with lack of sleep and if pain is preventing you from sleeping, then this is an important cycle to break and it may be that even in the short term, pain medication may be a helpful addition to your overall health care. It is however important to explore the root cause of your pain and for more information, please do refer to the separate leaflet on pain management in neuromuscular disorders on the Scottish Muscle Network website.

**Toilet breaks:** If you are up through the night using the toilet more than a couple of times and it takes you a while to get back to sleep, then this can interfere with your sleep cycle. Avoiding caffeine and alcohol before bed are helpful not just because of the fluid volume but also because both caffeine and alcohol can disrupt the sleep cycle and prevent you from going through the sleep cycles adequately. It might also be helpful to avoid other fizzy drinks as they also can contain caffeine. Fluid restriction later in the evening can help limit the volume of fluids that might mean you will not have to empty your bladder so often through the night. For more information, please refer to the continence care leaflet on the Scottish Muscle Network website - [www.nn.nhs.scot/smn/](http://www.nn.nhs.scot/smn/)

**When you have had enough sleep:** If you have had a nap through the day or wake up early after 5am, it may be that your body does not require more sleep. This is something for you to think about to see if it may be that your normal circadian cycle might be slightly less than eight hours. Everyone is different and while some people might feel better with nine hours sleep, you might feel better on seven.

**Feel breathless:** When we sleep, we know that our breathing rate changes as our respiratory muscles rest and for some people with muscle weakness, this can mean your sleep is disturbed. You may well already be under breathing a little through the day if you have respiratory muscle weakness and then when you add on a slowing of your respiratory rate during sleep, that can be enough to trigger your brain to wake you up and take a few deep breaths. If you wake feeling out of breath, or wake with a morning headache, then do discuss this with your healthcare provider.

**Stress and anxiety:** This subject is of great importance to your health and wellbeing, and we have touched on this earlier in the leaflet. If you are concerned about your levels of stress or anxiety, please do discuss with your GP or hospital consultant. There are also charities such as Muscular Dystrophy UK who can help support you.

## **Terminal sleep phase**

Waking up too early can be frustrating and may be because of any of the reasons already discussed in this leaflet. Exploring your sleep using the information contained in this leaflet may help you identify the cause of your sleep issues.

## **Conclusion**

The quality of our sleep is an important part of health and wellbeing, particularly if you have a neuromuscular condition. There are many factors that need to be considered when trying to improve our sleep profile and this is an area you can discuss with your physiotherapist. If it is your child who has disturbed or broken sleep, then you may wish to discuss a referral to a specialist sleep clinic or contact Sleep Action on: [sleepaction.org](http://sleepaction.org)