


Supporting Information
Leaflet (7):
The importance of Sleep



Introduction

Along with a healthy diet and regular physical activity, sleep is one of the most important factors in developing and maintaining a healthy lifestyle. In recent years, Doctors and Healthcare Professionals have become more aware of the importance of good quality sleep on health and wellbeing and how a poor sleep pattern is not good for anyone.

The common causes of poor sleep are stress (i.e. problems at work, school or home), a poor bedtime routine or drinking alcohol and drinks containing caffeine in the latter part of the day. However, in neuromuscular disorders, there are a number of other reasons that may affect sleep.

This leaflet explains some of the reasons why a good night's sleep is important to your health and how a poor night's sleep can make your neuromuscular disorder symptoms worse. It will give you suggestions on how to improve your sleep which in turn will help you feel better through the day.

Why do we need sleep?

In days gone by, we believed that sleep was so our bodies could rest but in actual facts, our bodies are very busy during sleep. It is only very recently that scientists have started 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 believe that it also increases in humans.

Scientists now 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). 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 well being is poor, then our physical health can also deteriorate as we become less keen to be active or socialise. If our physical health is poor, then lack of energy, as well as an increase in pain or weakness 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 what we call 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 1/3rd of all NREM sleep and 1/2 of REM sleep that we have lost. If this sleep debt continues we start to notice harmful changes to our physical and mental health.

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 together sentences and 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 or puffiness under the eyes and our skin becomes dull. Lack of sleep and long term sleep deprivation has an effect on our hearts and lungs and can affect our immune systems.

How much sleep do we need?

As a general 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 or 7 hours sleep and others needing 9 or 10. It is important to find out how much sleep you need. If you need to get up at a certain time for school or work, then this will give you an idea of when your bed time should be. Children need more sleep than adolescents and adolescents need more sleep than adults.

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

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.

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 or 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 a number of tools that can help you work through difficult thoughts and feelings and you may wish to discuss this in more detail with your healthcare professional who can give you more information.

There are also a number of sleep apps and CD's that can help you relax and clear your head to prepare you for sleep, however trying to get to sleep when you are not tired won't work so sometimes it is better to get up, have a soothing drink and try again when you are feeling a bit more tired.

Sleep Hygiene

How long we actually take to drift off to sleep largely depends on our bed time routine. Another term for this is 'Sleep Hygiene'. Our sleep hygiene has to be good in order to get a good night sleep. Developing a good bedtime routine is very important. 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: Another way to look at our sleep hygiene is to think in terms of calming our 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 hearing warns us of 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. However, calming our senses at night to help us to enter a more relaxed state 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.

Sight: Calming our sense of sight is a good place to start. Low lighting in the bedroom and making sure the room is dark enough on summer nights is helpful. Turning off the TV and not using a games console or computer is important as these electronic devices emit a blue light.

Our eyes are sensitive to light and as the room darkens, melatonin, which is a natural hormone that prepares our body for sleep, is released. Blue light is thought to slow down the release of melatonin making it difficult for us to fall asleep.

Lighting is an important part of our bedtime routine.

Sound: Trying to sleep in a noisy environment is tricky. Our brain often tunes in to 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 like gentle music, relaxation apps and CD's etc can be useful. However, this is a personal choice.

Smell: This sense is often underestimated but smell can evoke strong memories i.e. if we smell a certain perfume it can remind us of someone or sea air can remind us of holidays etc. We can use smell in our sleep hygiene as certain smells such as lavender and 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 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, e.g. warm milk or indeed any dairy product such as yoghurts (and even cheese) can help tryptophan enter our blood stream and help the sleep cycle. Tryptophan is an amino acid that can cause sleepiness. There are many foods that contain tryptophan and both proteins and carbohydrates are important so toast with peanut butter, a milky cereal etc may all be useful.

It's not a coincidence that we often feel sleepy after our dinner however, it is important that we don't eat large quantities at bed time either as this can make us feel uncomfortable and prevent sleep.

Touch: A comfortable bed, our nightclothes and bed linen are all important. Natural fibres such as cotton feels good next to our skin. Fabrics that help our skin "breathe" are important to prevent us overheating 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 have to think of our external temperature (the room and its 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 would expect a room to be in the daytime. Some experts recommend between 17° and 19°. 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 the blankets on and off due to muscle weakness. In these situations it might be useful to think about investing in a hot and cool fan or radiator that maintains the temperature of a room consistently. This means in summer it cools the room but in winter it keeps the room at exactly the same temperature all night. The body is then not working hard to heat up or cool down as the external environmental temperature is consistent.

Internal environment: This is more difficult to maintain as our body will heat up and cool down in cycles through the night as it goes in and out of REM and NREM sleep.

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

Mattress covers made of natural fibre are also helpful. If over heating at night is problematic, try to avoid foam mattresses and memory foam toppers as these can cause heat to build up although they are very useful for pressure re-distribution. If pressure is a problem during sleep and you often wake to get turned, then speak with your physiotherapist. There are various mattress toppers or sheets with properties that help take the heat away from your body (wicking) that you can use to regulate the temperature of the bed and some people find these useful.

Sleep posture: Night time 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 postures. If you wake up sore or uncomfortable, or you need help to turn more than three times per night, then you may need to think a bit more about your sleep position. You should 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, neck and shoulders in a good position. Use a pillow that is thick 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 too long. It is not good to lie on the same side for extended periods of time so always make sure you lie on the opposite side too.

If you only ever lie on one side, you may develop an asymmetric rib

cage 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 should gradually introduce this. Your physiotherapist can advise you further on this.

If you have shoulder or hip pain, you need to avoid pressure on these joints and make sure you are not lying on them. Your physiotherapist can show you alternate lying positions such as on your back or partial side-lying. You may need extra pressure re-distributing aids under your elbows and heels and your physiotherapist can advise.

Beds and Mattresses: If you wake up 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 four section single profile bed that rises and lowers as this helps your carers turn you. The four sections allow you to be assisted into the sitting position and the knee break will help stop you sliding down the bed. It is important that your carers use the bed at the correct height to avoid long term back problems. There are a variety of aids such as sliding sheets on the market and your OT or District Nurse can assess to see what would be most helpful for you and your carers.

It is also important to have access to both sides of the bed to make sure you can turn easily to either side. Try and organise your room so that the bed is not against a wall if at all possible.

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 more challenging. It is also more difficult sitting on the edge of the bed to dress, and standing from the sitting position can be difficult.

Therefore, a memory foam topper may be more suitable 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 whether you are lying on your side or lying on 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 specially 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 becoming sore or uncomfortable. If this is the case, your physiotherapist can give you more advice.

Intermediate sleep Phase

If you awaken through the night it may be because you have:

- Pain
- Need to use the toilet
- Have had enough sleep
- Feel breathless

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 mean that your medication requires review. If you have never used medication, then perhaps this is something 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 mean that even in the short term, pain medication would be a helpful addition to the care

and management of your neuromuscular disorder.

Please see the separate leaflet on pain management in neuromuscular disorders.

Using the Toilet: : If you are up using the toilet more than a couple of times per night, then this can interfere with the sleep cycle. Avoiding caffeine and alcohol before bed time and limiting the volume of fluids a couple of hours before you go to bed can help. Some fizzy drinks such as cola also contain caffeine so it might be helpful to check what you are drinking. You can find more information on this in the Continence Care Information Leaflet.

Feel breathless: At night time our breathing rate changes as our respiratory muscles rest and for some people with muscle weakness, this can mean your sleep is disturbed. If you wake feeling out of breath, discuss this with your Consultant, GP or healthcare professional at your clinic visit.

Terminal Sleep phase

Waking up too early can be for any of the reasons already discussed or may be that your body feels as though it has had enough sleep. Some people are naturally early risers and it can be difficult to try and get back to sleep when your body is ready to start the day. If waking up early is new for you, it could be that trying some of the ideas in this leaflet, may help you have a longer and better quality sleep.

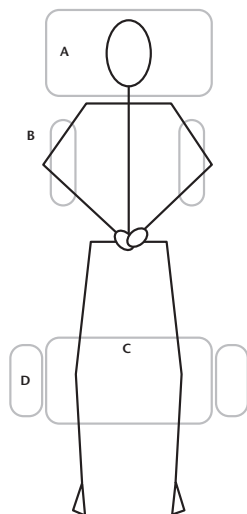
Conclusion

The quality of our sleep is an important part of our healthy lifestyle, particularly if we have a neuromuscular condition. There are many factors that need to be taken account of if we are to achieve good quality sleep and this is an area that you can discuss further with your physiotherapist.

If it is your child who has disturbed or broken sleep than you may want to discuss a referral to a specialist sleep clinic or contact Sleep Scotland on: <http://www.sleepscotland.org/our-services/sound-sleep/>

If you would like more information, please contact Marina DiMarco, Principal Physiotherapist at marina.dimarco@ggc.scot.nhs.uk or telephone **0141 354 9205**.

Good sleep posture when lying on your back



A	Hollow the pillow out under your head and try to support the head and neck in mid line.
B	Use small cushions or supports under the elbows to take the stress off the chest and support the shoulder joints.
C	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.
D	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’.
E	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.

