

Muscular Dystrophy Association Motor Neuron Disease Clinic

At
The University of Utah
Department of Neurology

SLEEP

Sleep can be a problem for anyone. However, it seems to be more of a problem when people have things on their mind that they are thinking and worrying about. Sleep can also be a problem when people are less physically active and less tired at bedtime. Both of these happen in ALS. In this handout we will review some of the features of sleep and suggest some solutions.

The Need for Sleep

There is still no clear answer to why we need sleep. We all know that sleep is important for our daily activities. When we get insufficient sleep we feel less alert. Some people may have a life long history of difficulty with sleep that may seem worse in the setting of ALS.

There are stages of sleep that we cycle through each night. We are not conscious of what stage we are in. Interestingly, in one stage called REM sleep, there are rapid eye movements, but the rest of the body, except for breathing muscles, is essentially paralyzed. REM sleep is important because this is when we dream. However, it is important in ALS because the relaxed muscles in the throat can increase the effort of breathing.

Insufficient Sleep and Non-restorative Sleep

With insufficient sleep, people do not feel rested and tend to fall asleep easily during the day. But there is no lasting harm from not getting enough sleep. Unfortunately, this can set up a cycle of using up sleep time during the day and not needing it at night.

With non-restorative sleep, people do not feel rested in the morning but can stay awake during the day.

Falling Asleep

There are many possible reasons why people have difficulty falling asleep. Early on, after receiving the diagnosis of ALS, some patients lie awake very fearful of the future. This is natural. Talking about fears and concerns is one way to relieve this fear and anxiety.

Later on, when patients are weak, they may have little physical activity to make them sleepy. The lack of physical activity gives them less to occupy their day and they will take frequent naps. This contributes to the cycle of using sleep time during the day and not at night.

Staying Asleep

Some people fall asleep easily but wake up and have difficulty returning to sleep. Perhaps the most common reason is that some of night time sleep time was spent during the day in naps, and thus less is needed at night.

Another reason is when people are weak and have difficulty shifting position in bed the discomfort of being in one position too long wakes them up. This can be helped by taking a non-steroidal anti-inflammatory medication before bedtime, such as ibuprofen (Advil®, Motrin®) 400 to 800 mg.

Very late in the course of ALS, people may have difficulty sleeping due to anxiety and shortness of breath. At this stage pain relieving medications are helpful.

Sleep Hygiene

Sleep hygiene is good sleep habits. Everyone has their sleep needs (number of hours). Sleeping some of these hours during the day with naps shortens the number of hours needed for sleep at night. Getting up later in the morning also shifts the sleep period later in the night.

We recommend the following:

- Set a time to go to bed (say 10 to 11 PM).
Do not go to bed earlier (watching TV, reading, etc).
- Set a time to get up (say 6 to 7 AM).
Do not stay in bed later.
- Do not take a nap unless absolutely necessary.
- It may take several weeks to reset a sleep cycle, so have patience!

Role of Sleeping Pills

Most sleeping pills, such as over the counter medications that contain benadryl, and prescription drugs such as Reston® (temazepam) and Ambien® (zolpidem), do not work in the long run. They are effective for a while, but lose their effectiveness after several weeks and sleep may be disrupted when trying to get off of them. They may also disrupt the sleep cycle so your sleep is not restorative. These medications are better to use short term or occasionally rather than every night.

Other medications are better when you have long-term problems with sleep that need a medication every night. These medications do not affect your sleep cycle and are better if you need something every night. Amitriptyline and Desyrel® (trazodone) are other medications that were initially used as antidepressants that are now commonly used in smaller doses to help sleep. These may initially cause morning drowsiness, but you will adjust after a few days.

Lunesta® (eszopiclone) and Rozerem® (mirtazapine) are newer medications that do not lose their effectiveness over 6-12 months of use and do not cause increased trouble sleeping when they are stopped.

A glass of wine in the evening can relax you and help bring on sleep.

We will be happy to discuss these issues with you. If you have questions between clinic visits please contact Kristin Jefferies, Pharm D at 801 587 8122 or Barbara Miano at 801.585.6052.