



# **Promoting Sleep Health: Practical Application for People Living with Multiple Sclerosis**

Presented by:

**Catherine (Katie) Siengsukon, PT, PhD, DBSM, CHWC**

## **Yahaira Rivera:**

Hello, everyone. Good evening. Welcome and thank you for joining our webinar: Promoting Sleep Health - Practical Application for People Living with Multiple Sclerosis. Tonight, alongside Dr. Siengsukon, we'll learn how to identify common sleep disorders in people with multiple sclerosis, their impact on health, and effective ways to improve sleep and manage fatigue. My name is Yahaira Rivera, and I'm Director of Mission Delivery and Program Development for MSAA, and I'm honored to be your host.

In case this is the first time that you're joining one of our programs, I'd like to share some information about MSAA and go over some housekeeping items. MSAA is a national nonprofit organization dedicated to improving lives today through vital services and support for the MS community. Our programs and services include a national helpline staffed with compassionate team members, available Monday through Friday, 8:30 a.m. to 8 p.m. Eastern Time. Equipment and calling distribution programs with products designed to improve safety, mobility and heat sensitivity, educational programs, award-winning publications, self-management tools, an online community forum, and much more. For more information about our programs and services, please visit our website: [MyMsaa.org](http://MyMsaa.org).

And now, just a couple of reminders. Please know that during tonight's program, you will have the opportunity to submit your questions by using the Q&A feature in your Zoom toolbar. As time permits, questions will be addressed during the Q&A portion of tonight's webinar after the presentation. Also, please know that this program is being recorded and will be available as an on-demand video on our MSAA's Video Library within the next couple of weeks. And know that at the end of the program, you will have access to a brief survey. Your feedback is extremely important and helps us to develop future content and programs. So we appreciate your time and your feedback. A link to the survey will be also included in our chat box. As a friendly reminder, this program is for educational and informational purposes only and does not constitute any formal recommendations. Please speak with your doctor for specific questions or concerns.

And now I invite you to welcome Dr. Catherine (Katie) Siengsukon. She's a professor and the Director of Research in the Department of Physical Therapy, Rehabilitation Science and Athletic Training at the University of Kansas Medical Center. She also directs the Sleep, Health and Wellness Laboratory. Doctor Siengsukon is currently working on research to examine the use of behavioral interventions to improve sleep in people with multiple sclerosis. She is certified in behavioral medicine, and her work has received support and recognition from the National Institutes of Health and other national organizations. Welcome Dr. Siengsukon, thank you so much for being here educating our MS community about this critical topic. We look forward to your presentation.

**Dr. Catherine Siengsukon:**

Thank you again so much for this opportunity. I always welcome being able to speak directly to the community and share this information. And I will make sure I save time for questions and answers at the end. So, again, feel free to call me Katie. I am board certified in behavioral sleep medicine, and I do quite a lot of research around behavioral sleep interventions to enhance sleep in multiple different patient populations but primarily in people with multiple sclerosis.

So for tonight, these are the three topics that we will be discussing. We'll talk about how to recognize common sleep disorders in people with MS, because we know that sleep disorders can be more prevalent in individuals with multiple sclerosis, and unfortunately, oftentimes they go unrecognized and undiagnosed. So that will be the first topic that we go over. And then I will present some evidence that behavioral interventions can be useful to improve sleep and fatigue in people with MS. And then we'll spend most of the time this evening, though, talking about practical application, hopefully tools that you can use if you are having sleep challenges, to start using tonight, ideally, to hopefully help enhance your sleep and fatigue as well.

So we know humans sleep a lot. Ideally, we spend about a third of our lives sleeping. And even though it may look like you're laying there not doing a whole lot, we actually know much better now, today, than we did even just a few years ago, that there's really a lot of processes that are going on in our brain and in our bodies. So that it really is a critical period of time that our bodies and brains are undergoing recovery, as well as various cellular activities to help support systems of the body, including our cardiovascular system, our neurologic system, metabolic and other life functions. So, there's a lot of really important processes that are going on while we are sleeping.

And so we know that if we are not getting adequate sleep, that that can have a negative impact on our health and well-being. And we could very easily spend the entire hour that we have together this evening talking about how sleep impacts health. But I'm going to go through this part relatively quickly. So, we know that sleep impacts pretty much every system of the body, if not every system of the body, including our immune system. So, we know that there are certain cells that are upregulated during the day. More cells that are more prominent at night time. And so if you're not getting adequate quality sleep, that disrupts our immune system and your immune system doesn't work as well. We also know that sleep is very important for tissue healing. And so most of these studies have been done in animals, where they sleep deprive animals, and they find that those animals are more likely to develop sores on their paws or their tails if they're sleep deprived.

And that, as a physical therapist by training, that really piques my interest. Because, you know, we see a lot of patients who have just undergone some sort of a surgery or an injury or an onset of a condition, such as multiple sclerosis. So we know that sleep is really important for that body and the brain to heal. We also know sleep's very important for pain modulation. And this is a

pretty hot topic in the research world right now. And it probably makes intuitive sense that if you have pain that that's going to disrupt your sleep. But we're really interested in understanding how if you're not getting adequate sleep, that that can actually set you up for developing pain conditions. And so some studies suggest that people who aren't sleeping well, they're more likely to develop chronic pain conditions 10 years, 15 years down the road.

We also know that sleep is very important for our cardiovascular health. When we get into the deep stage of sleep, which is called slow wave sleep, that's a period of time where our blood pressure goes down, our heart rate goes down. So if you're not getting adequate deep sleep, your body doesn't have that time to rest and recuperate, and so it just keeps added stress on that cardiovascular system, and you're actually at a higher risk of developing cardiovascular disease. We also know sleep's very important for cognitive function. And cognitive function refers to lots of different processes, but we know that it impacts people's ability to think clearly, to learn new information and also to form memories. So, in essence, what we learn during the day, what we practiced during the day, gets replayed in our brains at night. And so if you're not adequately sleeping, it also can impact your cognitive function in these broad categories, including the ability to think clearly, ability to learn, and also your ability to form new memories.

We also know that sleep is very important for our metabolic and endocrine systems. And so if you're not getting adequate sleep, that also puts you at a higher risk of developing obesity and diabetes as well. And sleep dramatically impacts our mood. And so this may not be a huge surprise that people who are not getting adequate sleep, it also puts them at a higher risk of developing depression, anxiety. And this is across the general population. This is not specific necessarily to people with multiple sclerosis.

But then if we do delve into sleep issues and people specifically with multiple sclerosis, we know that approximately 50% of people with MS have a diagnosable sleep disorder. So something like insomnia or sleep apnea, restless leg syndrome, there's many different sleep disorders. But up to 70%, if not more, of individuals with MS report having a sleep disturbance. So, perhaps not a sleep disorder per se, but some disturbance of their sleep. But unfortunately, sleep disorders and disturbances oftentimes go undiagnosed and therefore untreated in people with multiple sclerosis. So the prevalence of sleep issues is actually probably higher than what is even reported in the literature.

And so, we know that poor sleep has been associated with, for people with MS, with reduction in their physical function, with their psychological well-being, with ability to perform self-care activities as well as activities of daily living. It also negatively impacts ability to work as well as interpersonal relationships. And fatigue, as many of you likely know, is a very common issue in people with multiple sclerosis, and we know that poor sleep quality is significantly associated with fatigue as well. And so poor sleep has been a predictor of reduced quality of life in people with multiple sclerosis. And so that hopefully just gives a little bit of background about that high prevalence of sleep issues in people with MS.

And so I wanted to touch briefly on possible sleep disorders. And again, this could very easily be an entire, hour-long lecture just on this topic. But before we start talking about that application of sleep health promotion techniques, it is important to consider if you or your loved one could potentially have an undiagnosed sleep disorder. And so these are some common sleep disorders specifically for people with MS - insomnia, sleep apnea, restless leg syndrome, periodic leg movements during sleep. Those have an increased prevalence in people with multiple sclerosis. And so insomnia, that is the difficulty either falling asleep, staying asleep, or waking up too early three or more nights a week. And if it lasts longer than three months, it's

considered a chronic issue. So that would be when we consider it to be a chronic insomnia. And it also must impact daytime functioning as well. So there must be some type of negative daytime consequence, either frustration with sleep or feeling like it's affecting your thinking ability or function, but there's a negative consequence during the day.

Another common sleep disorder, and this is, again, underdiagnosed in the general population, but also in people with multiple sclerosis, is sleep apnea. And so that's when people have a period of time where they either have very shallow breathing or they even can stop breathing periodically throughout the night. And so, a common sign or symptom of sleep apnea is if you snore, or so if you have a bed partner who has observed you snoring or perhaps they've actually observed you pausing and taking a breath or gasping to take a breath, that is definitely an indication that you would want to talk to your physician about potentially being assessed for having sleep apnea.

Another common sleep disorder, and it has an increased prevalence in people with MS, is restless leg syndrome. And this is when people have a persistent or overwhelming urge to move their legs while they are resting. And then when they move their legs, it provides temporary relief. But then, that overwhelming urge returns. And so people are aware that they have this overwhelming sense to move their legs. And it oftentimes manifests, of course, when they are attempting to fall asleep. So again, if that's something that you recognize in yourself, I definitely would encourage you to talk with your physician. Because there are, typically, some labs that they will do to see if there might be an underlying cause for that restless leg syndrome.

Another common sleep disorder is periodic limb movements during sleep. And that, it's associated with restless leg syndrome, but it's actually a different sleep disorder. And so this is when the person is sleeping but they periodically move their limbs. And so oftentimes the individual is not aware that they have PLMS because they're sleeping. So oftentimes it's the bed partner that will report that the individual is periodically moving their legs.

And then another one to mention is REM sleep behavior disorder. And that, it's a fairly obvious sleep disorder, when people are acting out their dreams. Normally, typically when we sleep, most of our dreams happen during REM sleep. That's one of the sleep stages. But we typically have muscle atonia, so we don't typically act out our dreams. But people who have REM sleep behavior disorder, their muscles don't undergo atonia, and so they then act out their dreams. And that is a big safety issue, both for the person who has the sleep disorder, but also for their bed partner as well.

So those are some of the main sleep disorders, but also, too, I would suggest that if you are feeling like you are needing to sleep more than nine, ten hours at night., That can also indicate an undiagnosed sleep disorder as well. Or if you, wake up despite getting, or despite having a sufficient sleep opportunity window, if you still have excessive daytime sleepiness, again, that could indicate another undiagnosed sleep disorder as well. So if you're experiencing any of these things on this slide, I definitely would encourage you to speak with your health care provider, to do a full work-up, to see if you might possibly have a sleep disorder.

All right. So now we're going to shift gears a little bit. We've talked about common sleep disorders in people with multiple sclerosis. Now I'm going to shift to talking about behavioral interventions to improve sleep and fatigue in people with MS. So, we have done, now, a few different studies using cognitive behavioral therapy for insomnia, that's what CBT-I stands for. And so it includes addressing the behaviors and the negative thoughts surrounding sleep for people who have insomnia. And so this is a trial that we did now a few years ago. And we

published this in 2020. And this was an in person study, where we actually had three different groups. We had people who were either randomized into the Cognitive Behavioral Therapy for Insomnia group, where they received this specific intervention, one time a week for six weeks, or they received a brief bout of education. So basically everybody came in for a baseline assessment. And the people who are randomized into that brief education group, they received about 20 to 30 minutes of education, most of which you'll be receiving tonight, from a research assistant. And then we did see them for for six weeks, and then they were reassessed. And, then we also had an active control group. And so those individuals, they also came into the laboratory and they participated in stretching activities, they played games basically to interact with the lab personnel. They came in one time a week for six weeks. And of course, that was our control condition.

And so what you can see on this figure here, I mean, what we're looking at is called the Pittsburgh Sleep Quality Index, and that is one of our gold standard questionnaires to look at sleep quality. And a higher number indicates poor sleep quality. And so this triangle, so that's our active control group, you can see at baseline they scored at about a nine on the Pittsburgh Sleep Quality Index. And they maybe improved slightly over the course of that six week period. Of course we didn't expect them to improve. Interestingly, the brief education group, which we really thought would be sort of a control group, they actually saw a great improvement. So they saw a good degree of improvement from that baseline, through that reassessment, which was great news, right? Because if you can give an intervention in 15 to 30 minutes on these sleep education promotion techniques and people can see an improvement, to me, that is fantastic.

But of course, the largest improvement was seen in the Cognitive Behavioral Therapy for Insomnia group, which, again, is what we expected, because those individuals are receiving a standardized program where we are focusing on those negative thoughts and those behaviors that are perpetuating insomnia. So those individuals, they did see the largest amount of improvement, from that baseline through that reassessment, they are the dark filled-in circles. But again, we were very pleasantly surprised that even those individuals who received that brief education also saw a meaningful improvement in their sleep quality as well.

And we also, another outcome we used is the modified Fatigue Impact Scale to measure fatigue. And we saw very similar results that we saw in our sleep quality measure where the, and with this scale, again, higher numbers means more fatigue, lower numbers mean less fatigue, and we see again the active control group, which is the triangles, the upside-down triangles, they pretty much stay the same, from that baseline to the reassessment, which is what we would expect. We saw a nice improvement in the CBT-I group, which is the dark closed circles, had a meaningful improvement in their fatigue. And then again, the people in that brief education group also saw a very similar magnitude of improvement in their fatigue as well. And so, we've done this, this is the in-person study that we've done. We've also done an intervention CBT-I delivered via telehealth. We've also done CBT-I delivered via a web-based application. And regardless of the mode of CBT-I that we provide, we see very similar results as far as improving both sleep as well as fatigue.

And then I want to talk a little bit about, and this will be the last research article I talk about before we get to the fun stuff of, okay, so what can I actually do to improve my sleep? And so we, we wanted to do a systematic review where we looked at various behavioral interventions to improve sleep in people with multiple sclerosis. And so this was very much a team effort of individuals and David Turk, who is a research assistant in my lab. And so we, as a team, found all of these articles and, you can see on this pie chart, these are all the different classifications of behavioral interventions. And so there were 13 studies, but the largest number looked at

physical activity. Six studies looked at cognitive behavioral therapy for insomnia. Four of those are our studies. And then four studies used cognitive behavioral therapy. So CBT is a specific CBT to treat insomnia. But there are there are other CBT techniques, or I should say it's more of an umbrella, global term. Six settings use mindfulness for relaxation. Three used education or self-management. And then five used different types of complementary and alternative intervention.

And so if we look at these studies together, these different tables, let me just orient you a little bit first. On that vertical axis, this is the number of articles, and then we have them grouped by those categories that we just talked about. So physical activity, cognitive behavioral therapy for insomnia in the middle, on the top, and then CBT for psychotherapy in the upper right hand side, mindfulness / relaxation, education / self-management, and then the complementary and alternative interventions. And I will also point out that when we look at research studies, we ideally like to see randomized controlled trials, those are kind of our gold standards for how we compare an intervention to another type of intervention, as well as pilot randomized controlled trials, they're just not quite as rigorous. But then there are other study types as well that too provide us useful information but aren't considered as rigorous as a randomized controlled trial.

And so just by looking at these tables, or these figures, on the left hand side, those are the number of articles that showed an improvement. And then the next column is if they showed an improvement, but it wasn't statistically significant. The next column is if they had an improvement immediately, but perhaps it wasn't maintained, so they no longer saw that improvement when they did another reassessment later on. And the last category is if they actually saw a worsening or no improvement or they had mixed results, I think that we included kind of those other, either lack of results or negative results into one category. And so just by looking at this figure, you can see that there are mixed results with, physical activity. The most of those articles, though, they did see a positive improvement. But then there were some that maybe saw some improvement, but it wasn't statistically significant. And there were two that either saw no improvement or had mixed results or actually saw worsening. CBT-I, out of all of the studies that have been done, have shown positive improvements. Same thing with the CBT or the psychotherapy. And the nice thing about that category is all three of them were randomized controlled trials. Mixed results with the mindfulness studies, as well as with that education and self report, and then mixed results with the complementary and alternative interventions as well.

So if we take all of this together, here's kind of a take home point, from that article that we proposed is that interventions that used either cognitive behavioral therapy for insomnia, or the more broad umbrella term of cognitive behavioral therapy or psychotherapy, as well as education / self-management, did tend to have positive outcomes. Whereas those studies that looked at physical activity as a behavioral intervention or looked at mindfulness and relaxation or other complementary and alternative interventions, tended to have mixed results. And I guess I want to really emphasize, though, that in the general population, we do see that physical activity as well as mindfulness and relaxation can be very beneficial, again, in the typical population. We just don't have strong enough evidence for people with multiple sclerosis at this time.

But, what we really need to see is in this third point of this article, is that it was really a challenge to look at these studies all together, because a lot of them looked across different sleep issues. So, if one study was looking at insomnia, another study was perhaps looking at poor sleep quality, which could be due to a lot of different things. It's kind of like comparing apples to oranges almost. And then also the intervention dose differed across studies. So just thinking

about physical activity, they could be doing strengthening versus aerobic exercise. They could be doing one time a week versus three times a week. Again quite a bit of variability as far as the intervention dose. Differences in the outcome, the sleep outcomes that were used, a lot of them were fairly small studies, and so probably didn't include enough people to have competence in the statistical results. Problems with a comparison group as well as the training of the interventionist. So really, there's a lot of work to be done for us researchers still. And so again, I think the positive thing to take from this is we do know that there are some behavioral interventions that can be very effective for people with multiple sclerosis, but that we really do need to have more research to be done.

All right. So we're gonna move on from the research aspect and now get into the "what can I do to help myself sleep better?" And so, before we get to the "what," I find it very helpful to talk about the "why." So, you know, this will help give that explanation for why I'm going to make the recommendations that I am. And so we need to first talk about the two processes that underlie our sleep. And so we as humans, we have two processes that make us sleep, and control our sleep and wake cycle. And so for humans, we have what's referred to as our circadian rhythm, which we refer to as process C. And you've likely heard of circadian rhythm before, in humans that roughly lasts 24 hours. And it is regulated by the suprachiasmatic nucleus in our brainstem. And it pretty much controls all of our hormones, and when our hormones are released, and how much hormone is released.

And so for sleep, the most potent hormone is going to be melatonin. And that's really what's going to tell our brain to to switch from being asleep to being awake and vice versa. And so for humans, and this is actually showing our wake drive, so we have our wakefulness, you know, if we wake up at around 7 a.m., our wakefulness will build up during the day and gradually begin to dip down in the afternoon. So we'll have our lowest peak, or our lowest trough of that wake drive is going to be in the middle of the night, which is ideally when that happens. And then the other process is our process S, we refer to that as our sleep drive, or sleep homeostasis is another term, but basically the longer you're awake, the more sleep promoting substances, including adenosine, will build up in our brains and make us feel sleepy. And so during the day, again, you wake up, say, around 7 a.m.. that sleep drive is going to build up all day long. So then at 11 p.m., that sleep drive is super high, and ideally, then your melatonin has kicked-in and your brain is switching from being awake to being asleep. And so we want there to be as much distance as possible between that wake drive and the sleep drive. And so what we focus on in cognitive behavioral therapy for insomnia, our processes and strategies to both strengthen that sleep drive as well as strengthen that circadian rhythm. And we'll talk about ways that you can go about doing both of those things.

And so cognitive behavioral therapy for insomnia is a specific intervention for people with insomnia. But we have also then taken kind of those main principles, and we refer to it as a sleep health promotion, because everybody has sleep health, it's on a continuum. Some people have really good sleep health, and some people have really poor sleep health. And so we refer to promoting sleep health by filling up these four buckets. And we've already talked about we want to entrain circadian rhythm. We also want to increase sleep drive. Another important piece, though, is to make sure that we're reducing pre sleep arousal, or reducing stress is another way to think about it, because you can have a really strong circadian rhythm, you can have a really high sleep drive, but if your sympathetic nervous system, if your fight or flight system is really active, it disrupts the ability of those sleep systems to work and to do their thing. So we focus a lot on reducing pre sleep arousal, again, reducing stress.

And then the fourth bucket is what we refer to as sleep hygiene. And those are kind of a general environmental, the general behavioral things that can impact your sleep health. So things like smoking, cigarette use, alcohol use. You'll see that I have kind of an etched line around sleep hygiene. Because, yes, we certainly want to talk with people about sleep hygiene, but typically it's not sleep hygiene that is the primary driver of people's sleep health. So yes, talk about it. But it's not usually the big main bucket that we need to be addressing.

Okay, so now for the fun part. How do I actually go about doing these things? So to entrain circadian rhythm, the two most important things that you can do is... and let me, sorry, I know that was just a big cliffhanger to say, "the two most important things you can do," but I also say that these strategies, this is like best case scenario, this is in an ideal world. And so I would maybe as we're going through these next few slides, for the next, you know, 15 minutes or so, maybe think about if there's one, maybe two of these strategies that really resonates with you, that might be something that you could implement. Because it is a challenge to do all of these things all the time. So I just want to point that out that this really is best case scenario.

So the three most important things that you can do to help and train your circadian rhythm. The first thing is to wake up at the same time every day. And I wake up at the same time. I mean, within an hour, ideally even within about 30 minutes. Because what happens is when you wake up at the same time every day, the other second most important thing can happen, and that is exposure to light. And so we have a direct connection from our retina to that suprachiasmatic nucleus in our brainstem. And that light tells the brain to stop secreting melatonin, and that it's time to switch from being asleep to being awake.

So wake up at the same time every day and expose yourself to bright light. Ideally sunshine, if it's possible. You know, with daylight savings, it's getting to be in winter, it's much harder to have natural light. Turning on the lights is okay. Sunlight, of course, is best. But what happens is when you wake up at the same time every day, that's really what helps entrain your circadian rhythm. And so I don't encourage people to have a regular sleep schedule, have a regular wake up time. And when you're very diligent about that, your bedtime will naturally emerge as your circadian rhythm develops. And so I usually, when I work with clients around who have sleep challenges, we usually talk about, like, a bedtime window, that they're kind of, you know, just having in their mind, but that they should not be going into bed to fall asleep until they are fairly confident that they're going to fall asleep. And that gets into the concept of stimulus control, which we'll actually talk about in the next slide.

So strategies that we've used with clients, to wake up at the same time every day. A very easy one is to set an alarm. Some people will set a couple alarms. And also, to think about scheduling a morning activity is one thing to do. But to think about what is something like a reward? What would you do with the gift of extra time? Because everybody likes extra time. Everybody likes gifts. You know, so, for example, you know, I had a client who was like, oh, I'm going to drink my coffee on my porch and enjoy the scenery. Or I had another client who was like, you know, I used to really like to watch this morning show, I'm going to start watching that again. Or, another one wanted to start exercising again, which that was fantastic to use that time. So, again, what would be something that would be motivating to you, to help you get up at the same time every day? But that does require a little bit of, you know, again, intention of what that might be. And then also, of course, if you do have a bed partner or people who live in the house with you, having their support is definitely very helpful as well.

And then exposure to light. I mentioned having that bright light first thing in the morning is very important because that helps to entrain circadian rhythm. But what we also know is that people



oftentimes are not getting adequate light throughout the day. Because a lot of times people are spending most of their time indoors. And so ideally, getting outside if you can, or having light exposure during the day is also very important to help entrain circadian rhythm. But then as we start to wind down into the evening, getting closer to bedtime, thinking about dimming the lights. We also want to try to avoid having electronics held very close to our face, because that bright light, specifically the blue light that gets emitted, can actually reduce the amount of melatonin that gets produced. And then making the sleeping environment as dark but safe as possible, you know, so if you need a nightlight on to safely get to and from the bathroom, that's fine to do. But again, having it as dark and as safe as possible. There are, of course, exceptions. Some people have a shifted circadian rhythm, so they tend to go to bed really early, but wake up really early, or go to bed late and wake up late. How we treat that then, is with, oftentimes, with melatonin and also with light exposure and dark exposure. So if you do identify with having a shifted circadian rhythm one way or another, again I would encourage you to talk with your physician. Because these recommendations will likely be different for for you.

Last bullet on this page. There's really some fascinating research that's coming out about how the regularity of other activities may also help at least inform our circadian rhythm. So like regularity of meals, regularity of exercise, that also can contribute to helping to entrain circadian rhythm, not to the same degree that light and dark will, but can also have an impact as well. So I do encourage clients to have regular meal times and also, ideally, have physical activity and have regularity of the timing of that activity if possible. And so that's how we entrain our circadian rhythm.

The next thing that we focus on is to have that sleep drive be as high as possible. And so one way that we, or a caveat of that or association of that, is what we call stimulus control. And so we want the brain to associate the bed with sleeping. We don't want the brain to associate the bed with worry, with anxiety, with watching TV, with thinking about your to do list, with all the other things. So we really encourage people to use the bed for sleep and sex only. And if you are not asleep and what feels like, because we don't want people looking at the clock, so it really should be what feels like 15 to 20 minutes. Or, you start to feel worried or anxious that you're not sleeping, ideally, you get out of the bed, go somewhere else, if that's possible, and do something that is relaxing and distracting. So like listening to an audiobook, listening to music, relaxing. Some people meditate, some people pray. It doesn't matter what the activity is, as long as it's relaxing and distracting. And then you return to bed when you feel adequately tired, like you are fairly confident, are going to fall asleep.

Definitely with our clients with multiple sclerosis, if we or they are concerned about their mobility limitations, or concerned about falls, then do not get out of bed, but instead stay in bed and do the relaxing and distracting activity in bed. If you are able to get out of bed, I always talk with clients about having a plan. Where are you going to go? What are you going to do? Having that, we refer to it as the cozy nest, have your cozy nest set up with, if it's going to be a book that you're going to read, or maybe it's an audiobook that you're going to listen to, have your phone there, have your earbuds, whatever you need. Have a blanket, have your slippers, have a cup of water. So that way it makes it a little bit easier to get out of bed and go to that cozy nest.

And you can probably imagine that this is not people's favorite thing to do. But we do know that when people are able to do this and do it consistently, it can be very effective to improve that association with the bed meaning "equals sleep." So we do have to focus a lot on the why., because, again, this is going to increase your sleep drive, it facilitates that association with the bed with sleeping and also eliminates sleep effort because you cannot make yourself sleep no matter how hard you try. And we really want to get away from the "trying" of sleep. And so by

getting people out of bed or by doing a relaxing, distracting activity in bed, it wipes out the “trying” of sleep. And you are adequately tired and ideally then are able to fall asleep. So that's one way that we increase sleep drive.

Another thing is physical activity. We know that exercise is good for us for lots of reasons. We also know that exercise and physical activity also helps people sleep better. And it doesn't appear to matter the type of exercise, it can be strengthening, can be aerobic exercise, it can be meditative type movements. They all appear to be beneficial to help people sleep better, including people with multiple sclerosis. So again, we looked at those 12 or 13 studies, some mixed results. But again, likely because for various, again, methodological reasons that we've talked about. You've maybe heard that you shouldn't exercise within 2 to 3 hours of bedtime. But there was this big, national poll that was done, now it's about 11 years ago, where they looked at people who exercise within four hours of bedtime, or more than four hours of bedtime, and they found that there was no difference in ability to sleep. So the recommendation is exercise is good regardless of time of day.

That being said, there is some emerging research that shows that for people who are doing vigorous exercise within one hour of bedtime, that that might actually be disruptive to people's sleep because it increases body temperature, and increased body temperature can affect melatonin production. And so if you are having challenges sleeping and you are doing vigorous exercise within one hour of bedtime, then you might want to move that exercise earlier in the day. With all the clients that I've worked with over the many years now, I've yet to have this be an issue. Typically we are encouraging physical activity, again, regardless of time of day.

Another thing to think about that we oftentimes see in our clients with multiple sclerosis is the question about naps. And I am a, I know on here it says to avoid or limit naps, but I'm a big believer that people know their bodies best. And if you feel like you need to take a nap, then by all means do that. But just try to limit it to no more than 30 minutes and try to do it as early in the day as possible. And also know that you might have to delay your bedtime to give that sleep drive sufficient time to build back up. Because what we see is that when we are awake, we have that sleep drive build up, and then if you take a nap, you just have a dip in that sleep drive. So it just might take time again for that sleep drive to build back up. And then the other thing too is, you know, obviously, a rest break is very different than a nap. If your intention is not to sleep, and you're just intending to rest, then I would say don't do that in the bed, because we, again, we want the brain to associate the bed with sleeping. We don't want the brain to associate the bed with other things. And I also will usually recommend that people, if they are going to do a rest break, that they think about using like a timer or an alarm clock. So that way if they do happen to fall asleep, inadvertently, then it does limit that nap period and shorten it as they can.

So those are entraining circadian rhythm, increasing sleep drive. Again another big thing we focus on is reducing pre-sleep arousal. So that way those two physiological processes can actually do their thing. So two things that we really focus on with our clients. The first thing is to develop a relaxing bedtime routine. And it can be short and sweet, that's great. Take a warm bath, take a shower, read, meditate, journal. It doesn't really matter what it is, but what that relaxing bedtime routine does is that it tells the brain, it trains the brain that what comes next is going to be the bed, which equals sleep. And that's what we want to train the brain to know that. So I'm going to do this activity, and then I'm going to get in the bed and I'm going to fall asleep. And the brain knows to do that.

And the other thing that we focus on is doing relaxation throughout the day, because our day is 24 hours. I know when we think about sleep, we're oftentimes thinking about those nighttime

hours that we are going to be sleeping. But what we do during the day also impacts our sleep. And so oftentimes what happens is that people, we stay busy during the day and we keep our brains occupied during the day. And it's not until then we get into bed and we're attempting to sleep, and now we're not distracted, that all the thoughts from the day, all the to do list, all the worries, all the things that I've got to get done now are coming to my brain.

And so we ideally want to mitigate that as much as possible. Can't usually get rid of it completely. But if we can practice that relaxation throughout the day, that can help, again, kind of reduce that stress and reduce it from building up throughout the day. And we really encourage people to practice because we want you to be able to elicit a relaxation response. There's lots of relaxation strategies to use. The ones that we tend to use is deep breathing - five, seven, eight, you breathe in for five seconds. Hold it for seven, exhale for eight. Another one is progressive muscle relaxation, which is one where you progressively tighten and relax different muscle groups within the body. Mental imagery is another strategy. Doesn't really matter which one you use, whichever one you're going to use and use it consistently is the one you probably want to go with. And again, practice it throughout the day.

We also work with people on mindfulness. Oftentimes people are not aware of the kind of negative thoughts that they have surrounding sleep. And so working on mindfulness can be very helpful. Some people like to journal, and journaling can take many different forms. We have the to-do list, gratitude, plan your next day. Again, whatever would be most effective for you. And then getting off of screens two three hours before bedtime. Because again, that blue light can reduce melatonin secretion, but also the content can be stimulating and is also a time suck. You know, maybe you intended to watch just one episode of a show and then, you know, three episodes later, your bedtime is not blown by an hour or so.

Sleep hygiene. Again, these are probably things that you've heard of. To avoid caffeinated food or drink. Refrain from smoking. Alcohol consumption is a conversation that I oftentimes have to have because it is true that alcohol can help you relax and it may help you fall asleep. But it actually can increase the number of awakenings that you experience throughout the night. So the general recommendation is no more than one drink each night.

And then avoiding large spicy meals. Also thinking about your liquid consumption. You don't want to be dehydrated, so certainly drink sufficient liquid. But also not having it be excessive so that that doesn't contribute to the number of trips to the bathroom throughout the night. And then if you are finding that you have to go to the bathroom throughout the night, making that as quick and as easy as possible. So if you are having bed mobility limitations or gait limitations, mobility limitations, definitely seeing a physical therapist can be very helpful. And then also thinking about fall prevention, again, to get to the bathroom as quickly and easily as possible. And then thinking about your environment, ideally making it as comfortable and relaxing as possible, trying to eliminate as much light, but again, keeping it safe as well, reducing noise, keeping the temperature comfortable, and then also using a comfortable pillow and mattress, again, in an ideal world.

And I just want to share a few other resources before we move on to question and answer. These are some resources that we have used with clients. And so I feel fairly confident in the quality of them, so Insight Timer is a nice app if you maybe enjoy mindful meditation. Insomnia Coach is a great app for people who do have insomnia. It was developed by the Veterans Affairs Office, and so it's a good quality app as well. And then Mindfulness Coach, it was developed by the Department of Defense and the Veterans Affairs, so that also takes you through a mindfulness practice. And then Breathe to Relax has some different breathing

activities that people have found enjoyable. And I will go ahead and stop there and would be happy to take any questions that you might have.

**Yahaira Rivera:**

Thank you so much, Dr. Siengsukon, this presentation was so informative and we appreciate all the research, all the insights and also all the resources that you just shared. We do have questions and I'm going to start with this one: I'm curious what you recommend for people who wake up in the middle of the night but then can't fall back to sleep?

**Dr. Catherine Siengsukon:**

So for those individuals, I will go back to the stimulus control. So those are people that we would really encourage that if you're not, if you wake up in the middle of night and you're not able to fall back to sleep in what feels like 15 to 20 minutes, if it's safe for you to do so, then getting out of the bed and going somewhere else and doing a relaxing, distracting activity to help keep your body relaxed, to keep your body calm, and also to distract you. Because oftentimes what happens when people are not able to fall back to sleep, they get frustrated, understandably so, I do myself. But to, again, distract from those kind of negative thoughts, if you're not able to safely get out of bed, then do the distracting, relaxing activity in bed. So again, listening to an audiobook, listening to a book on tape, listen to music, doing mindful meditation. We'll also encourage people once they've practice their preferred relaxation strategy throughout the day, and they're able to elicit a relaxation response, that's another great time to be practicing that relaxation strategy as well as during that time where you are doing a relaxing, distracting activity.

**Yahaira Rivera:**

Thank you so much. Our next question reads, Does MS cause sleep disorders, for example, because we have a lesion in that part of the brain, or are they secondary to the MS?

**Dr. Catherine Siengsukon:**

It's a great question. And the answer is both. So it can happen that the MS lesion can occur in the areas of the brain or the circuits of the brain that regulate that sleep wake cycle. But then also there are, of course, a lot of common symptoms, common issues that people with MS oftentimes experience that can very much contribute to sleep issues. So motor challenges, sensory challenges, depression, anxiety, the stress with having a chronic condition, all those things can certainly be contributing to having sleep issues as well.

**Yahaira Rivera:**

Thank you. Our next question: When you say lack of sleep affects my immune system, since our immune system is overactive, would impacting it actually help? Please explain.

**Dr. Catherine Siengsukon:**

That's a good question. And so, you know, there really hasn't been enough studies specifically done in people with MS to see if too much sleep, too little sleep, how does that impact people with MS specifically, or other immune conditions for that matter; to look at their sleep issues. What we have, what the general population will see is that for people who are not getting adequate sleep, that also can cause a inflammatory reaction as well. So we'll have an increase in those inflammatory biomarkers as well. And so, I would not suspect that not getting adequate sleep would actually reduce those MS autoimmune and inflammatory biomarkers that are experienced. But that's just what I would base on kind of the general population, the evidence

that's out there. But again, no one's actually done that specific study in people with MS or other autoimmune conditions.

**Yahaira Rivera:**

Thank you. Our next question is: can my MS medication affect my sleep?

**Dr. Catherine Siengsukon:**

There's, of course, lots of different types of medications that people with MS are oftentimes on. The medications that generally will impact the progression of MS, they do not appear to be impacting sleep, in a good or bad way. Typically what we will see is people who are on antidepressants, they can experience changes in their sleep architecture. But improvement in depression oftentimes has an improvement in sleep as well. Same thing with anxiety. We oftentimes see people who are on anti-anxiety medications will improve their sleep. For some people, though, with multiple sclerosis, if they're on a stimulant because they have excessive fatigue or excessive daytime sleepiness, you know, they, sometimes, by taking that stimulant, that can then negatively impact their night of sleep. So, if that's the medication that you're on and you're having challenges with sleeping, I would definitely talk with your physician about the timing of the stimulant and see if there would either be a different stimulant or the timing perhaps needs to be altered, if that's what perhaps is contributing to your your challenges with sleeping. The disease modifying medications don't seem to have a negative impact on sleep.

**Yahaira Rivera:**

Thank you. Thank you for that. Our next question is: Is it necessary to get sleep hours consecutively, or is it okay to get the daily sleep requirement throughout the day?

**Dr. Catherine Siengsukon:**

That's a good question. And so, you know, and there's actually been, if you have any fascination with learning about, kind of, you know, through history how sleep has changed, you know, way back when, there used to be kind of this mode or pattern where there would be, you know, nighttime sleep and then, you know, people would wake up during the day and then it would be hot. And so people would take kind of a nap, in the afternoon. And there wasn't like an increase in health issues with that. But, in general, the recommendation would be to have that consolidated sleep during, again, in humans, typically it's during the nighttime. Just because we know that there are certain processes that are happening while we are sleeping, and specifically, the rotation between those sleep stages. So we cycle between REM sleep and the different stages of slow wave sleep. And so ideally you want that cycling to happen so those processes can occur. Now, that being said, again, that's in an ideal world. If it's not possible for you to get a solid chunk of nighttime sleep, then certainly, you know, again, if you need to take a nap to help manage that, you know, then that certainly is an option, if need be. But again, I think in an ideal world, it would be that consolidated one period of sleep, if possible.

**Yahaira Rivera:**

That was very interesting. Thank you for sharing with us. Our next question is: Is it safe to take supplements such as magnesium or any other supplements that you recommend?

**Dr. Catherine Siengsukon:**

With... I mean, I would definitely... I always encourage people to talk with their physicians to see if you are reduced in those specific areas. You know, there is some interest in magnesium, you know, of course, I often get asked about like melatonin, those sorts of supplements as well. And certainly for some people, those are appropriate. You know, if you have low levels then it might

be appropriate to be taking those. But definitely talking with your physician. I also... I mean, my general philosophy is that our bodies are made to sleep. And, oftentimes, again, it's the environment or these negative thoughts or these behaviors that disrupt our sleep. And so, I hesitate to, you know, for people to be taking these supplements or medications and have that be something that they feel like they are required to take or they have to take. And again, for some people, it might be absolutely appropriate to be doing that if their physician recommends. But certainly we see that people are oftentimes over prescribed sleep medications or over prescribed sleep aids, or taking supplements that really are not effective for their sleep. And so, we try to get away from doing those if possible.

**Yahaira Rivera:**

Thank you. Our next question is, I think that's a question that we all usually ask, and we have different opinions: So how many hours of sleep do we need?

**Dr. Catherine Siengsukon:**

Also a great question. You're probably not gonna like this. So, it depends. We all have a different sleep need, or we have a biological sleep need. Across the US adult population, the general sleep need will fall somewhere between 7 and 9 hours of sleep. Again, in general. Some people might be able to get by without negative health consequences with six. And there might be some people who need 9.5 hours of sleep. But again, that can.. generally is... between 7 and 9 hours is typically what's recommended. You know, for some people, I'll have them think back, you know, was there ever a time in your life that you were able to go on vacation and you didn't have to work, and you could truly relax and you could sleep when you wanted to. You know, what was your preferred circadian rhythm? What was your preferred sleep duration? Sometimes that gives us at least a window of insight into those kind of preferred and ingrained sleep-need and also circadian preference.

**Yahaira Rivera:**

Thank you. Our next question says: No matter how many hours I sleep, I feel exhausted and tired the next day. What can I do to feel more energized?

**Dr. Catherine Siengsukon:**

I would suggest talking with your physician. When I hear people say that, you know, that they have an adequate sleep opportunity, you know, so if you're giving yourself 7 to 9 hours of window to sleep, and you feel like you're actually getting that amount of sleep and yet you're still feeling tired, exhausted, that's when you should go talk to your physician, because it is possible that you have a sleep disorder that you're not aware of. And we see this a lot in the people that we work with. You know, they have undiagnosed sleep apnea or they have irregular movements of sleep and they're not aware that they have that. So definitely, talk with your physicians, especially if this has been going on for a while.

**Yahaira Rivera:**

Thank you for that advice. And our last question of the night is for those living with multiple sclerosis, and they suffer from pain or bladder issues or stress during the night, what is your suggestion or your advice?

**Dr. Catherine Siengsukon:**

So some of it, well, I mean, those are very different issues oftentimes, you know, and so I think it obviously if we could talk about pain first, you know, I think it would depend on, you know, what's the underlying issue with pain? Is that something that can be addressed? You know,

sometimes different positioning can be very helpful. These strategies, these sleep health promotion strategies have also been done in people with chronic pain conditions, I didn't do this research, and this wasn't in people with multiple sclerosis, but doing these techniques have been shown to improve sleep and improve pain in people who have both chronic pain and have sleep issues as well. So that would be one thing.

And then as far as bladder issues. So, oftentimes we do see in the individuals that we work with who have MS, if they do have to get up to go to the bathroom, you know, 2 or 3 times during the night or more, you know, sometimes doing these suggestions can be very effective because if you can get into a deeper stage of sleep, it reduces your number of nighttime awakenings. And so sometimes what happens is, you know, people will wake up and they're like, oh, I'm awake. I have to go to the bathroom, I'll go to the bathroom, but it's not the going to the bathroom that actually wakes them up. Now, for some people, they actually do have spasticity of their bladder and that that is causing them to go to the bathroom more often. And so those are people that may, you know, even though we're doing this intervention, if they continue to you have to get up to go to the bathroom more than one time a night, I will encourage them to talk with their physician, because, again, there's medication that can help with that spasticity of the bladder. So it kind of depends on what specific symptom might be contributing to your sleep issue.

**Yahaira Rivera:**

Thank you so much. And I'm going to give an opportunity so that you can share with our audience what was the website that you recommended. They're asking about the website.

**Dr. Catherine Siengsukon:**

Yes. So should I put that in the chat?

**Yahaira Rivera:**

Thank you so much.

**Dr. Catherine Siengsukon:**

Is that where I should put it, is the chat? Okay. So I have... so, we did... we have developed a sleep health toolkit. It's not specific to people with multiple sclerosis. But it does include resources around these techniques that I've just mentioned. So I am going to drop that into the chat. And so the toolkit is, we have a section that's geared towards clinicians. And then we have a section that's geared towards clients. And so I would, again, check it out. Hopefully that's something that's helpful as well. And then we are, we do actually have a cognitive behavioral therapy for insomnia study going on right now. And it's being done nationally, so it doesn't require any visits. So if you do have any interest in participating in that, we are recruiting people who have insomnia. So I'm going to drop that. It's also on our web page, but it's a different link. So I'm going to just post that for anyone who might be interested.

And then one last resource, we also had written an education pamphlet that was geared towards people with MS. And so I'm going to share that website and it is freely available. So you just have to... actually, I think I can... let me just download the PDF. That would be even more straightforward. And I can share that link as well. So all three of those are in the chat now. So there's hopefully resources that are helpful. And if you would have interest in the study, feel free to provide that contact information. And our study coordinator will get back with you. I thank you so much for having me. I really appreciate the time and the platform to share this information.

**Yahaira Rivera:**

Thank you so much. Thank you for being here with us and teaching us about sleep health, especially tailoring your presentation and all the research for people living with multiple sclerosis. And I promise to the audience that all the links that Dr. Siengsukon can just shared in the chat, we'll put them in a document and when we add the recording on our website, we can add that as a resource so you can go back and revisit.

So thank you once again to Dr. Siengsukon for your informative presentation on sleep health and its impact on the MS journey. Thank you for sharing all the strategies and resources with us. And to our friends at home, thank you so much for joining. We hope that you have enjoyed this session, and that you can go back and apply the learning and enjoy a better sleep at night, because we know how important that is for our physical and emotional health. And know that this program was recorded and will be archived on our MSAA's website in the upcoming weeks. And please don't forget to take a few minutes to complete the brief survey. On behalf of MSAA, thank you everyone and have a wonderful evening. Bye-bye.