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Understanding Insomnia and Fatigue

Wednesday, May 6, 2009

Ann M. Berger, PhD, RN, AOCN, FAAN

OPERATOR:

Greetings, ladies and gentlemen, and welcome to the Living Beyond Breast Cancer "Understanding Insomnia and Fatigue" conference call. A brief question-and-answer session will follow the formal presentation. As a reminder, this conference is being recorded. It is now my pleasure to introduce your moderator, Ms. Elyse Caplan.

ELYSE S. CAPLAN, MA:

Thank you, Scott, and welcome, everyone, to Living Beyond Breast Cancer's teleconference, "Understanding Insomnia and Fatigue." I'm the education director here at Living Beyond Breast Cancer, and I'm happy to serve as today's moderator.

These topics, insomnia and fatigue, are of great importance. For women affected by breast cancer, most often after diagnosis, you will face issues related to sleep and fatigue whether it's recently diagnosed . . . or if you're in the midst of consultations with physicians or other healthcare providers and in the midst of treatment. Or, if you've completed treatment, and you're trying to move forward in the recovery phase, or even years beyond your breast cancer diagnosis.

Sleep-related and energy concerns can affect us for weeks, and sometimes even for many months after breast cancer [treatment]. Also, emotional or psychological factors can impact our energy levels and our quality of sleep. We need to pay attention to that as well. Whether you've had sleep problems prior to your cancer diagnosis or not, all of these things may impact your quality of life. Living Beyond Breast Cancer's mission — to empower all women affected by breast cancer to live as long as possible with the best quality of life — truly resonates with today's topic. Quality of life is really underneath every decision we make. These subjects, insomnia and fatigue, are so important to the staff here at Living Beyond Breast Cancer that we have developed a brochure

titled, "[*the Guide to*] *Understanding Insomnia and Fatigue*" [<http://www.lbbc.org/content/news/lbbc-releases-new-brochure-on-insomnia-and-fatigue.asp>]. Our featured speaker today, Dr. Ann Berger of the University of Nebraska Medical Center [<http://www.unmc.edu>] College of Nursing, served as our lead reviewer for this publication. And we're so grateful for her guidance, her support, and her technical assistance. Also, you will learn some of the latest updates to ensure your well-being, including some strategies that you may integrate into your life, and questions you may want to take back to your healthcare team.

. . . Living Beyond Breast Cancer's toll-free Survivors' Helpline is another way you can get pure emotional support (888) 753-LBBC or 5222. We also encourage you to post messages on Living Beyond Breast Cancer's message boards [<http://www.lbbc.org/forum>].

. . . The LBBC staff truly values your input — it helps us design future programs. So, when you get your program evaluations e-mailed to you today, please take a few minutes to give your candid feedback on what went well, and what you'd like to learn more about. We definitely will integrate your thoughts into future programs.

. . . Now, I'd like to tell you just a little bit about our featured speaker, Dr. Ann Berger. Dr. Berger is a professor, a Dorothy Hodges Olson Endowed Chair and director of the doctoral program in nursing at the University of Nebraska Medical Center. She's an advanced practice nurse in general oncology at the University of Nebraska Medical Center and an advanced oncology certified nurse. Dr. Berger was selected to present the State of the Science Lecture on Sleep/Wake Disturbances at the 10th National Conference on Cancer Nursing Research in February 2009.

She has been researching fatigue and sleep disturbances in cancer patients since 1992, and recently completed a research study funded by the National Institutes for Health

on fatigue and breast cancer patients during and after chemotherapy treatments [http://www.unmc.edu/nursing/grant_fatigue/fatigue_home.htm]. Dr. Berger was inducted into the American Academy of Nursing in 2005, and serves on an NIH grant review panel. Her articles have been published widely in a variety of journals, and there are many more credits to Dr. Berger's name. But, without further delay, I am pleased to welcome Dr. Ann Berger.

ANN M. BERGER, PHD, RN, AOCN, FAAN:

Thank you so much, Elyse. . . I'm very happy to be here today to talk to all of you, and I hope that you'll be writing down your questions as we go along. . . Do bring those up during the question-and-answer period.

I have been working with cancer patients for 25 years, and as a researcher for over 15 years — fatigue has been my focus that entire time. It was when I first started [researching] fatigue that I found out that negative mood — such as depression — sleep disturbances, and nausea were the three symptoms most closely associated with fatigue as women went through breast cancer chemotherapy. I sought to design an intervention that might focus on helping people sleep better, with the end result of lowering their fatigue. That [intervention] was successful in a pilot study, and I just completed an NIH-funded research study in which sleep intervention definitely improved the sleep of patients. The fatigue-outcome was a little bit more complex. The study demonstrated how important it is when we look at fatigue that we not focus only on sleep. We also need to look at things like physical activity and psychological distress — such as anxiety and depression — as well as other symptoms.

I'd also like to mention . . . that I am currently engaged in a study where we're looking at fatigue, factors associated with fatigue and sleep in



patients with colorectal cancer. We've done such a wonderful job over the last 15 or 20 years in supporting women with breast cancer, but we certainly need to continue that same type of effort for patients who have colorectal cancer, which is the third leading [type] of cancer in the United States.

In summary, my career is committed to advancing supportive care, and by that we mean the care that nurses and other healthcare providers give to help you as you go through your cancer treatment . . . and survivorship.

The first thing I'm going to do is ask you, the audience, to assess your fatigue. And I'm going to use a question that's from the National Comprehensive Cancer Network [<http://www.nccn.org>] to measure fatigue. If I asked you, "How would you rate your fatigue on a scale of zero, being none at all, to ten?" In a clinic appointment, we might ask you [for a rating of sleep quality] over the last week, or over the last two weeks. So, how would you rate your fatigue on a scale of zero to ten today? Go ahead and write that number down, because I'm going to be referring to it later.

So, during the last two weeks, on a scale of zero . . . please rate the severity of your insomnia. How much difficulty did you have falling asleep? None would be zero; mild would be one; two would be moderate; three, severe; and four, very severe. So, write down that number.

How about difficulty staying asleep? Use the same scale of zero to four — zero being none; mild being one; moderate, two; severe, three; and very severe, four. Then, use that same zero-to-four scale and answer the question: "Rate the severity of your problem waking up too early in the morning." So, this is the situation where you wake up at 4:00 or 4:30, and you cannot get back to sleep.

Now, I'm going to change the question a little bit and ask you a general question. "How satisfied or dissatisfied are you with your sleep pattern right now?" If you're very satisfied, put a zero; one if you're mostly satisfied; two if you're quite satisfied; three if you're not very satisfied; and four if you're very dissatisfied.

Then, the next question is: "To what extent do you think your sleep problems interfere with your daily function?" "Daily function" means your ability to function at work or your daily chores, your concentration, your memory, your mood. If you feel it does not interfere at all, then put down a zero; a slight bit, one; a moderate amount, two;

severely, three; and four would mean you have significant interference, that it's really interfering.

The next question is: "How noticeable to others are your sleeping problems, in terms of impairing the quality of your life?" So, in other words, do people tell you that you're falling asleep? Are they concerned about you driving, or your work performance, or something you're doing at home? If it's not noticeable at all to others, put down a zero, otherwise, rate it one, two, three or four if it's very noticeable to others.

And my last question is, "How worried or distressed are you about your current sleep problem?" If you're not at all worried, put down a zero; a little bit or a mild amount, put down a one; moderately, two; severely, three; and very distressed, four.

. . . Go ahead and tally up your score and see what your total is. And that is a very good lead-in for my next component, which is to talk to you about how chronic sleep problems can affect your daily life.

The American Academy of Sleep Medicine [<http://www.aasmnet.org>] [was established in 1975, with the purpose of studying the impact of sleep on daily life]. But, its [studies have] mostly been in individuals with chronic insomnia who have no other chronic illnesses. They've actually excluded people with chronic illnesses from their studies until the last ten years when they started to examine what we call comorbid, or secondary insomnia: insomnia that's present in the context of a chronic disease, such as breast cancer. We have begun to learn a great deal about how sleep [disturbances] in chronic disease compare to sleep [disturbances] in patients with chronic insomnia, without other chronic illnesses.

Four major types of sleep problems have been observed in people. The first one, which gets most of the publicity, is OSA [Obstructive Sleep Apnea Syndrome]. If you have Obstructive Sleep Apnea syndrome, which only approximately 7 [percent] to 9 percent of women do, it's very important that this be treated. I'll be talking about the consequences of untreated sleep disturbances later. The next [sleep problem] is Restless Legs Syndrome (RLS). This is a feeling of having creepy crawling critters going up and down your legs, and is most noticeable when you first try to go to sleep at night. Another one is Periodic [Limb] Movement Disorder. If you were sharing a bed with a person with PLMD, you would say, . . . "Wow, do you ever thrash around during the night.

Your arms and your legs are flailing and it's very hard to sleep in the same bed with you." The fourth major sleep problem is insomnia: 70 percent of sleep disturbances are related to insomnia. Insomnia can be acute, and it can be chronic.

Many of you have a history of sleep problems that date back to other times in your life. Some people have primary insomnia — their mother told them that before they ever went to kindergarten they had trouble sleeping, or didn't sleep as well as their parents did, even as children. Most children sleep longer than their parents. Other people might have first noticed a sleep problem with menarche, [or when they first started] menstrual periods. Other people noticed it when they had pregnancies. Some women talk about the challenge of sleep during perimenopause and menopause. So, some people bring a history of sleep disturbances into the cancer experience. And cancer, in many cases, does make their existing sleep problems worse.

Now, I'm going to be referring to a model called the Lee Model of Impaired Sleep. That model does a very good job of talking about impaired sleep in both the general population and in populations of those who are ill or have chronic illnesses. Sleep deprivation can be due to inadequate amount of time that you set aside for sleep. So, pretty much everyone you know can talk about whether or not they allow enough time to get adequate sleep. I want to emphasize that almost all individuals need seven to nine hours of sleep. You often hear people talk about how they can get by on five or six hours, but that is very uncommon.

What many people do is they delay their bedtime. They wake up early in the morning, often to get to work. They have poor sleep hygiene. They stay up watching television at night and then can't fall asleep. They have multiple roles and responsibilities, as well as caregiving roles. They leave themselves for last and only get the sleep-time that's left at the end of a long day. Or they could end up working shift work, or traveling that gives them jet lag. [Other issues also contribute to sleep deprivation, such as illness, pregnancy, going through a postpartum period while caring for young children.] As people age, they're more likely to have sleep deprivation, because the quality of sleep does not remain as good as it is when you're young.

Now, sleep disruption is the second major category. Remember, the first one was sleep deprivation, so inadequate amount of sleep. Sleep



disruption — or fragmented sleep — would be characterized by an increased number of nighttime awakenings and an increased percentage . . . of the night that you spend awake. It's very important for sleep to be uninterrupted. One of the major reasons that people have fragmented sleep is that Obstructive Sleep Apnea that I was referring to earlier, also, the leg movement from the Restless Legs Syndrome, or the Periodic [Limb] Movement Disorder. But, also things like reflux: when people eat their evening meal late in the evening and then lay down flat, they can have reflux that disrupts sleep. People who get up and sleepwalk or do unusual behaviors at night would also have disruptive sleep. And sometimes the environment is very disruptive: you may live in a noisy place, or a place where you can't have your room dark. Those who ingest caffeine or stimulants late in the day; people with a history of substance abuse, alcohol abuse, violence, or a distress syndrome, all may have disrupted sleep.

And, finally, health conditions such as heart disease, pulmonary disease, diabetes, and gastrointestinal diseases often cause disruptive sleep; as does obesity and [chronic or periodic] pain. I can't emphasize enough how important it is that pain be managed for control of both fatigue and sleep.

Both disruptive sleep and sleep deprivation lead to adverse health outcomes. We talk about the swine flu — influenza — about how inadequate sleep alters your immune function and may interfere with your ability to fight infection. It also can change the way you handle your stress response. And it also influences the way blood pressure and depression are controlled. If you're currently being treated for things like hypertension and depression, or if you have an open wound such as surgery for breast cancer, it is very, very important to get adequate sleep, or the outcome may be that these [conditions] are not well controlled.

Also, people talk about daytime consequences. They just can't function as well, because they're fatigued. They're more likely to be in car accidents. Estimates show 100,000 car accidents a year are related to sleepy drivers behind the wheel. [Other daytime consequences include] memory problems during the day, problems coping, altered mood, and low motivation. You know it'd be good for you to exercise or to be active, but you just don't have the motivation because you had a restless night last night. Finally, a very important part of our lifestyles, social outcomes, [are affected by fatigue].

People who have impaired sleep are less likely to interact socially, to do things with their families, to want to do well at work and be productive at work. [The sleep deprived] tend to use healthcare services more than the average person who doesn't have sleep disturbances.

I hope that I've really emphasized how having chronic sleep problems — whether there's sleep deprivation or sleep disruption — really do affect your daily life.

Let's move on to how breast cancer treatments in particular can impact your energy level and your sleeping patterns. We could have had a conference just on fatigue or just on sleep disturbances — there are so many things we could talk about. In both cases, they have so much interrelationship that it's really good that we're talking about them at the same time.

When a person is treated for breast cancer, surgical procedures require your body to increase its metabolic rate — to work harder. [That is true] whether it's wound-healing after surgery; and in particular, a more major surgery, such as a mastectomy with reconstruction; or women who go through several procedures. It's very similar to when your body was stressed by basic infection, the flu, or maybe you had a traumatic accident of some kind, such as a broken leg or arm. [During those infections or injuries], you knew your body was asking for more energy, really, or fuel to run properly.

We often start chemotherapy or radiation therapy approximately four weeks after the surgery for breast cancer. In that process, the goal of the radiation or chemotherapy is to destroy any remaining cancer cells that are circulating in your body. Because this is a destructive process, the result is the body tries to repair itself, just like it did after surgery. The repair process is going to ask the body for more resources, because it's going to work perhaps 20 percent more actively than it does when your body is in what we would call homeostasis. Even being on endocrine therapy — such as on tamoxifen or aromatase inhibitors — encourages your body to behave in a different way. It's sometimes hard for it to strike a balance and not have to work overtime.

On top of those procedures, we have treatment-related side effects, which many of you, I'm sure, have experienced: nausea, loss of appetite. So, that's less energy-in, isn't it? Change in bowel function, pain, depression or anxious mood, a change in your concentration. What we know now

— from the 15 years of research I've been involved in, and [from communications with] many of my colleagues who are dedicated to improving supportive care — is that all those symptoms lead to decreased physical function and decreased activity. And as Elyse said in the introduction, we have a very good handle on the fact that when people have decreased physical functioning and decreased activity, they consistently report lower quality of life.

So the body is in this situation — it needs more fuel to operate, but it has less. When your [body] functions [as it should], it's like stoking the fire, the furnace of your metabolic rate. The more active you are, the more energy your body creates. The more inactive you are, the less energy it creates. What ends up happening is the reserve-tank gets emptied. Many times with fatigue, we put it on a continuum, and people go from saying, "I'm really tired," — and most of us have had experience with that during our health — to saying, "No, this isn't tired, this is *really* fatigued. I can hardly go at all." Then they move into a state of total exhaustion. It's beyond fatigue. And they report major interference with their life.

What, actually, is fatigue? I've talked quite a bit already without defining it. This is from the National Comprehensive Cancer Network [<http://www.nccn.org>]: "Cancer-related fatigue is a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to either the cancer or the cancer treatment that is not proportional to recent activity, and it interferes with usual function."

So, what is insomnia? Insomnia, as defined by the American Academy of Sleep Medicine [<http://www.aasmnet.org>], is complaints of difficulty initiating — that means falling asleep or maintaining sleep — or non-restorative sleep. Insomnia lasts for at least one month and causes clinically significant distress or impairment in social, occupational or other important areas of functioning.

With that in mind, I'd like you to take a look right now and see if you can find your scores. How did you score your fatigue? If your score was four or more today, this would indicate that you could ask for a referral to the fatigue expert at your clinical setting. We can talk about this more during the question-and-answer. If your score to the seven insomnia questions that I asked you was seven or above, this also would indicate that you could ask for a referral to the sleep expert at your setting.



So, what are the medicine and lifestyle choices you could make to help you get better sleep and to lower your fatigue? We're going to start with medicine, but I want to spend a shorter amount of time on medicine than on lifestyle. The focus of my work has been that lifestyle or behavioral therapy has shown to not only be as effective in the short-term, but definitely in the long-term, for managing chronic insomnia and fatigue. Medicines are divided into categories for sleep, and one category is called the benzodiazepines.

And those of you that have taken things like the trade name would be Ativan, the generic name lorazepam, would be familiar with benzodiazepines. They can be short-acting, long-acting or intermediate-acting. And that sometimes is an important thing to know. Then, we have the non-benzodiazepines, and these sleep aides include antidepressants or antihistamines, or some other drugs known as antipsychotics. Another category [of medications prescribed during breast cancer treatment is] the antidepressants. And the ones that are usually referred to the most are venlafaxine, or Effexor, because it is also helpful in helping people that are having hot flashes. Antidepressants are never prescribed only for sleep problems. They are prescribed for people who are experiencing depressive symptoms. But, some antidepressants are more effective than others in helping people sleep. And venlafaxine is one of the ones that has been most helpful. [Editor's note: Always speak with your oncologist before taking an SSRI medicine like venlafaxine, especially if you take tamoxifen. Some SSRIs may decrease the effectiveness of tamoxifen.] Another category is over-the-counter drugs, such as tryptophan, melatonin, and valerian. Those have not been studied to the same extent as the first three drug categories.

If you are having acute insomnia, in other words, insomnia that lasts a few days or a week, then you might talk to your healthcare provider about getting a prescription benzodiazepines, non-benzodiazepines, and antidepressants. But, all of these are intended for short-term use. And although we have newer drugs for sleep, such as Ambien and Sonata, those drugs were designed for short-term use as well.

[As for long-term solutions], I'm going to move on to the behavioral interventions. First, let me talk about lifestyle. Our general health information is consistently giving messages to be physically active and to have good nutrition and stress management. But, it really wasn't until the last five

years or so that we started getting the messages about how important sleep is in our lifestyle. A very noted sleep expert talks about [our] living on a "three-legged stool approach." The three legs were activity, nutrition and stress management. I'd like you to trade in that stool for a four-legged stool and to think about lifestyle choices that include sleep. What we say is to get the sleep your body needs, to make sleep a priority. When you make sleep a priority, and also work on things like physical activity, stress management and nutrition, you're giving yourself the best opportunity to have lower fatigue. Because, as I mentioned earlier, fatigue is a multi-component symptom.

What are the behavioral therapy interventions to improve sleep? The National Cancer Institute [<http://www.cancer.gov>] has a very nice summary of sleep disorders, as well as one on fatigue. [One behavioral therapy] currently being studied that has been shown to be the most effective in patients with chronic insomnia, without cancer, is called stimulus control. When you get a stimulus and it's a positive one, that [results in] positive [behavior]. And when you get a stimulus that's a negative one, such as when something creates pain, it makes you stop doing the act that is creating pain. Many people have turned their bed into a negative stimulus. They say, "When I go to bed, I can never sleep there, and I can never fall asleep, or stay asleep."

Stimulus control trains you to reassociate your bed and your bedroom with sleep, and to reestablish a consistent sleep-wake schedule. The first step for someone following sleep-control therapy is to use your bed only for sleep and sexual activity. In the American population, many people have turned their bed into their living-room couch. Bedrooms got bigger and more things moved into the bedroom. So, that's a pretty tall order, and one that's very hard for many women as they go through breast cancer treatment, to use the bed only for sleep and sexual activity.

If you're unable to fall asleep within 20 minutes, get out of bed and select a dark, quiet place to go relax until you're ready to fall asleep again. And we tell women to have a headset there and to listen to relaxing music, and go back to bed when they feel sleepy. Then, only to stay in bed for ten to 20 minutes if you're unable to fall asleep. So, go to bed only when you're feeling sleepy and ready to sleep, and go at the same time each night, such as 10:30 or 11:00. Get up each morning at a consistent time, no matter how much or how little you slept the night before.

This is a key element of sleep — stimulus control. And it's one that people have a very hard time with. They've had a bad night. They think they should stay in bed throughout the morning. But, we want you to try to get up at a consistent time every morning. That's almost like the orchestra conductor telling your body it's time to start turning on all its engines. And when that time varies, your body gets a mixed message.

Do not take naps during the day if you can avoid it. But, if you do take a nap, then take a power nap, which would last about 30 minutes. While you sleep, do not watch the clock or panic if you wake up during the night. Many sleep psychologists actually recommend that people turn the clock away, so they don't see what time it is or look at it as they go through the night.

Relaxation training is another technique that's been found to be very effective in chronic insomnia patients. Within two hours of your bedtime, use a warm bath or a shower, or a massage, or read, or listen to soft music, or do muscle relaxation activities such as yoga. This does not mean that you do things like get on a treadmill and start exercising because you think exercising will relax you. We're trying to let your body reduce its tension and also cut out intrusive thoughts that you take to bed. So, if you're worried about something, it's important to deal with that in the early evening, and then to relax and have a plan for how you're going to handle that thing you're worried about the next day.

Sleep restriction limits the amount of time that you have in bed to approximately the time you spend sleeping. A sleep psychologist would tell an individual to set the limit on the amount of time in the bed to the actual time spent asleep. Many people will tell a sleep psychologist: "I only sleep for five hours," and are instructed to stay in bed for only five hours, for at least five nights. Then they try to increase their time by 15 minutes and see if that helps them remain sleeping soundly. The idea is that we want you in bed when you're sleeping. We don't want you in bed when you're tossing and turning.

Sleep hygiene teaches you a variety of health practices and environmental factors that support sleep. Those actions reduce stimulation of your sympathetic nervous system, and they help you sleep. The first one is to establish a regular wake-up routine. Do not oversleep in an attempt to catch up on lost sleep. Sleep hygiene would say to get up at the same time, seven days a week. That's very



hard for workers, when they get inadequate sleep during the week and try to make up for a lot of time on weekends. The second one is get exposure to bright light, like sunlight, as early as possible after waking. We recommend 20 minutes in bright light for [adequate] vitamin D levels. [That bright, early morning light] can be artificial, but [natural] sunlight is preferred, as early in the day as possible. During the day, follow a schedule for meals, for exercise. And if you're going to take a nap, try to take the nap as early in the day as possible, for your 30 minutes. Always complete your naps within four hours of bedtime. For those of you who work and don't get home until 5:00, take your nap when you get home, as opposed to after dinner. Complete your exercise within two hours of bedtime, and develop a nightly pre-bed routine. So, that kind of gets you ready for that relaxation activity. Try to make sure that your last hour before bed is relaxing and quiet, and that your bedroom is dark, cool and quiet. Turn off phones. Don't have your computer in your room, or pets. And I know that's a really hard one, but if your pets wake you up at night, you may want to consider having them be somewhere else in your home or your apartment while you are sleeping.

Wear light cotton clothing, and use light covers and cotton linens. This is particularly important if you have trouble with hot flashes. The last item is to replace your mattress every ten to 12 years, and to replace your pillows much more often, approximately every year. Make sure that the linens you use are cotton linens. So, that overviews the four major types of behavioral therapy [to address sleep problems].

Sometimes people need to see a sleep psychologist to talk about cognitive therapy, when they start to have thoughts such as, "I can never sleep at night," or, "There's no way I'm going to get enough sleep tonight," or, "There's no way I'm going to function tomorrow without eight hours of sleep today." Those thoughts are definite cues [that one needs] to see a sleep psychologist.

The next thing to talk about is what a challenge it is to make behavioral changes in your daily lifestyle patterns. It's very similar to when someone has been given instructions to lose weight, or to increase their physical activity. Developing patterns to improve your sleep is going to take time. In the intervention study, we worked with women for six to eight weeks before we really expected to see a change. Give yourself some time. So, in summary, I'm going to talk about how your

healthcare professional can help you if you are experiencing these problems.

Screenings for fatigue and sleep disturbances are being integrated into oncology clinics, and you may have already experienced this. Similar to the beginning of this talk when I asked you to rate your fatigue on a zero to ten, or maybe just to ask you a question, such as "How satisfied or dissatisfied are you with your sleep pattern on a zero to four?" We should be asking those questions for all people in cancer-clinic settings, so that we can see if they need to have follow-up.

In many of your settings, there is a person to be referred to, such as an advanced practice nurse, also known as a clinical nurse specialist, who handles fatigue consultations, sleep consultations or other symptoms you may be experiencing. If the physician or mid-level practitioner knows that you're having sleep problems, [he or she] may do some initial screening for Obstructive Sleep Apnea, Restless Legs Syndrome and Period [Limb] Movement Disorder. It may be determined right away that you need to be seen in a sleep center by a specialist.

In the sleep center, one of the sleep disorders may be diagnosed and appropriate treatment prescribed, such as pharmacology or behavioral therapy. I would also encourage you to seek referral to a psychologist to assist with coping and stress management. We know that anxiety and depression play key roles in perpetuating both fatigue and sleep. And also, pain fits into that same category. So, if you have unrelieved pain, that [pain] needs to be addressed before you're going to benefit in regard to your fatigue and your sleep.

I'll close at this point and encourage you to learn more about this topic, reading in the Living Beyond Breast Cancer newsletter [an article] on insomnia and fatigue [http://www.lbbc.org/content/newsletter-article/counting-sheep-coping-with-insomnia-and-fatigue.asp?section_tag=G]. And at this time, I'm more than happy to entertain any questions you may have.

ELYSE S. CAPLAN, MA:

In about 45 minutes time you ran through an incredibly detailed agenda, helping all of us understand insomnia and fatigue in a number of different ways. The variety of interventions you reviewed are all cause for listeners to step back, take a look, then go back to our healthcare practitioners and find out what we might be able to do to enhance our sleep and our energy.

OPERATOR:

We will now be conducting a question and answer session. Our first question comes from a woman in Wildwood Crest, New Jersey.

CALLER:

I've had breast cancer for eight years. It was inflammatory breast cancer, and it moved to my ovaries 18 months ago. It is metastatic now. I have had problems ever since my beginning diagnosis, and my chemo with hot flashes. I did take Effexor for a while, but I found that I didn't care for it. It made me a little fuzzy-headed.

Through my entire cancer experience, I've worked. But since my breast cancer moved, I've been on Faslodex, which is a once-a-month injection. I also take methotrexate for another lymphatic condition. My hot flashes are just terrible. I have no problem falling asleep, but unfortunately I fall asleep by 8:00 at night. I get exhausted at the end of my day. And I wake up every hour-and-a-half or two hours, soaking wet. I'm wondering if there's anything that I can do that isn't Effexor.

ANN M. BERGER, PHD, RN, AOCN, FAAN:

Right. Well, the problem you have is experienced by many people. Women with breast cancer and ovarian cancer, as you mentioned, are limited as far as what can be prescribed for hot flashes. One possibility would be to go back over that whole environment about keeping your room really cool, perhaps having a fan blowing directly on you, having the lightest clothing possible and the lightest covers possible. People have found in research studies that Vitamin E might be helpful at a dose of 800 milligrams each day. And that would be compatible with the treatment that you're receiving. [Editor's Note: Make sure your oncologist knows about any supplements or herbs you take for insomnia.] Sometimes, even though you had a bad response to the Effexor in the past, it might be worth another try. Because it is the one that has been found to be the most helpful. But, definitely I would address this with your healthcare provider. And I'm sure you probably have, but see if they can offer other suggestions for you.

CALLER:

Okay.

OPERATOR:

Our next question comes from a woman in Las Vegas, Nevada.



CALLER:

My question is related to research — affects on the brain itself. I finished all my treatment and a year later found encephalopathy on a brain MRI and had the test redone, and now they say possibly [it's a] cerebral neoplasm. I don't sleep at all. I'm just wondering about the long-term effect that could have. We're trying to sort out everything.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Well, that certainly is a very unusual situation. I must say that in all my years, I have not experienced a situation like yours. So, like you say, you're trying to sort it out, and I'm sure [your doctors] are trying to see if they're related. So, you said you're not sleeping at all?

CALLER:

I just lay there, and I'm up constantly. I can't fall asleep. And if I do, it's for short periods of time. But, the problem is that aside from the hot flashes — I do have a fan over my bed — I already had fibromyalgia and chronic Epstein-Barr before the cancer. So, it's — probably difficult — you know, a mess. But, I was just wondering, even from long-term effect, if it could have actual impact on changes in the brain that you've maybe seen more in research or something.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

No, we have not observed a relationship between the breast cancer and changes in the brain as you're describing.

CALLER:

Okay. One more thing to rule out. It's a mystery, and we're trying to figure this all out, so —

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Well, I wish you well. I know that's a challenging situation.

CALLER:

I keep having serial brain testing to see if it's growing or what. And it's in a place that's inoperable as far as even biopsy in the brain. So —

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

— Well, we wish you all the best and think it's wonderful you're uncovering every stone and trying to explore everything, as you said, to rule out. Sometimes ruling things out can be helpful when you're dealing with a more complicated

situation. So, our best wishes to you for figuring this out and moving ahead.

CALLER:

Thank you. I appreciate it very much.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

You're welcome.

OPERATOR:

Thank you. Our next question comes from a woman in Flushing, New York.

CALLER:

Thank you, doctor. Is there a Web site we can go to in reference to everything you've talked about with fatigue and so forth — sleep and waking? Do you have a Web site yourself?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

No, I do not. I would recommend The National Cancer Institute's Web site at <http://www.cancer.gov>. The National Comprehensive Cancer Network [<http://www.nccn.org>] has a link for supportive care [<http://www.nccn.com> or more specifically <http://www.nccn.com/Living-with-Cancer/Default.aspx?id=2952>], and there is supportive-care information for fatigue, but they don't have it for sleep disturbances yet. So, the NCI has all the information about sleep, and NCCN has all the information about fatigue.

CALLER:

Thank you.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

You bet. ...

OPERATOR:

...Our next question then comes from a woman in Amherst, Wisconsin.

CALLER:

I have — I've had breast cancer. I've had radiation. I'm on Arimidex now —

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Uh-huh.

CALLER:

I have terrible insomnia. My doctor is treating it with Ambien, which will work, but I've been on Ambien every night for two months. He just seems like I will — just to stay on it forever, and I'm kind of concerned. What do you think?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

The group of drugs that Ambien falls into was first brought into the market about ten years ago, and it has fewer side effects than the sleep-drugs that were prescribed prior to about 1990. In general, we like to say that drugs are not intended to be used indefinitely. But if you are experiencing a good night's sleep and you're not experiencing what we would sometimes call a "hangover" in the daytime, where the drowsiness from the pill continues through the day, then I would say that two months is a relatively short period of time, and that I would give a little time. Are you currently still taking radiation?

CALLER:

No. No, I'm done with it.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

You're all done? Uh-huh.

CALLER:

The other thing I was going to ask you is, the aromatase inhibitor is — I have a very — I've been having just one cold after another. I feel my immunity must be down. And I'm wondering if that's due to the insomnia, the aromatase inhibitor, or both?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Well, the aromatase inhibitors are there to basically block the estrogen, and so they're not going to [impact] your immunity. It could be that if you're not getting adequate sleep, or haven't for a period of time, that may be influencing your frequent colds. But, one thing is to [consider your colds] in context. It seems like sometimes we all have that one virus that we just can't get over. So, hopefully you can get over this cold that you've been having and remain well.

So, in that case, if you didn't sleep well before the Ambien and you are getting a positive response, then it would be helpful to your immune system to remain on it for a period of time. I would say that you would want to reevaluate. Perhaps try to adopt some of these behavioral techniques to improve sleep. Then on a monthly or a quarterly basis, try a few nights without the sleep medication, and see how well you sleep.

Sleep-drugs can be psychologically addictive in the sense that you feel like, "Oh, gee, I won't sleep tonight because I didn't take the pill," after a



long time [of taking it nightly]. You should be able to sleep a night without them, without having any kind of what we call “rebound,” or your body knowing that [the medicine is] not there.

CALLER:

Well, I did try that one night, and I stayed up the whole night.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Right. So, it sounds like you're not quite ready to go off of it. I think you just want to keep in the back of your head that you'd like to go off of [the medicine]. But, there are no health risks from remaining on it, really. It's not the same kind of controlled substance as some of the drugs were over ten years ago. What we want you to do is sleep, and we want you to function during the day.

CALLER:

Sounds good.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

We're all so individual that for some people the behavioral therapy will be enough. For other people, they've done studies with chronic insomniacs where they've combined the medication with a behavior, and then some people that have the benefit from the medication alone. And, of course, as Americans, a lot of people will want to just take a pill and have it be all better. But, definitely, when the pill is combined with a behavior, or the behavior alone, people have the best long-term benefit.

OPERATOR:

Our next question comes from a woman in Marina Del Ray, California.

CALLER:

I have had breast cancer for the past year. I'm on tamoxifen. I went through chemo and radiation last year. To follow on the Ambien question: I've had horrible insomnia, and Ambien's the only thing that really helps me. Every time I try to sleep without it, I just — I'm up all night.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Uh-huh.

CALLER:

And I'm wondering if there are strategies to sort of wean yourself off of Ambien and toward these other therapies. Interestingly enough, if anybody's in the L.A. area, there's an insomnia

study going on at UCLA for cancer patients and survivors [“Tai Chi Effects on Chronic Insomnia in Breast Cancer Survivors, Immune Mechanisms” <http://clinicaltrials.gov/ct2/show/NCT00690196?term=insomnia+%2B+UCLA&rank=3>]. So, you should look into that. But, my question is about easing myself off of Ambien.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Right. There are no standardized ways to do it. I would encourage you to talk with your doctor about, perhaps, trying a lower dose. But it sounds like you've had some difficulty with that. The other thing would be to see a sleep psychologist or, through the study, to learn about behavioral techniques [to improve sleep] and to take those on. Things like that regular bedtime, seven nights a week, a regular wake-time, seven nights a week, and avoiding napping can have a very strong impact. I would encourage you to adopt the behavioral techniques and, under the advice of a medical care person, to consider reducing the dose of your sleep medication.

CALLER:

Thank you.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Uh-huh. You bet.

OPERATOR:

Our next question comes from a woman in Madison, Wisconsin.

CALLER:

Yes, I'm 65. At the age of 58, I had a mastectomy and reconstruction followed by chemotherapy and radiation. At the time, I was prescribed lorazepam. I have been on that for seven years. I take one .5 milligram tablet every night. I [wonder whether] I am ... addicted to it, because if I don't take it, I have difficulty sleeping. My question is similar to those that have already been asked, I guess, in that I'm wanting to know [if there are negative effects from being on this medicine for seven years], and of the weaning process.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Okay. Well, first of all, we want to congratulate you for being a seven-year survivor. That's wonderful. Lorazepam is one of the drugs that is much harder to get off of than the Ambien classification of drugs. And, so, you're on a 0.5 milligram tablet, and I believe that can be cut in

half, can't it? That you could try first 0.5 one night and 0.25 the next night, or get a lower dosage of it? But, lorazepam, under the healthcare provider's direction, you would gradually try to be off of it, [instead of trying to stop all at once].

Many healthcare providers have attempted to take people off lorazepam, and instead to have them take a drug that is in the less-addictive classification, such as Ambien. People have sometimes found that has worked for them, and other times not. That would be one thing to consider, would be to talk about either reducing the dose of lorazepam or switching to a classification that is not as [habit forming].

Most people who have taken lorazepam for a period of time do have difficulty stopping. But it really sounds like it's working for you. So, there really aren't any major negatives to it, if it works for at least six hours. [It would only be a problem if] you took it in the middle of the night — then you might have some daytime challenges with driving or with role performance.

OPERATOR:

Our next question comes from a woman in East Norriton, Pennsylvania.

CALLER:

Thank you, Dr. Berger, for all this information.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

You bet.

CALLER:

On the subject of sleep control therapy, and particularly under sleep hygiene: One of the things that I do one hour before bedtime is reading. Is that appropriate, to be reading in order to relax? Or is that a stimulant?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Okay. When it comes to reading — and it is included in the list [for good sleep hygiene] — the challenge of reading is how bright the light [in the room is]. Reading, for most people — as long as it's not a mystery suspense thriller or something — is a relaxing activity. Many people choose to read at night. We would encourage you to get one of those little lamp-lights sold in bookstores — the ones that attach to the book page. Dimly light the room, but have light on the page [in the form of a book light]. But, certainly, an hour before bed, if you're in the main part of your house, and you're reading a book, that is just fine.



What we don't want is for people to be in bright lights, because the light goes right to the retina of your eye, and that activates your sympathetic nervous system. It makes you feel like you need to be on alert and stay awake.

CALLER:

Thank you.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Uh-huh.

ELYSE S. CAPLAN, MA:

I think that was a great distinction, Dr. Berger, about the intensity of light. I certainly learned something right there, and I'm sure a lot of participants on the call did as well. Your environment has to be very carefully controlled. And I think you highlighted that beautifully, you know, over the course of the past hour so far.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Well, thank you. And just to reinforce that, light is the strongest [behaviorally controlled] stimulant to stay awake.

ELYSE S. CAPLAN, MA:

Uh-huh.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

If you are in a bedroom that has the lights bright and the television on, and maybe you just jump over to the computer to see if somebody replied to your e-mail, your eye is getting all kinds of signals that say, "Stay awake now, stay awake now." Then you turn off the light and say, "Why can't I fall asleep?"

ELYSE S. CAPLAN, MA:

I think that's a good point to highlight — something within all of our control. When we've dealt a diagnosis of breast cancer, we often feel like we're not in control of many things. But this is definitely something we can control.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Right.

OPERATOR:

Our next question comes from a woman in Brattleboro, Vermont.

CALLER:

I had hepatitis C and breast cancer, back-to-back, and spent about nine months in

chemotherapy, mixed with some distressing life circumstances. And my —

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Hmm —

CALLER:

Insomnia runs in approximate ten-day cycles for me. I'm always up four to five times a night. I've taken a sleep study for apnea. It was negative. Before my question, [I have] a warning to those on Ambien. I took Ambien briefly, and it caused me to sleepwalk. I fell down the stairs and broke all the bones inside of my face. So, there's a sleepwalking warning on Ambien.

My question is for all of us who have been subjected to great deals of trauma, can this lingering subconscious trauma contribute to insomnia?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Well, thank you very much for your question. I want to start out by saying you're exactly right, and I probably underemphasized that, in March of 2007, the FDA did have to change the label on all sleep disorder drugs such as Ambien. [That change] made people more aware of what they call complex sleep-related behaviors, one of which was [as described by the news media] "sleep driving." People [were documented] eating food while they were asleep, and then certainly going down staircases and falling. So, there's such an individual response [to any given medicine], and we want to say that these drugs have never been tested in a group of cancer patients. You are your own control subjects.

Your question about trauma is a very interesting one, because we know the brain does store memory of past traumatic events. That's why when people come back from war they have Post-Traumatic Stress Disorder, and that that has been linked to poor sleep. And it's all due to heightened arousal.

I talked about light being a stimulant to staying awake: elevated cortisol, or stress hormones, are also a major reason that people feel a sense of what we would call heightened arousal. [Elevated cortisol] can be related to past trauma.

I can't explain at all about the ten-day cycle [you are experiencing], because it's much more consistent. For example, people who come back from war wouldn't have a pattern like that. In a very brief answer to your question: yes, trauma can be stored in the brain. When you're undergoing stressful days and, of course, stressful nights, then

you can recreate in your mind that stressful situation. And that makes it very hard — we haven't even talked about the stages of sleep — for you to go into deeper stages of sleep. You're in a very mild type of sleep that makes you easily aroused. So, the answer to your question is, yes.

OPERATOR:

Our next question comes from a woman on Lummi Island, in Washington.

CALLER:

I just wanted to thank the organization for putting on these teleconferences. This is the second or third [teleconference] I've listened to, and I've just found them so helpful, and I really appreciate it. Doctor, I wondered if you had any thoughts about complementary therapies that could help with sleep, such as acupuncture?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Okay. ... [Acupuncture] has been used in people with chronic insomnia. It's never been shown in any kind of a large study that had two groups, one that got it and one that didn't, that it would have benefit. The majority of the complementary therapies that have been used for sleep have been the melatonin and the valerian. [Editor's Note: Always consult with your doctor before using any complementary or herbal therapy.]

CALLER:

Okay. All right, thank you.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

So, what we're talking about that I just would like to mention, that the reason people often use a complementary therapy is because they think it's going to help them relax. Based on the question from the woman prior to your call — the one with hepatitis C and breast cancer — when you know that you've had trauma then relaxation techniques, and learning to get your body to be on a much more lower metabolic rate, [may be effective] in improving your sleep.

ELYSE S. CAPLAN, MA:

And thanks for the nice comment about Living Beyond Breast Cancer and our teleconferences. We always appreciate hearing that.

OPERATOR:

Our next question comes from a woman in Arlington, Virginia.



CALLER:

I don't have any trouble sleeping at night. As a matter of fact, I'm tired all the time. I wake up at night to urinate, and I have a night light on, do not turn anything else on, and I can go back to sleep. But during the day I'm not functioning at my best because of fatigue. And I wondered, is there any problem in taking something like NoDoz, or Jet-Alert that's a caffeine pill, to wake up more during the day?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Well, thank you very much for your question. We've focused so much on sleep, we really haven't talked about when people have fatigue, when it reaches the point of exhaustion. What I would say is, in answer to your question, that would be under the category of what we were just talking about, complementary, or over-the-counter type of products. A stimulant like that may help you function during the day, but it is something from outside your body, the caffeine. Do you drink coffee, or tea, or colas, or any drinks where you could get natural caffeine?

CALLER:

I do occasionally. It's only recently I can have beverages with caffeine. I'm older now.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Right. When you first get up in the morning — remember when we talked about the [bright] light [exposure first thing in the morning] to kind of get the body going? Caffeine in the morning definitely does help kind of arouse the body from sleep and help you wake up and get going. So it would be good to have some caffeine in the form of green tea or coffee, as opposed to a pill.

We haven't talked about physical activity. Sometimes when people really feel fatigued, it's very hard to be active. But activity can sometimes help — back to that kind of cue, to [cue the body to] wake up and to keep moving. So, the short answer to your question is: I would try to avoid over-the-counter pills. The one reason things are [classified as] over-the-counter is they are considered to not have the same side-effect profile as a prescription [medicine]. And every prescription drug does have side effects.

That's why whenever we can use natural substances, nutritional ways [it may help ease symptoms without the side effects of a medicine]. I talked about fatigue being multi-focal. I would

focus on trying to be as active as possible; to eat a healthy, balanced diet, and to try to identify any other symptoms you might have. It could be, for example, you're anemic, that your hemoglobin is low, or that your thyroid is low. Rather than self-medicate with an over-the-counter medication, see if you can get to the bottom of the problem and have a fatigue consultation.

OPERATOR:

We have a question from a man in New York, New York.

CALLER:

My wife's about a year-and-a-half done with her chemo and radiation treatments for breast cancer. She's had insomnia since that time, and has tried a few sleep aids, including Ambien. She's had varying success with them. Every night she's taking melatonin.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Uh-huh.

CALLER:

She's been taking that, and it's been working for her, a little bit, but she doesn't get a full night's sleep with it. She gets maybe a couple hours of solid sleep. And I guess my question is twofold. Is melatonin addictive, and does it have any known long-term side effects? And, is there anything she can do to increase the length of her sleep, maybe doubling up the dosage? Are there any bad effects to doing that?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Okay. The first thing you should know is that melatonin is actually a natural substance. You have a lot of melatonin circulating in your body at all times. And so, supplemental melatonin is considered safe. It's in its natural form, as if it was in your body.

And we know that as people age they tend to have decreasing melatonin levels. Those decreased levels may be one of the explanations why, in general, older people do not sleep as well as younger people. The recommendation for melatonin is to take it when you have set aside eight hours for sleep, or seven to nine hours for sleep. So rather than taking it a second time during the night, which would be too close to morning, it could be that she would need to increase the dose of the melatonin she's taking.

Melatonin seems to have a lot of individual differences among people. And so, it's not uncommon that people need a higher dose of melatonin than the dose they first started to take. Hopefully you would have someone at the sleep center [or on your medical team] to consult with for an [individualized, recommended] dose. Melatonin is not addictive at all — it's a natural substance. The best thing to do would be to increase the dose gradually, and see if you can get a longer response. It does work better the first half of the night. The other thing we could mention is that increasing physical activity during the day [may result in a] deeper sleep, [and] then the [duration of her sleep] may be longer. [Editor's Note: Please consult with your physician about any supplements you take, including melatonin. Melatonin and other supplements are not regulated by the U.S. Food and Drug Administration, so dosages may not be the same among different manufacturers.]

OPERATOR:

Our next question comes from a woman in Casselberry, Florida.

CALLER:

I not only have been diagnosed with inflammatory breast cancer, but chronic leukemia. You were mentioning anemia — my red cells are down, my white cells are down, my hemoglobin's down. I am totally fatigued. I have the CPAP [continuous positive airway pressure machine, a common treatment for Obstructive Sleep Apnea], and it's okay. How else do we get some rest?

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

...At the University of Nebraska, we're a national center for patients to come with lymphoma, and so I'm very familiar with people with lymphoma and leukemia. For those in the audience that aren't as aware, they're much more likely to have lower hemoglobins, and have much lower basic energy. It's much harder to design intervention for fatigue in someone with leukemia or lymphoma. You add that you've already got the Obstructive Sleep Apnea. We know that that CPAP machine — for those of you that don't know that, that's for the Obstructive Sleep Apnea. How are you doing as far as adherence to wearing the CPAP? How many hours a night do you keep it on?



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CALLER:

Oh, about six.

ANN M. BERGER, PHD, RN, AOCN, FAAN:

Oh, well then you do better than many, because one of the most frequent problems is that people don't like the CPAP — we'll call it the mask — or the way it's connected, and tend to not keep it on ...

CALLER:

I take it off some nights in my sleep. I go to sleep with it on, and I wake up, it's off —

ANN M. BERGER, PHD, RN, AOCN, FAAN:

Right —

CALLER:

Then I try making it tighter so that I don't take it off.

ANN M. BERGER, PHD, RN, AOCN, FAAN:

That's the number one recommendation is to keep the CPAP on. And then [make a plan to change behaviors in order to improve sleep]. You want to start the day with goals, but you have to keep your goals measurable. It's almost like the body [has a] fuel tank — it's like you can't make enough energy to use a lot of energy. And someone with a case like yours, I would recommend you do what we used to call the three Ps: Plan, Pace, and Prioritize.

We know that you are not going to have the energy of someone who's healthy, and so you're going to have to plan your days [around goals that are reachable]. Let's say leave the house to shop, go to one store, but not three stores in a row. Pace yourself — whatever it is you're doing, keep it a slower pace, and then prioritize it. At the end of today, if I've only got these two things done, which of those things that are going to make me feel best about how I behave today?

The first thing about fatigue is to treat any contributing factors. In your case, the CPAP and the Obstructive Sleep Apnea are your [contributing factors to prioritize, to treat first]. Next would be the anemia, then [address other] nutritional [changes]. I would really try to get adequate protein and adequate calories. If you're losing weight — we know people are fatigued when they lose weight — then try to keep an activity level that's right for you. If you have any other comorbid illnesses, such as heart disease — the more those are kept in good

control, the more likely you're going to experience a lower fatigue.

OPERATOR:

Our next question comes from a woman in Eastern Pennsylvania.

CALLER:

I had breast cancer five years ago, and I had a recurrence, which resulted in a mastectomy. Now I am going through reconstruction. I noticed my energy level seems to be lower. I do try to — what you mentioned — prioritize activities. I do try to exercise. But, sometimes even if I don't exercise, all I can do is take a nap — I'm so exhausted. My energy level is coming back, but now I'm going to have to be going back in for surgery again. And I'm just tired again. I was just wondering if that's a part of it?

ANN M. BERGER, PHD, RN, AOCN, FAAN:

Most definitely. We just can't underestimate — it's often been said that as hard as it was to hear [when you were first diagnosed with] breast cancer, it's even harder to hear that it's come back.

CALLER:

Right.

ANN M. BERGER, PHD, RN, AOCN, FAAN:

Your body's probably going through a real emotional, traumatic event. [Processing that trauma has] got your body burning a lot of energy, so you just don't have any to spare right now. So that's why you can feel that fatigue that doesn't seem to relieve itself. It kind of gets back to that four-legged stool I was talking about earlier.

But I think in preparation for surgery, you should keep trying to be as active as you can. Try to eat a good, balanced diet. And try to have someone, or more than one person, [listen to you so you can] get your feelings off your chest. [That support can help you] to feel you've got your anxiety and your mood under control. You're in a very challenging time — recognize that. Try to maintain a homeostasis: keep your body active, try to sleep on a regular schedule, eat well, and get your stress under control. I really wish you well as you go through your surgery.

CALLER:

Well, thank you. It was very — it's been very informative with you and the others, too.

OPERATOR:

Our next question comes from a woman in Los Angeles, California.

CALLER:

I'm a four-and-a-half year survivor of breast cancer, and I've been doing pretty well. I was on Ambien for about two years, and I weaned myself off that. Now, my problem with sleep is I have to make three to four trips to the bathroom during the night. And usually at 5:00 a.m. it's the last time. So I cannot go back to sleep. I am just dragging myself through the day. And if I do go back to sleep, I usually sleep till 8:00.

When I look at myself in the mirror, I can tell, just looking at my eyes, if I have had sufficient — enough sleep. My pupils are large if I've had sufficient sleep. And if they aren't, they are like a little pin. And I can tell in how I feel.

A sleep study has been introduced if I want to take it. I've found out there [are] many different types of sleep studies. Is it one that I should look into? Because I have no problem falling asleep at all. I did say I go to sleep at 9:00 p.m. — I am absolutely exhausted at 9. I'm a [Type-A] personality, and I have a problem pacing myself. I'm aware of that.

I don't want to take naps during the day. I know why I wake up. I know why I have to go back to bed — because I haven't had enough sleep. But, when they look at it and say, "Oh, you have — you've been in bed for ten hours." Well, it's true, but it's these constant interruptions that take away from the quality of my sleep.

ANN M. BERGER, PHD, RN, AOCN, FAAN:

Okay, so getting to the basic problem of waking up three to four times to go to the bathroom. Of course, this is a problem that both sexes experience as they age. Men complain about it. It's the number one reason that men don't sleep well, is to get up to the bathroom at night. And so, the first thing would be, have you been treated for that? For that urgency?

CALLER:

No. I did see a urologist, and she said, "Well, you're a very difficult patient to treat because you only have a problem at night, not during the day." So, I left it at that.



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**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

When are you drinking fluids during the day? If you know that you're waking up at night that many times, it sounds like you either have a lot of fluid, or your bladder doesn't hold very much without sensing that you need to get up. So if you go to bed at 9:00 p.m., then I would say that you would want to stop drinking right at your dinnertime, which really is four hours before bedtime for someone who has a lot of frequent night awakenings.

I would not have any beverages in the evening at all, and just see if that helps you. But, otherwise — even though you're only experiencing the problem at night — I would work on trying to see if you could reduce the number of awakenings ... first.

In answering your question about sleep studies, there are studies that are a little more extensive. They kind of run people through the first round to see how challenging it is. Then when they see that someone, for example, has Obstructive Sleep Apnea, like the earlier caller, then sometimes the second half of the night they'll start using therapy, to see if they can improve their sleep during the second half of the night. So, there are some variations. But, any certified sleep center should give you a good, quality study.

I do agree, also ... that most people should be out of bed, at the maximum, nine hours after they go to bed. So, if you're going to be [in bed at] 9:00 p.m., the very maximum [wake-up time] would be 6:00 a.m. And that would be [consistent with] the small percentage of the population that really needs nine hours of sleep.

CALLER:

Uh-huh.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

I would think that if you start to get up at 5:00 in the morning — and the idea about the pupils, your pupils are reacting to how much there light there is in the environment ... So, I would not use that as a guide to let you know if you've had good sleep or not.

CALLER:

I see. Well, I do have glaucoma, so —

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

Uh-huh —

CALLER:

I don't know if that is a factor in the matter at all.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

I think the main thing to work on is your frequent urination at this point. If you still feel like you're waking up with non-restorative sleep, then I would pursue the sleep study.

CALLER:

Thank you so much, Dr. Berger.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

You're most welcome.

ELYSE S. CAPLAN, MA:

Thank you. And with that, I would just like to say thank you again to Dr. Ann Berger for spending so much time with us and our participants. Many of you describe some very hard circumstances that you're facing, not just breast cancer, but perhaps some other illnesses or other problems that impact your day-to-day quality of life.

I'd like to know if Dr. Berger has a closing comment.

**ANN M. BERGER,
PHD, RN, AOCN, FAAN:**

My closing comment would be, for those of you who are experiencing fatigue to always try to address any treatable contributing factor. I tried to emphasize the importance of managing pain, anxiety and depression, anemia, your nutrition, and your activity. And then, the last ... one of those is sleep.

And we know that if you're having poor sleep with daytime sleepiness, that does impact your role performance and your quality of life. So, please try to consult the experts, wherever your healthcare setting is, if you are experiencing either fatigue or sleep disturbances.

ELYSE S. CAPLAN, MA:

[To participants], listen to the podcast [<http://www.lbbc.org/transcript-category.asp?transcriptcategory=psychosocial>] if you'd like to hear some of the points reviewed again. And remember, we have peer support available at any time by calling Living Beyond Breast Cancer's Helpline at (888) 753-5222. And don't forget to utilize our message boards so you can get peer support in that way, if that's useful to you.

OPERATOR:

Ladies and gentlemen, this does conclude today's teleconference. Thank you very much for your participation and have a wonderful afternoon.

[END OF TRANSCRIPT]