



Fatigue & Sleep Solutions

Host: Rebecca Gillett, MS OTR/L

Guest Expert: Susan Bartlett, PhD

Pain is the worst symptom of living with arthritis, but for most people, especially those with inflammatory forms of arthritis, fatigue is a close second. The fatigue that comes with arthritis, which may result from the underlying inflammation, is depleting — far beyond the common tiredness that results from a poor night's sleep. This fatigue leaves people without energy to get through daily tasks, it enhances pain sensitivity, and it worsens stress, anxiety and depression, undermining daily living as well as quality of life for people living with arthritis.

Susan Bartlett, PhD, who has extensive research experience in fatigue and inflammatory arthritis, joins us for this episode of the Live Yes! With Arthritis Podcast. She discusses some of the causes and effects of fatigue, its impact on sleep as well as some solutions to improve sleep and help relieve fatigue.

Dr. Bartlett is a professor of medicine at McGill University in Montreal. A licensed clinical psychologist and epidemiologist, Dr. Bartlett is one of the few psychologists who specializes in conducting research in inflammatory arthritis, and she has been counseling patients with rheumatic diseases for more than 30 years. Her research focuses on identifying what matters most to people with arthritis and other rheumatic diseases, and capturing these outcomes efficiently in arthritis research and care. She has led clinical trials to improve quality of life in people with rheumatic diseases through changes in diet, exercise, treatment adherence and other health behaviors. She is a board member of the Arthritis Health Professions Association, the Arthritis Research Professional Board, the NIH PROMIS Board of Directors, and the American Thoracic Society Board of Directors.

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PODCAST OPEN:

You're listening to the Live Yes! With Arthritis podcast, created by the Arthritis Foundation to help people with arthritis — and the people who love them — live their best lives. If you're dealing with chronic pain, this podcast is for you. You may have arthritis, but it doesn't have you. Here, learn how you can take control. Our host is Rebecca Gillett, an arthritis patient and occupational therapist, who is joined by others to help you live your Yes.

MUSIC BRIDGE

Rebecca Gillett:

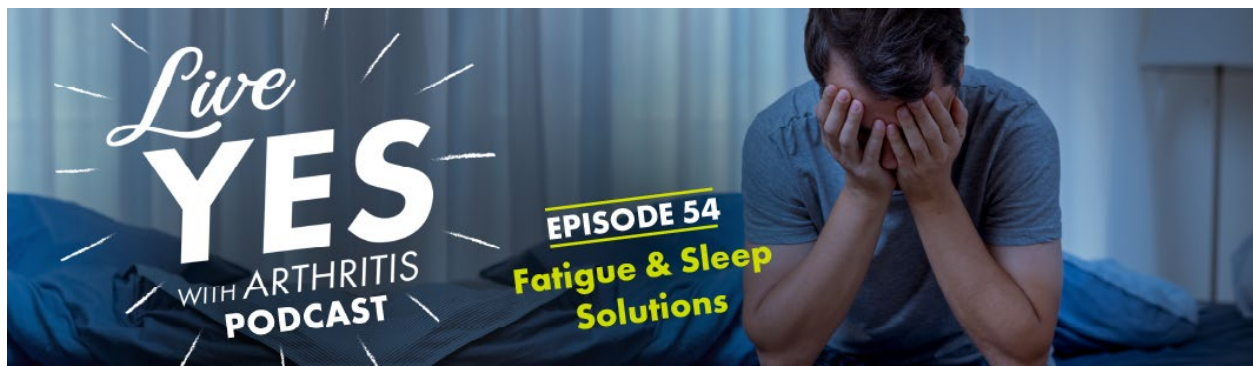
Thanks for joining us on this episode of the Live Yes! With Arthritis Podcast. Today, we're talking about something that people with chronic pain and arthritis struggle with often, and that's fatigue. Fatigue is almost as troublesome as the pain that many of us live with, whether we have rheumatoid arthritis or any other form of arthritis. But this symptom for such a long time has typically been neglected and poorly understood by our medical community.

Unlike just being tired that most people experience from overdoing something or from poor sleep, arthritis-related fatigue is a level of exhaustion that just saps strength and leaves people incapable of performing or completing daily functions. Many of you already know this and experience it.

Dr. Susan Bartlett spent much of her career researching chronic diseases like rheumatoid arthritis and ways of mitigating symptoms, including fatigue. She joins us today to explain this phenomenon, its causes and effects and how people can learn to minimize and cope with it. Dr. Bartlett is a professor of medicine at McGill University in Montreal and an adjunct professor of medicine at Johns Hopkins Arthritis Center. She is a licensed clinical psychologist and epidemiologist. She's one of the few psychologists who specializes in conducting research on inflammatory arthritis and also has been counseling patients with rheumatic diseases for more than 30 years. Dr. Bartlett, thanks so much for joining me on this episode.

Dr. Susan Bartlett:

Lovely to be here, Rebecca. Thank you for the opportunity to talk about this very important topic.



Rebecca:

Can you just describe to us the kind of fatigue that we're talking about and how it differs from tiredness that maybe the general population experiences?

Dr. Bartlett:

When we talk with patients and we say to them, "What's most important to you in learning to live a full and fulfilling life with rheumatic disease?" They say, "You know, I just want things to feel normal again. I wanna be able to enjoy my life. I wanna be able to do the things that I wanna do and not have to plan everything around my disease."

When you ask, "Well, what interferes with your life?" The first thing that people will often say is pain, but the second thing is always fatigue. And usually it comes with a caveat, and it goes something like this, "You know, I've learned how to manage the pain. I can deal with this. It's the fatigue that is completely overwhelming. It's the fatigue that is turning my life upside down."

So how is this fatigue different? Well, it's not the normal tiredness that people might think about. You know, the tiredness you experience if you only slept five hours instead of seven hours last night. It's fatigue that's not relieved with sleep. It has this systemic quality to it. So, it feels like, you know, that day or two you feel really off before you come down with a flu or something like that.

Rebecca:

Yeah.

Dr. Bartlett:

It's that kind of fatigue. They'll use words like exhausting. "I'm completely wiped out." There's that sense of heaviness or a weight that goes with it. Other terms people will use is, you know, being completely drained. So, it is this sense of depletion, and it's all-body depletion, and it's not relieved with sleep. That's a very important difference. How they refer to it in the UK, for example, they'll often use the term knackered. Heard that word before? Are you familiar with knackered?

Rebecca:

No, I've never heard it, but I like it.

Dr. Bartlett:



Knackered is what happens to the horse when the horse is at the end of its life, and it's taken away and disposed of. That feeling of just sort of... There's nothing left. And that's probably the best description that I've heard overall. But it is, yes, a very different kind of experience than just being tired.

Rebecca:

I think I'm gonna use that term now: I'm knackered. (laughs) The UK has the best slang. I loved the term that you used: depletion. Because, exactly what you've heard from other patients is the kind of stuff I've experienced with my rheumatoid arthritis, as well, is that almost feeling like you have the flu, when you're so run down and you just feel like that all day; you just never feel refreshed. Could you tell us what rheumatic conditions is this type of fatigue typically associated with?

Dr. Bartlett:

Inflammation is a hallmark of rheumatic diseases, and inflammation is very much tied to fatigue. Really all of the rheumatic diseases are very much plagued by fatigue. In rheumatoid arthritis, for example, some 80 to 90% of people indicate that they experience moderate to severe fatigue at various times.

Rebecca:

Fibromyalgia is one that often we hear a lot of people talk about fatigue.

Dr. Bartlett:

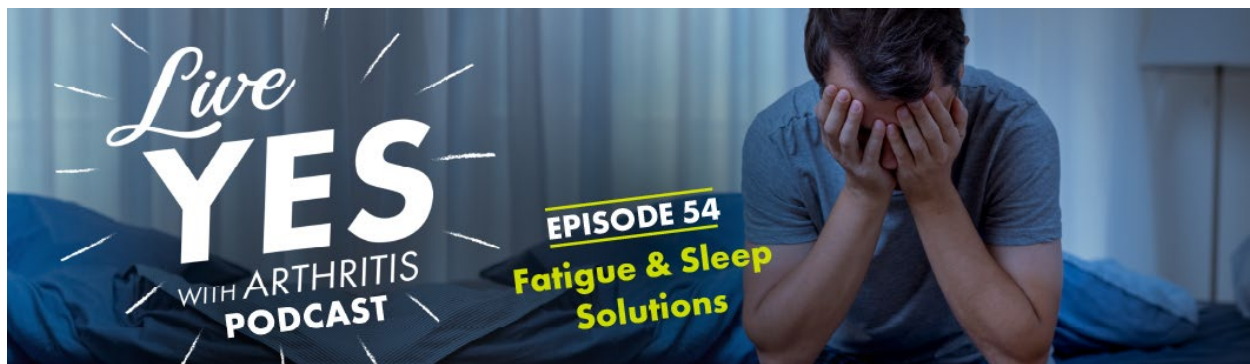
And the fatigue is really disabling because it robs people of the stamina. That's what you were mentioning, Rebecca, this feeling that you've just run out of energy. But it also affects emotions. A lot of people will find that they feel like they just have less control over their own emotions and less control over their life. They're more prone to saying things that they may later feel were embarrassing. They're more easily upset. They're more likely to feel down and discouraged because of the fatigue.

Rebecca:

What about osteoarthritis? Is fatigue an issue for people with osteoarthritis?

Dr. Bartlett:

It sure is. It seems to be almost as much of a problem. You know, there's increasing evidence that there may be inflammatory components to osteoarthritis, so that may be behind it, but definitely the pain, dealing with pain every single day. That's exhausting; it's exhausting physically and it's exhausting mentally.



It also changes the way we think. So, when you're fatigued, you're less able to think clearly. That's obvious. Concentration goes down. People are more prone to making mistakes. Another thing that fatigue really has a major impact on is everyday life. For so many people, there's an uncertainty. They feel like they have to often cancel plans, especially plans on the weekend, or they begin avoiding making plans. 'Cause they're just not sure that they'll have enough energy come the weekend or come even a vacation to be able to do the things that they wanna do.

And lastly, one of the most important consequences of fatigue is that it robs individuals of the ability to take care of themselves, to do the things that they need to do. To exercise regularly, to prepare healthy foods, even to bathe. So, a major impact every day on all aspects of life.

Rebecca:

What are some of the causes of this type of fatigue?

Dr. Bartlett:

The first one that comes to mind is inflammation or disease activity. We know that when inflammation and disease activity are high, fatigue is always high. But one of the things that we found in some of our research at Johns Hopkins was that even people in remission can also experience high levels of fatigue. They look like they're doing very well except for this fatigue. But we know that many of the hormones and the neuromodulators that are often elevated in inflammatory disease can also directly impact sleep, and as sleep is impacted, so can fatigue be as well.

But there are other medical conditions besides the rheumatic disease that go along, comorbidities that can also impact energy level, and things like anemia or hypothyroidism, diabetes, fibromyalgia. A third of people with rheumatoid arthritis, for example, have fibromyalgia. And fatigue is a very big component of that.

What else? Well, pain, of course. Pain is exhausting. As patients lose sleep, their pain increases. So, it becomes somewhat of a vicious cycle. There's also this stress, just the stress of living with a chronic disease.

Physical activity is another thing that comes to mind. People who have arthritis, for example, osteoarthritis or rheumatoid arthritis, tend to be less physically active, and the less physically active you are, the more likely you are to experience fatigue. That's not just in rheumatic diseases, that's in everybody: the fact that our natural tendency is to stop being as active when we're in pain.



And so those higher rates of sedentary activity are also an important contributor, I think. And then, last but not least, the medications. Many of the medications that are especially important for controlling disease also have that unwanted side effect of additional tiredness or fatigue. Methotrexate. Steroids; steroids might give you energy in the short term, but they also cause insomnia, which contributes to the fatigue. Plaquenil. There's the whole host of medications that just have a side effect of making you feel more tired.

Rebecca:

How do you weed out perhaps the cause of your fatigue? What's triggering your fatigue?

Dr. Bartlett:

I think this is one of the reasons that many physicians are reluctant to talk with patients about their fatigue levels, because they don't know where to begin. And they realize it could be any one of this dozen or more factors. So, it feels overwhelming to patients, but it also feels overwhelming to the rheumatologists who treat the patients in trying to understand where to begin.

Working with the same doctor over long periods of time, you get to know each other. Over time, I think many rheumatologists get a better sense of things that may be shifting. The factors that would contribute to fatigue in a 30-year-old woman with rheumatoid arthritis may be very different than the factors that contribute to someone who's 40 or 50 years of age and has just different roles in their life and different demands.

Rebecca:

Since it can be a difficult thing to discuss on either end, do you have any suggestions for patients to bring it up? If they feel like the fatigue really is a problem and they want the doctor to help them address it?

Dr. Bartlett:

One of the things that I'm most sensitive to is the role that mood or emotions play in fatigue. And so often when somebody comes to speak with me, the first thing they're talking about is how tired they feel. And for me, what that does is cues me to look at how they're feeling overall emotionally. How sad they're feeling, how overwhelmed or stressed they may be feeling, because often people are really unaware that they've experienced some changes in their mood.



It's not uncommon at all for me to uncover the depression or the anxiety, whereas the person really feels, "No, no, I, I don't think I'm much different." A kind of a rule of thumb that I'll just share is that if you're having trouble falling asleep at night, that's anxiety. But if you're waking up at 4:00 in the morning, you can't get back to sleep and you feel very unrefreshed, you're still as tired as you were when you fell asleep, that early morning awakening, that's a hallmark of depression.

About 30 to 40% of people with rheumatic diseases also have anxiety or depression. The same inflammatory pathways that are activated with the rheumatic disease also appear to be involved with mood disorders as well. So, it's not uncommon to find that this is an important contributor.

Rebecca:

Yeah. So, you're experiencing both of those: difficulty falling asleep and waking up. And it is a good clinical sign for having both anxiety and depression that obviously are leading and helping contribute to the fatigue.

Dr. Bartlett:

And it's also one of the markers for us, by the way, that antidepressant medications might be useful in that case. They do seem to help rather quickly.

Rebecca:

Hearing that the mood and emotions can really play into the role of how we experience fatigue is really eye opening, I think, maybe to some of us who are listening, like not even putting that connection together, that, "Oh, wait a minute. That's what that is," you know? And so really addressing sleep, too. That's also a red flag. If you know, the sleep is really an issue. Well then, yes, you might have some fatigue. It's not just being tired.

Dr. Bartlett:

We're learning more and more about sleep all the time. There hasn't been a lot of work that has been specifically done in rheumatic diseases. But what is emerging is that it's a major problem. More than 80% of people with a rheumatic disease report that they also have sleep problems. And if you are not sleeping well, nothing is gonna go well in your life.

Your health will be much worse because you'll have more stress hormones, and those stress hormones can lead to disease flares. The sleep disturbance also will contribute



independently to the depression and anxiety. And it even changes the way that our brains process pain. It makes people much more sensitized to pain. So, even at the same level of pain, they have much more difficulty coping. Sleep is a major, major issue. There's so much more happening in the world that is keeping people up at night as well.

Rebecca:
Yeah, for sure.

PROMO:
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Rebecca:
What triggered your interest in this area of research? Have you dealt with insomnia or fatigue yourself?

Dr. Bartlett:
Well, as I've gotten older, I've certainly experienced what my father always said, which is that people are really lucky, in their youth, in the quality and the quantity of sleep that they can amass. That certainly changes as we age. But I think I was interested in sleep and fatigue, most of all, because it's the thing that matters most to patients, and patients are stuck in this difficult position where the rheumatologists are still really reluctant to ask about it. It surprises me. It's 2022. We've been doing a lot of research on this for at least 30 years. But rheumatologists are still reluctant to ask about it because my sense is that they often feel they have nothing to offer.

Rebecca:
What's some of the research that you are doing in this area?

Dr. Bartlett:
I've looked at fatigue in a number of different ways. We looked at it in relation to disease activity. The relationship was not as strong as we suspected it would be. We thought we would find a very high correlation, but then, of course, we found that there were people in remission who had really low or negligible disease activity, but still had moderate to high levels of fatigue. Their disease was smoldering, although it wasn't showing up. Oftentimes, those were individuals that, if we waited another month or so, we saw they were going into a full-blown flare.



We know that fatigue is a really important marker of flare, and almost everybody is gonna have that surge and fatigue just before the flare really shows itself. But the other thing that we learned is that there's so many people who are very creative in knowing how to manage their fatigue effectively and how to prevent, or even reverse, a beginning flare.

In one of the studies, I always remember a person who talked about her chocolate and duvet dates. She recognized that when she was going into a flare, for her the best thing to do was to go into bed. To close the curtains, interestingly enough. To be in a dark room, to just have a nice bar of chocolate beside her. I can understand that chocolate.

Rebecca:

Yeah, we all need that sometimes.

Dr. Bartlett:

Chocolate can work wonders ... But if she just stayed in bed for the day, and sometimes it took two days, she could reverse an impending flare. Others talk about the importance of hot showers, or listening to the body in some way, understanding what the body is telling you. But it's this quietness and this stillness that seems to be so very important to reversing flares, or reversing fatigue, that just doesn't seem to go away. You're not gonna be able to power straight through it.

Rebecca:

Yeah.

Dr. Bartlett:

That's for sure. I've also done a considerable amount of work looking at yoga. We know that yoga does great things for physical health in terms of strength, flexibility, endurance and balance. But as an activity for mental health, yoga also is associated with better energy, more positive feelings, fewer negative feelings and a respect for the body. And an acceptance of where you are today and the importance of listening to your body and understanding: Some days are better than others. So, you need to be able to adapt to that.

Several years ago, we conducted I think what remains the largest randomized controlled trial of yoga and people with rheumatoid arthritis and osteoarthritis. Those classes introduced yoga poses. They were all modified to the person's level of ability.



And what we found at the end of eight weeks were meaningful improvements in physical health, in flexibility and balance and in mood. A year later, when we looked in to see how many people were still exercising, we found much higher rates of adherence than we typically see. In other words, this was an enjoyable activity that people were willing to stick with.

Rebecca:

Yeah. I feel like that mindful movement, like you're talking about, is a great gateway for people to get moving. Doing yoga or any of that mindful movement, like even tai chi, that gentle movement of that mind-body-based kind of exercise, you really do feel better. Then you can move on to something like resistance training or walking and/or something like that.

Dr. Bartlett:

Now it's the only way I wanna do exercise. I've really come to love yoga and found it's a very important part of my everyday life.

Rebecca:

I think that's one of the hard things, when people are struggling with fatigue, for us to hear: The best research supports physical activity and exercise. How do we overcome that fear?

Dr. Bartlett:

Well, exercise is important for everybody. But I like to say it's especially important for people with rheumatoid arthritis, 'cause you've gotta keep the joints mobile. You've gotta make sure that you're getting nutrients into the joints, and exercise is the best way to do that. You've gotta deal with that stress that I talked about. Exercise is one of the best ways. It's the best insurance plan that you can buy for sleep because, when people are more active, their sleep tends to be much more regular and restorative.

And it also is really important for just stress management quite frankly. There's nothing like exercise to distract you from the worries of the day and to get you to focus on something differently. Even if the exercise is brief, 15 or 20 minutes a walk, I'll feel better. I'll feel more capable of tackling what's ahead of me.

Rebecca:

Can you talk about some of the other potential approaches that we can take a look at when we're trying to get more restful sleep and improve or decrease any fatigue symptoms?



Dr. Bartlett:

I am gonna start by saying that the principles of sleep hygiene are necessary, but they're not sufficient. If you are not able to get to sleep, it's really important that you do get out of bed and you do something else that's relaxing for an hour. Nothing too interesting, nothing too stimulating. Don't watch TV, that's a mistake.

But don't lie in bed either, because we don't want the brain to associate being in bed with fretting about sleep. We want to associate beds with sleeping and sex only. It is normal to have bad nights now and then, but certainly don't lay there and worry about it. Get up, get out of the room, do something differently.

You don't wanna exercise strenuously in the evening. You don't wanna have caffeine or too much alcohol because those things will of course interfere with sleep. Anything that you can do to help relax, like a warm bath or soft music or reading. Do you have a comfortable bed? Do you have a pillow that works for you? If there's more noise than you would prefer, then think about things like earplugs. Would that be helpful? Or a white noise machine? Is it dark enough? Or do you need curtains that will help block out more of the light? These things really do make a difference, but it may not be enough.

Rebecca:
Right.

Dr. Bartlett:

And if you're still having problems, and fatigue is a part of your everyday life, and it's interfering with life, then you need to talk with your doctor. And you may need to talk with them more than once. I find that often patients are very tuned into their physicians, and if they bring something up and the physician doesn't respond, they stop bringing it up. This is one of the cases where you need to keep bringing it up. Otherwise, your doctor's gonna assume there are no problems.

So, the first thing to look at is: Is your disease under as good control as it can be? Because we do know that meds stop working, or stop working as well, over time. Either your doctor or your pharmacist should also take a look at your medications. I remember somebody that I worked with, and she went through her nighttime routine, and it turned out that she was taking her thyroid medication just before she went to bed. That's gonna interfere with your sleep, absolutely. Prednisone is gonna mess up your sleep, too.



Rebecca:
Oh, yeah.

Dr. Bartlett:

There may be some medications that will help with your sleep, and that's worth talking about, too. Very small doses of tricyclic antidepressants can often make a huge difference for people. And hypnotics also can be used on occasion if you're into an insomnia cycle and you need to break it; it's not an answer long term, but a hypnotic can really make a difference in the short term.

There are apps that are out there that many people find really help them to relax. There are mindfulness apps. One I'm most familiar with and find very effective is the Calm app. UCLA has a mindfulness app that's very good. Headspace has some sleeping music. The Arthritis Foundation has some excellent tips on your website.

Rebecca:

Are there some evidence-based strategies that can help with fatigue and sleep?

Dr. Bartlett:

Well, you know, sleep hygiene has a very robust evidence base. The importance of following a routine. The importance of avoiding naps; nap no longer than 15 to 20 minutes during the day. The importance of getting yourself, even if you have a really bad night, get yourself outta bed at the same time in the morning. It won't help you feel better that day, but it will contribute to the likelihood that you're going to have deeper, more refreshing sleep the next night.

So, all of these things: There's very strong science. In fact, some of them seem so simple. How is this really gonna make a difference? But in fact, they do. But it may not be enough. And at the point where it's not enough, talk with your doctor. Things like a sleep disorder, a formal sleep disorder. And that's important to rule out. Insomnia basically is: if you have gone about three months or so, where you're really having trouble falling asleep or staying asleep.

The second one is obstructive sleep apnea. I think this is a little less common. It's actually much more serious though. Obstructive sleep apnea is where the muscles in your throat actually begin to collapse at night. And, in effect, you cease breathing for momentary periods of time. If somebody tells you you're snoring at night, it's worth talking with your



doctor and following through to see if in fact this could be OSA: obstructive sleep apnea.

PROMO:

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Rebecca:

In this segment, we reach out to our listeners on social media and ask if they have any tips or strategies that might work with them for fatigue and sleep. One says: "Don't fight it. If you try to power through, the sensation gets worse. Take the nap, find the sunshine, take a shower. Sometimes taking a shower eases the fatigue and the pain a little." I think those are all things that you mentioned, although maybe the take a nap... Shorten that period of time, you said?

Dr. Bartlett:

10 to 20 minutes will be fine. If it's much beyond 30 minutes, it is pretty certain to interfere with your sleep that night.

Rebecca:

Somebody also said sun and exercise, if possible.

Dr. Bartlett:

If you can do it in bright sunlight, all the better, because that really helps to set the circadian clocks that we have in our body. So, the earlier you can be exposed to bright sunlight in the morning, the better. And then you really do want to have things much more dim in the evening.

Rebecca:

That brings up another question, circadian rhythms. Here in the U.S., we went through another time change, which is always the worst. How does our circadian rhythm affect our ability to sleep and our levels of fatigue, and how do we reset it?

Dr. Bartlett:



Going to bed at the same time each night and getting up at the same time each morning, whether you're on vacation, whether it's the weekend, that's what helps us establish and keep to a routine. It is important to get up and have breakfast. Mom was right: Breakfast stimulates metabolism, and there's nothing like metabolism hitting in high gear to really signal to the rest of the body: The day has begun. That's also part of the reason why you don't wanna be eating late in the evening.

Rebecca:

Somebody actually says: "Quit sugar. Eating more protein and fiber and moving more." So, getting that metabolism going, right? Somebody said: "I gave up fighting my limitations. I make relaxation, rest and recovery a priority."

Dr. Bartlett:

So many people with rheumatic diseases just are very stoic, and they power through. They power through the day, and then they collapse at night when they get home so that they just don't have anything left. And they power through the week, and they collapse so that the whole weekend is devoted not to enjoyable things that add to the quality of life, but really it's just basic recovery.

So, I love that idea of, you know, making sure that you're taking breaks during the day, that you are working to try and stay relaxed, and you are staying within your own comfort zone, not exceeding it.

Rebecca:

From an occupational therapy standpoint, that's why we talk about energy conservation and spacing yourself, so that you save time for the things that are important for you throughout each day. So, thanks for that; that's a great tip.

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Rebecca:

Thank you so much, Dr. Bartlett, for all of the wealth of information that you shared with us today. Before we go, I'd love if you could share with us what you see as your top three takeaways from our discussion about fatigue and sleep solutions.



Dr. Bartlett:

First and foremost, take your fatigue seriously. It's telling you something really important. Be sure you talk with your doctor about it. Just because your doctor may not respond doesn't mean the conversation should end. Fatigue might also be a sign that your disease is not in as good control as it could or should be. I think that we do have to acknowledge that sleep problems go hand in hand with having a rheumatic disease.

Poor sleep is gonna worsen your pain, make you feel more stressed and more vulnerable to depression, and getting adequate sleep has to be a priority. It has to be one of the things that we really guard very, very carefully. And I said before: Sleep hygiene is important for everyone, but it's especially important for people with rheumatic diseases because, the better you sleep, in many ways, the better you're going to feel.

If you're struggling with this, and sleep remains a problem after you go through those strategies of looking at your own sleep hygiene, and using some apps, and making sure that you're balancing rest and activity, then speak with your rheumatologist. Because maybe a referral to a sleep center would be helpful to rule out a sleep disorder. Or to just be able to talk with a sleep specialist who can personalize some of these recommendations specifically for you.

Rebecca:

I think one of the great tools that we have at the Arthritis Foundation is our new pain management app, Vim. You can learn strategies and have some resources to learn how to make sleep a priority. That's something that I highly recommend to anybody listening. If sleep is an issue, I always tell patients, talk to your doctor, get to the bottom of it.

Just like Dr. Bartlett said, unless you address sleep, everything else is gonna be hard. We need to tackle the fatigue and the sleep. Thank you so much for all that information. And if you want to, take a look at Vim. Just make sure you go to our website, <https://www.arthritis.org/vim>, to learn more about our app. And thanks everyone for listening. Thanks for joining us, Dr. Bartlett.

Dr. Bartlett:

Thank you, Rebecca. And I wish you good sleep and lots of energy.

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