

## THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

### ***Episode: 'Cancer-Related Fatigue: Syndrome Not Symptom'***

#### **Description:**

Fatigue is the symptom most frequently reported by individuals with cancer. However, cancer-related fatigue (CRF) is very different from daily fatigue. Listen in as Alicia and Lizette speak with Patrice Al-Shatti, LMSW, who shares how calling cancer-related fatigue a symptom does it as a disservice as it is actually considered a syndrome. She explains the difference between fatigue and cancer-related fatigue, the varying physiological and biological factors, and helpful strategies known to improve quality of life. Patrice also discusses energy conservation and activity management and how to actively pace, plan, prioritize and deal with 'energy leaks'.

#### **Transcript:**

**Alicia:** Welcome to the *Bloodline with LLS*. I'm Alicia.

**Lizette:** And I am Lizette. Thank you so much for joining us on this episode.

**Alicia:** Today, we will be joined by Patrice Al-Shatti, an oncology social worker. So, let's jump right in. Patrice, can you tell us and our listeners a little bit about your background and what piqued your interest in your field?

**Patrice:** I am an oncology social worker, last at the Mayo Clinic in Arizona; have been working with adults with cancer for—I don't know—15, 20 years or so. My interest in cancer-related fatigue syndrome popped up pretty naturally in my counseling work with patients because they seemed to be almost immobilized by this condition. I was wanting to talk about their family troubles, or their money troubles, or their anxiety, or their depression and they were just wanting to talk to me about how darn tired they were. I noticed that we didn't really do much talking about fatigue on the medical team, other than to note that people were complaining about it so I became really curious and started investigating, mostly because I wanted to have something to offer

these patients I was speaking to. I started presenting these solutions that were clearly there in the research to my peers on the medical teams, to groups of nurse practitioners, and physician assistants, to physical therapists, to nurses.

So, it became kind of a mission and passion of mine to talk to patients about it. First, figure a paradigm under which to talk to patients about it, and that sort of spread to my docs because I was eternally referring patients to doctors for x-y-z-related to their fatigue. I started educating physician groups, nurse practitioner groups, nurses groups and then I was asked to speak to patient symposiums; then I developed patient education materials for the Mayo Clinic, including their first actual patient education brochure on the topic of cancer-related fatigue. In a library of 10,000 pieces of patient education, the clinic did not have one single thing to give to patients on cancer-related fatigue, which sort of spoke to the idea that it was very much—maybe not so much at the moment—but at that time, it was very much kind of under the table. Patients did not ask about it. Providers did not talk about it. We designed our first patient education course where people could come and learn about their fatigue; got our nursing staff really involved and, lately, have been educating other oncology social workers about our role in fighting cancer-related fatigue. I think it is an arena in which there is a lot of hope for patients to have a really big impact on their own lives.

**Lizette:** We deal with all the blood cancers and throughout all the different diagnoses, we hear how patients are really affected by fatigue.

**Patrice:** Of course.

**Lizette:** I am really surprised that we didn't have more items out there to address fatigue.

**Patrice:** You know, as a starter, cancer-related fatigue isn't a symptom. It does it as a disservice. It does the patient a disservice. It does the medical community a disservice. It is actually a syndrome. A syndrome is a number of symptoms that come together in a particular setting, under particular conditions to cause problems. It is

rather surprising what all—and there is actually—we have a diagnostic and statistical manual that is used to sort of explain medical conditions and problems, and cancer-related fatigue syndrome isn't actually in the ICD. It has a list of actual symptoms and some of them are obvious that you would know, like having less energy and struggling to get things done, but some of them are less obvious. Cancer-related fatigue syndrome includes problems like having trouble concentrating, finding sleep is not particularly restorative, having trouble with motivation, having trouble with what we call inertia, a very, very strong sense of being completely like set in cement and unable to move, memory and concentration problems, incredible short-term memory problems. It is a syndrome. It is a number of different symptoms that come together to cause problems. And it is almost universal. 99% of patients who receive chemotherapy have reported, at one point or another in their treatment, feeling as though they are experiencing this type of fatigue. It is described by patients as more distressing than any other thing—than the nausea, the vomiting, or the pain, or the worst of the symptoms is the fatigue is what stops them in their tracks.

**Lizette:** It really goes to somebody's quality of life. If you feel that you can't get up and do things that you were doing.

**Patrice:** You can't move. You can't think. You can't move. You are basically immobilized. You know a third of cancer survivors report that their fatigue, on some level or another, lasts more than 10 years after their treatment is done.

**Alicia:** I know that people think that everyone gets tired and usually we know why we are tired and a good night's sleep will solve the problem for regular fatigue, but for those who are experiencing cancer-related fatigue, what is the difference between the two? How can they identify what is CRF and what is simply fatigue?

**Patrice:** Right. So fatigue is—we all know fatigue—and actually, that knowing of what fatigue is in normal life is part of the problem I will talk about a little later because the problem boils down to interpretation and perception and how we respond

and how we cope based on what we know of our life experience thus far. Usually, when we are tired, what do we do? You get a good night's sleep; you take a nap; you feel restored; you feel better. As I said, cancer-related fatigue syndrome is a number of things coming together to cause the symptoms that I just described to you. It is stuff like a person's symptom burden, their blood counts, fevers, changes in organ function. It is physical function changes like the fact that the body does not want to fall into a normal sleep rhythm. It is other medical issues. A lot of the medicines we give folks when they have cancer affect things like if they have diabetes, it affects their thyroid problems, it affects cardiac problems. Medications play into cancer-related fatigue syndrome. A lot of medicines are sedating and a lot of people on treatment are given a number of these kinds of medicines. Treatment side effects play into cancer-related fatigue syndrome—the diarrhea, the infections, the weight loss, the nausea and vomiting. Psychological stressors—the anxiety, the depression—that plays into cancer-related fatigue syndrome. Nutritional imbalances are huge—the mouth ulcers when people are getting not enough calories, when their electrolytes are imbalanced. People I used to work with who had 2 feedings—so there are about 7 or 8 kinds of factors that come together and sort of create this biochemical soup. We know that it is, again, truly biochemical, a lot of pro-inflammatory sorts of cells get riled up when someone is in cancer treatment and that has a depressing effect on a person's biochemical capacity to function well. Cancer-related fatigue syndrome is, by and large, the physiological things coming together whereas normal fatigue is normal fatigue. The two things have nothing to do with each other essentially.

**Alicia:** And you mentioned energy conservation earlier. Can you go into more detail about that?

**Patrice:** Sure. What I think what I would like to do is kind of give you—can I give you kind of an a-b-c of it?

**Lizette:** That would be great.

**Patrice:** So “a” is all the physiological factors that come together to create the soup in the body that gets it into this state where you got pro-inflammatory cytokines that are released by the tumor cells; they are released by the normal cells; you got kind of a sick syndrome in the body which causes this strong sense inertia. It screws up sleep. Then you have the nausea, the vomiting, the weight changes, the dehydration, the diarrhea, the fever, the anemia, the pain, etc., etc., etc. That is on the biological side. On the psychological side, the person is kind of attacked by trying to figure out what all this physical stuff means, as well as the natural psychological reactions that come with being diagnosed with a blood cancer—grief reactions, anticipatory anxiety, intrusive thoughts, all kinds of just stuff is in your head. You have to do something with that. We have to make some kind of sense out of what we experience. When we are bombarded like that and feel so bad, we feel like it feels like tiredness, but it is, again, this physiological process that doesn’t have anything to do with the lack of sleep, by and large. What patients do, is we pull—what we do as human beings under attack like this is that we don’t really know what is going on, but we think if we can serve if we get rest, if we pull in, if we can serve our physiological resources, our psychological resources, our social resources; if we pull in, we are going to be able to take a breath and kind of get restored, so we contract. We contract on all levels of our functioning in order to try to get a grip on it, but unfortunately, all that contraction makes the cancer-related fatigue syndrome worse. When we pull in and we get more sleep, our bodies aren’t in need of more sleep. Sleep was not the problem. When we pull in and we don’t move, we become even more deconditioned because we are not moving. When we isolate because we are too tired to deal with people, we become naturally depressed, which is what you do when you self-isolate. All the kind of contraction that we do in order to try to feel better actually contributes to making the problem worse, unknowingly to us. We sort of end in that cycle with our body’s vis a vis our coping choices. Again, it is kind of a weird thing and I can sometimes see the light go on when people kind of understand that it isn’t about the idea that I didn’t have enough sleep last night. I slept 15 hours last night and I feel awful. Well, if I

asked you two to go to bed and sleep 15 hours tonight, how do you think you would feel tomorrow. Too much REM sleep is associated by itself with depression and, actually, when you sleep too much, generally it is associated with early death—just across the board, across all kinds of people. In a really natural and understandable way, the choices people make trying to interpret what is going on with their bodies, makes things worse. The National Comprehensive Cancer Network sort of laid out, through a lot of research, what are the things. So here is the “c” part; so the “b” part is patients tend to pull in. They don’t see other people, they rest, they do a lot more sleeping, they do a lot of sitting around. They are trying to get their energy back, but all of those choices are actually feeding into the biological problems that are causing the fatigue.

There are really 4 strategies that are known to fight this and known to turn it around. The first and most important one is exercise. The first and most important one is exercise. The second one is kind of an occupational therapy strategy called, “energy conservation and activity management” and that is sort of a form of budgeting. It is kind of fun. We will talk about it in a minute if you want. Then there is sleep hygiene. Then, there is education and a little bit of counseling. The education piece is huge because, again, this is all about how you interpret things.

**Lizette:** You did mention exercise.

**Patrice:** I did! I did! Now, my experience is more in solid organ tumors and all the research is indicating that exercise is by far and away the most helpful thing that people can do because what it is doing it is fighting the deconditioning. If the cancer and the treatment are pumping out pro-inflammatory cytokines, exercise is pumping out anti-inflammatory cytokines. If the cancer and its treatment is, by its very nature, causing muscle wasting, exercise builds muscle. If the cancer and its treatment is causing anemia, exercise builds blood cells. If the cancer and its treatment are causing depression, we know exercise is a treatment for depression. Across the board,

the exercise across all disciplines of study, both medicine, nursing, PT, OT, all the research has, by and large, found it is the most helpful thing. Now, my concern for your population is people's blood counts really are what they are. This is not in anybody's imagination. Those are real things.

**Lizette:** Right.

**Patrice:** I still suggest that exercise is super helpful, but you also have to have good what we call VO2 max. You have to have a good oxygen exchange in order to get exercise and have it to be useful. I certainly still encourage any blood cancer patient who is feeling fatigued to be seen by a physical therapist for a physical therapy evaluation, but I can't exactly speak to what kind and type of nature of exercise would be most helpful because, again, these patients are, by nature, fighting issues with blood count. In solid organ tumors, we say get your blood counts fixed and then start your exercise program. These patients—your folks—might have a little more trouble trying to get that done. But it still is at the top of the list of everybody's known helpful interventions.

**Lizette:** Yeah. We do have patients all the time calling in to our telephone live education programs and asking key opinion leaders (hematologists, oncologists) what they can do for their fatigue. When the doctor tells them exercise, I think they take a step back because they can't believe that exercise would actually help when they feel so tired.

**Patrice:** It really is a conundrum, but remember, one of the symptoms of cancer-related fatigue is a sense of absolute inertia. When I would counsel and do fatigue assessments with patients and counsel around this subject, I can see it on their faces. It is like, "really, are you kidding me?" You first have to be able to buy into the idea that it is a possibility and so what I will ask any patient is, "Is what you've done so far helping you?" Is the sleeping; is the sitting; are the endless Netflix series trying to get through this treatment; is the sedentary; is the getting rest helping you, are you

feeling better? If so, keep doing it, but I have yet to meet anybody that has told me that has helped them. It becomes—you know, what is the saying about continuing to do the same thing, wanting to get different results.

**Lizette:** Right, that is—what is it?

**Alicia:** It's Einstein.

**Patrice:** And sometimes, honestly, families can be super helpful in this. I have literally met families who were the ones giving the message--I told Mom to stop cooking, I will take care of that; to go sit down; she needs her rest. There is this huge belief that rest is the magic bullet for getting through cancer treatment and rest is actually the thing that is going to put you down for the count. What you need is the same amount of sleep you needed the month before you ever thought you were sick. If that is 7 or 8 hours, then it's 7 or 8 hours. It does not change the need for sleep.

**Lizette:** I do have a question. You did mention fatigue assessments, which I think are very beneficial. Now, I don't hear that from patients that they are all getting a type of fatigue assessment.

**Patrice:** I can't make assumptions. I just know I developed the practice of doing this in my world, with my patients because it was an area of interest of mine and I felt like the strategies that were known to be useful were things I could talk to people about. It wasn't anything crazy and super high-tech. It was how much sleep are you getting? Are you getting some exercise? Get out of the chair. Here is how this kind of works.

**Lizette:** But it is so important to just open that discussion because patients don't even know that they can discuss fatigue or that fatigue is part of their treatment or something that should be assessed.

**Patrice:** That is a super good point because I have seen research on this. This is a 2-way street. Patients don't ask about it because, again, by and large, these are



issues of interpretation. A patient will often take one of these internal approaches that “man, this is just the price of the whole situation. I have to buck up, suck up, just deal, get through it however I can” or “what I am feeling is so alarming, does this mean I am dying? I am certainly not going to say that because I am not going to wish that into reality and maybe I am being a baby here, but I am scared beyond description. I don’t know that I can make it through this, so I am just going to shut up and buck up.” That is often either stoicism or fear or the position I would find patients coming from. With the physicians—and, again, it depends on the practice and how much these NCCN guidelines are filtering down to the medical practices as in there are definitely things you can encourage people to do. Doctors—they have so much on their plate—I don’t think they are bringing it up. You have a scenario in which the most distressing symptom patients feel across the board is something they are not bringing up because they are either scared or they are feeling the need to just support the doctor and be tough and just deal. The physicians aren’t proactively asking because there is a perception that they are not really sure what to do to treat it because they are giving the medicines that are probably contributing to it and need to. It’s sort of the don’t ask, don’t tell.

**Lizette:** Right. Exactly. And we are trying to encourage patients to have more open communication with their treatment team and that their treatment teams are open to discussions about every part of their treatment journey including these quality of life issues. A lot of times that is really what people—it is in the forefront of patients’ minds as well as caregivers is these quality of life issues because that is what you are dealing with day in and day out. You may not have a treatment regimen that day, but you still have the effects of the treatment that day.

**Patrice:** Of course; of course.

**Lizette:** So just empowering patients to talk about fatigue because you are right.

**Patrice:** Well, again, keep in mind that the concept of hugely hampered motivation and inertia--so the patient, themselves, might just be saying, "oh my God, I can't deal. Just leave me alone. I am not going to mention anything I don't have to mention because I don't have the energy to mention it", but then certainly, family members can be the advocates and know that cancer-related fatigue is definitely something that is, on a lot of levels, addressable. They can go into those physician visits with the presence of mind to even ask for a physical therapy evaluation.

**Lizette:** Yes; definitely.

**Patrice:** Many physical therapists I have met who worked in cancer centers are really interested in this topic, too. It is in their arena and even being sent for an evaluation. But I can tell you that I met more than one patient who was beyond exhausted with cancer-related fatigue syndrome and looked at me and said, "you know, Patrice, I cannot add one more appointment to my schedule. I can't do it. I can barely make these." I think about the young woman I worked with who had been a huge exerciser before she went into treatment and was reporting to me (say 7 out of 10 fatigue, if 10 is the worst you can possibly imagine). We sort of looked at her routine in her day and what she felt she was capable of and she had been someone who walked 4-5 miles a day and what she was capable of was maybe walking around her swimming pool one time. We talked about walking around that swimming pool one time and then the next week, making it maybe 2 laps, and the next week seeing if she could do 3. It is just starting where you can start and if you can't start with a full out physical therapy evaluation, can you start with walking in your house and can your spouse or other loved one kind of be your coach to get that done and build up from there?

**Lizette:** Sure. a lot of patients didn't even think that a physical therapist could be part of their treatment team. We did have a virtual lecture on the topic with a physical therapist and what we found was most patients really didn't even think to see a

physical therapist and they were not referred to a physical therapist, but we really think that it's really beneficial for patients.

**Patrice:** Yeah. The American Journal of Nursing just this year found in a meta study, which is studies looking at lots of studies, that exercise was more effective than pharmaceutical options and should be considered the first line treatment.

**Lizette:** Wow!

**Patrice:** It rebuilds the muscle strength. It normalizes blood counts. It pulls out those anti-inflammatory cytokines. It addresses physiological distress. It addresses oxygen exchange and the capacity of the lungs to kind of get more O2 in so it addresses almost all of those characteristics I was talking about at the beginning, the factors that cause the fatigue in the first place. Do you want to talk about something super fun and interesting called energy conservation and energy management?

**Alicia:** Absolutely. Tell us some more.

**Lizette:** What is that?

**Patrice:** It is an occupational therapy concept. It's energy conservation and activity management. It is kind of like—I would explain it to patients like we are going to talk about your bank account now and budgeting—fun, fun! If you used to have 10 coins of energy to get you through your day when life was normal, how many would you say you have now? I would commonly hear things like 3, 4, 2. Okay, so you are walking around with this little purse. We can make it a coach. We can make it whatever you want. With your 2 or 3 coins of energy, what you have to do is smartly use it because you don't want to run out at 1 p.m. And when people say, "O my God, I did a-b-c and then I crashed and I hit the wall and I was in bed the rest of the day"; that's running out of your coinage. You kind of manage on a short budget with 4 specific little strategies.

The first one is called planning. You plan for when you do things during the course of the day so that you do the things that are most important to you when your energy is best. If going to see the physical therapist, you have that appointment, you want to make sure to keep it, try to schedule those appointments at times of the day that are good for you; not 7 in the morning and not 5 in the afternoon. If you are someone whose role in your home is to cook meals and want to continue to try to do that because it is meaningful and helps you feel normal, maybe you take that meal prep and you break it up and you do some chopping of vegetables at 10 in the morning, and you go back and do something else at 2, and you go back and you throw it together at 5. You break up a task over the course of the day into smaller bites so you are sort of titrating. You are pacing as if you were doing some kind of athletic event where distance is what matters and not speed. You prioritize. I call it the 3 D's, drop, delegate or defer. I was always talking about guys about lawn work. I don't know why that always came up, but it is like lawn work. It is like, "dude, what are you doing mowing the lawn?" Now, with some guys, mowing the lawn was the thing they did even in the middle of cancer treatment because it helped them feel normal and it helped them feel like they are in their role in their family. But, for a lot of people, it is grunt work so it is like what is in your life that is grunt work because remember that is taking 1 or 2 coins of this very limited purse of energy that you have so how can you delegate it to somebody else? How can you defer it until a later time or defer it until you have a really good energy time? If you only have 3 coins in the bag, spend them on things that really, really matter.

The last one is a super interesting thing called energy leaks, addressing energy leaks. Energy leaks are things if you think about that bag and maybe it had a little hole in it and over the course of the day, pennies are falling out just randomly that you are not actually trying to spend, they are just falling out because there is a hole in the bag. Energy leaks are things like if you got respiratory difficulties and you are not on oxygen; if you are home or workspace is not ergonomically efficient. I remember working with a pharmacist and, if you think about it, pharmacists have to stand at

counters for long periods of time. Just his very action of standing was an energy leak so I encouraged him to talk to his whoever at work about just pulling up a stool so he wasn't draining energy out the bottom just by vis a vis the action of standing, where he could still talk to patients and counsel patients and do the parts of his job that he loved, without having that leak. Pain is an energy leak. I remember talking to one guy once who had had a hip revision or replacement—I don't know maybe 10 years earlier—and it had never quite been right, and it bugged him. He had been encouraged to use a cane or some other kind of thing to take a little bit of weight off that hip—had never really done it—and as we are going through his fatigue assessment, we are talking about energy leaks and I discovered that he kind of has this chronic pain. It affects how he stands, how he sits. That is most definitely an energy leak. He is losing pennies out of the bottom of his bag without ever having actually spending them in any useful way he would want to spend them, so energy conservation. I think with folks, when their blood counts are low and they are in treatment and there is not much they can do about it, on some levels, you can always look and see how many coins do I have in my bag, how do I want to spend them? Pacing, planning, prioritizing and then dealing with energy leaks. And a physical therapist can also help with that.

**Lizette:** Sure. I think that is great. I think this would benefit all patients and I really wish that this was spoken about more often with patients and was a regular part of the conversation with their treatment team.

**Patrice:** Agreed. Agreed. getting folks including those PT/OT professionals in almost any patient's treatment plan can help round out and get these kinds of things on board. Again, they are not incredibly complicated and difficult things to understand. You just kind of have to know to think about them.

**Lizette:** Right; exactly and this is very important. This is one of the top issues that we get when we ask people. When we just say quality of life and how has that been

impacted, the first thing we hear is that we have so much fatigue that we can't do any of the things that we would have normally done so we don't feel normal.

**Patrice:** Right. As I said at the beginning, 99% of patients reported that it is the most distressing symptom they have to deal with. Sleep. Sleep is another big one. Sleep is one of the biggest ones. As I sort of alluded to, we know from tons of studies, people actually don't need any more sleep than they needed before this all happened. There is nothing in this that is fixed by more sleep; and, in fact, too much REM sleep, like I said, is linked to depression. And actually, slight REM (sleep deprivation) again, in kind of low levels, is actually a form of treatment for depression—kind of constricting people's sleep a little bit. Cancer patients sleep a lot longer.

**Lizette:** Oh yeah.

**Patrice:** In a way, without knowing it, when your spouse lovingly sends you to bed for a nap because you are so tired, or sends you to bed early, or encourages you to sleep in and, you know, a lot of people are not working while they are in treatments so they are just sleeping in naturally anyway. I don't have to be anywhere until 8 or 9 o'clock maybe if they have an early appointment, but people are going to bed earlier; they are sleeping later and if you think about it, is that helping your muscle mass? No. You are getting deconditioned. We know that 24 hours of bed rest has somebody significantly deconditioned. People sleep—oh my gosh—sleep is huge. Cancer patients sleep longer and later in the morning. They don't have the responsibilities because they have so often side-lined a lot of the rest of their life. For some people, sleep is a way to escape.

**Lizette:** Sure.

**Patrice:** I mean I have worked with plenty of folks who "talk to me about your sleep". Well, I take a nap in the morning, get up for a few hours, take a nap in the afternoon. Just sleep all by itself is so debilitating. Then, we have the biochemistry of

this interferons and the interleukins that are produced by the inflammatory response make people sleepy. Medications make people drowsy. Again, that whole choice issue, people interpret their fatigue as being fixed by sleep, so they sleep more which exacerbates the fatigue. Fatigue, insomnia and depression are really, really common things that kind of go together. When I talk to people about sleep, and this I did with 100% of patients because it was a problem with pretty much 100% of patients, I ask about what were your sleep habits before your cancer? What was your baseline, because that is your goal, to get back to your base line. When do you get up? When do you go to bed? What are your habits before going to bed? You know that TV watching that you could do when you were working and all and were really tired, you could probably do, but now, having the blue screens in the couple of hours before bedtime probably isn't something that your body is going to handle. What keeps you up at night? Is it pain? Is it having to go to the bathroom? Is it worry? What's keeping you up and waking you up and how can we address that? What time are you going to bed? Again, I kind of try very hard to give people a look at, if I was someone who went to bed at 10:30 and got up at 6:30, how can we work you back that way instead of your going to bed at 11 and waking up at 11. How can we work you back toward what would for you be a more normal sleep pattern? Those daytime naps are killers, literally. I try to get people to work their way down to maybe a 30-minute catnap that you set with an alarm so that you are not sleeping more than that. Daytime drowsiness—daytime drowsiness can be—again, folks are loaded with a lot of medication and a lot of them can cause drowsiness. People will then also use over-the-counter medicines. How are people using these? What about recreational drugs? Stimulants—one of the common treatments medicinally for fatigue is something like ritalin, but what is the effect of that on someone's nighttime sleep or how much caffeine are they doing? Again, something that could have worked for you when you well and active, you may want to look at in this period of time. What are the attitudes towards sleep? Again, what I would mostly get, and what I got a whole lot of, is, again, you are hit by that wall of inertia. "I feel like a lump of lead. I can't think. This

doesn't really make sense to me. I cannot imagine as bad as I feel now and I am sleeping 11 hours, you asking me to sleep 7 or 8. I have no idea how on earth how that is going to help me." And I have a wife who is sending me to bed, and a Mom who is sending me to bed (laughing), or a husband who is sending me to bed to get better. It's no bueno. It is really not good. It is not good. Try to limit your total in bed time, day and night, because we add these hours up together so if you tell me you are in bed at 7 at night and I find out you are in bed at 2 in the afternoon, granted we are adding those 2 things up. Limit your naps. Like I said, 20-30 minutes. Much more than that and you are going to get into a REM cycle and too much REM sleep is not good. Become more physically active. Do as much as you can, whatever that looks like; if that's one lap around your pool walking; if it's one lap down your hallway, whatever it is you can do. Practice an evening relaxation ritual. If you find that anxious thoughts (they do tend to come out at night when it is quiet and people don't have the distractions of other stuff), in all seriousness, it is a time when worrying about dying comes up a lot. Am I ever going to get through this? What is going to happen? What is going to happen to my family? People tend to worry at night. I think we all do normally, but you put yourself in this pressure cooker and it is pretty bad. What can be put on board in your life medicine-wise to help you either to be able to turn the brain off a little bit or to address anxiety if it is something that is also hitting you in the daytime because you have to try to be able to sleep at night in a healthy way. Getting those consistent waking and sleeping times. Addressing things like pain and hot flashes. Having to go the bathroom at night so that if you can get to sleep, you can stay asleep because a common thing I would see is people who awaken 3, 4, 5, 6 times at night and they are napping a lot during the day, but the whole sleep rhythm is really messed up, you know.

**Lizette:** Right.

**Patrice:** And basic sleep hygiene information is stuff that almost any medical practice should have on board to share, as well as energy conservation techniques. You can



even just Google “energy conservation techniques when you are sick”. You will probably come up with a lot of good ideas.

**Lizette:** I know that a lot of our patients tend not to bring up sleep as an issue, even if they do have sleep issues because they are taking medications and they find themselves doing well with these medications and they are scared that if they tell their treatment team that, you know, they are not resting well, they are not getting good sleep, they are too fatigued, that the medication will be taken away.

**Patrice:** What kinds of medicines are you thinking of? Or what do you think the medicines are doing?

**Lizette:** Well, there are a lot of our folks that are on oral medications that are actually keeping their type of blood cancer at bay. These are newer medications. They are oral and when they go to the doctor, a lot of time is spent on just going over their blood counts. As you mentioned before, this is part of what our blood cancer patients are going through is getting their results of their blood counts and their tests and they are doing well in that respect, but then they are not bringing up any quality of life issues. They are not bringing up the fatigue; they are not bringing up sleep issues because the doctor is saying, “oh, you are doing well with your blood count.”

**Patrice:** Okay; I hear what you are saying. What I also think is possible there is a possible  $1+1=3$ . Remember--what I hear is an assumption that I am on this medicine; therefore, the medicine itself is the thing that is causing me all these quality of life issues,  $1+1$ . What if you have the medicine on board that you have that keeps your blood count at a good place, but you still go see a physical therapist for an exercise regime that you can manage? You still talk to that same PT about energy conservation strategies. You still look at how much sleep am I actually getting because if these people are not having enough sleep, then there is nothing saying you can't address nighttime pain, nighttime anxiety or any of those other kinds of things. I wouldn't see a reason to have to stop a treatment medicine; it is just adding something else on

board to help. I am not sure, personally, that I would see this—I think there, again, interpretation is everything. And what I hear you saying is people aren't interpreting—again, it's that I just have to buck up and suck up because this is part of the gig-- and I would say, it is not part of the gig per se; I would say that, certainly, there is a physiological soup that is in there, but the things that you are choosing to do and the way you are choosing to live, thinking you are helping yourself might be working in the opposite direction. What would it be like to still be on your medicine, but try some different lifestyle strategies?

**Lizette:** And I am so glad you are on with us because you are really bringing this issue to the forefront that it is an important issue. People don't look at fatigue sometimes as part of their treatment and it can be addressed. People, you know, should be talking to their social workers. People should be talking to their physicians. We have heard of patients that have talked to other patients and have discovered that there is a possibility of taking their medication in a different way that will actually help them during the day be less fatigued and actually get better sleep.

**Patrice:** Yes; if you are taking medicine and you have to take it once a day, there is a logic as to when you might want to take it. You take it before you go to bed and a) it can help you sleep and; b) it's not giving you--, but again, I really do want to throw in those other pieces to really holistically look at fatigue, we want to look at what are people doing to fight the muscle wasting and the muscle loss and the loss of respiratory capacity from the deconditioning? We have to fight the deconditioning. We need to work energy conservation strategies so that whatever energy you have is being put towards a) building more through exercise and; b) focusing on the things that really make you happy. Then, looking at your sleep really long and hard. How can you get it as close back to normal as you can? And if some of that is that it took you a while to get to a place of really messed up sleep, it might take you a while to get back. Trusting the process that maybe—you know I actually encourage people who were routinely now sleeping in until 10, because they are off work and super-fatigued,

to set the alarm 15 minutes earlier. If you need to do it for a whole week 15 minutes earlier, then the whole next week, 15 minutes earlier, it took you a while to get to where you are at, you know, just work it backwards. Just try it. Small changes, but small changes might consistently make a difference.

**Lizette:** Definitely. And, again, I want to thank you so much for bringing this to the forefront. Is there anything that you feel that we haven't covered today that you just want patients to know about fatigue?

**Patrice:** Well, I would say cut yourself some slack in that if you feel completely demotivated and unable to do anything, that makes really good sense. That is your body working this syndrome. It's really, really normal, but if you can think of whatever one small change you can make to make it again, I just ask one last time, is what you have been doing working? And if the answer is no, then let's try something a little different, starting with seeing what you can do to get your body a little bit stronger, moving a little bit more. For families, I would say try to really—try to be coaches in this department. It might feel a little bit like tough love because your folks look so exhausted and you really want them to do is go tuck in and take a nap, but if you can kind of absorb the way this syndrome works, that is not the thing you are going to want to be doing for their well-being (and, again, it is a little bit of a tough love approach), but when I have been able to get a family member to understand that, they are often my best advocate because they are not in the physical and psychological thick of the biochemistry and they are somewhat more objective. They can coach toward health.

**Lizette:** Well, thank you. I think that everything that you have said is so important for our patients—for any cancer patient—and just to know that there are people like you, Patrice, that really do understand the importance of fatigue and how it plays a part in people's lives and in people's recovery.

**Patrice:** Thank you for the chance to share.