

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Quality-of-Life: Managing Cancer-Related Fatigue'

Description:

Cancer-related fatigue can be a tremendous burden on patients and caregivers. In this episode, we speak to Dr. Mariam Nawas and oncology nurse, Mary Lappe, of University of Chicago Medicine, about how cancer-related fatigue is identified and managed.

Patients and caregivers will be empowered to work with their treatment teams, addressing cancer-related fatigue to improve quality of life during cancer treatments and survivorship.

Transcript:

Elissa: Welcome to *The Bloodline with LLS*. I'm Elissa.

Margie: And I'm Margie.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Elissa: Today we will be speaking to Dr. Mariam Nawas and Registered Nurse Mary Lappe about cancer-related fatigue. Dr. Nawas is a Hematologist/Oncologist at the University of Chicago Medicine who specializes in the treatment of leukemia and myelodysplastic syndromes, or MDS, as well as in allogeneic hematopoietic stem cell transplantation. Her research focuses on improving patient-reported outcomes and survival of older adults undergoing transplantation and cellular therapy. You may recognize Dr. Nawas from when she joined us on a previous podcast titled, "*Transplant Support and Graft-Versus-Host Disease*," in December of 2021.

Mary Lappe is a transplant and cellular therapy nurse coordinator at the University of Chicago Medicine. She has worked with patients with lymphoma at the hospital for over a decade and is passionate about educating patients and their families.



Welcome, Mary, and welcome back, Dr. Nawas.

Mariam Nawas, MD: Thanks so much.

Mary Lappe, RN: Thank you.

Elissa: Our episode today is on cancer-related fatigue. Could you tell us what that is and how that is different from normal tiredness that all of us experience?

Dr. Nawas: Sure. When I think of cancer-related fatigue, I think that that is a very broad term that can encompass a lot of different experiences. There can be fatigue related to the cancer diagnosis itself, like a presenting symptom other than your cancer diagnosis; and even that can be very broad. If a patient, for example, has leukemia or myelodysplastic syndrome and because of that they have anemia and low blood counts, that can cause fatigue. Separately, maybe patients with lymphoma, other types of malignancies even if their blood counts are normal, just the cancer itself and the inflammation that comes with it can cause fatigue. So that's one part of the experience.

And then separate from the diagnosis itself, we see patients every day who are going through cancer therapies and cancer treatments and the radiation, transplant, chemo, whatever it may be, can cause fatigue through a number of different mechanisms.

And then, finally I think there's also cancer-related fatigue that we probably don't talk about enough related to afterwards, for survivors of cancer who are no longer getting treatment, who are in remission, who are still experiencing fatigue for years and years. All of those things fall under that bucket of cancer-related fatigue.

And in terms of how it's different, as a presenting symptom, often, Mary and I will see patients who come in and they're presenting symptoms where, you know, "I just sort of felt off. I felt more tired, more short of breath," maybe losing some weight. I think sometimes people do write that off as just their normal fatigue, and they ignore it for a few weeks at a time. But when you see that in combination with other symptoms that

are unusual, like weight loss, fevers, things along those lines, and when it's really persistent and you don't have a good explanation for it, that's what should trigger. They're saying that that's a little bit different than usual where I'm tired from work or I'm tired the way that everyone's tired. The persistence of it and when it is in association with other symptoms.

Lizette: Is that how people recognize it because they have fatigue, but it feels different because it's more ongoing?

Dr. Nawas: Yeah. And sometimes it takes a long time. I have patients that'll tell you, "It's been months that I have felt this way," and it took the encouragement of a spouse or a family member to say, "Hey, this is not normal." So, it's not uncommon for people to write that off, but, yeah, I would say sort of the persistence of if this is just a daily thing that's not normal. And, again, if there are other symptoms that are unusual for that person – fevers, weight loss, things along those lines – that really should be a trigger.

Elissa: I think that we hear that a lot from patients when they're trying to get diagnosed. They're coming in, particularly patients with young children, and doctors can be like, "Well, you're chasing around young kids all day, of course, you're tired." And they say, you know, "This is a different kind of tired. This isn't normal for me. As much as I've been taking care of my children and doing all the things, this doesn't feel normal for me."

Dr. Nawas: Yeah. There can be dismissiveness, unfortunately, not just on the patient themselves, but also sometimes their primary care doctor or whoever it is that they go to first. I understand that as a primary care doctor, not every patient you're going to see has a very serious diagnosis and fatigue is a very, very common symptom even for noncancer patients. It's probably one of the most common symptoms that people go to their doctors complaining about. So, the first thing you're going to think about is not necessarily cancer, but that's where I think you just have to advocate for

yourself if you really feel like this is not normal and you just have to keep bringing it up until someone takes it seriously.

Lizette: Right. And, Mary, do you feel that people bring this up to you or do you tend to ask patients if they're feeling a little bit more tired or explain fatigue as different than tired?

Mary: Absolutely, in both situations. They bring it up to us, but more often than not, we have to bring it up to them to see how they're doing. But to Dr. Nawas's point, whether you're going for a first visit to a primary care or someone like seeing Dr. Nawas or myself, when assessing it, it's a cluster of symptoms; it's not just one thing. And I think it's where you're at in your journey. If you're first visiting your primary care, you have to maybe be a little more articulate in what that fatigue and the cluster of symptoms are.

And for us, we're concerned about, is it all day? Are you not sleeping well? Are you worrying? Are you a little depressed? And sometimes they won't even call it fatigue. They'll say, "I'm depressed" or "I'm just so worried about so many things and things just aren't right." And then you can gather that information from them.

Margie: What can we say that are the causes of cancer-related fatigue?

Dr. Nawas: That goes back to what part of the experience of cancer-related fatigue are we talking about. On diagnosis, for example, leukemias, lymphomas, blood cancers; often what we see are patients who are anemic, who have low blood counts. It's easy to understand if you have low hemoglobin and not enough red blood cells to carry oxygen how that can cause fatigue, that can cause shortness of breath. But that's just one of many potential mechanisms.

Lymphoma patients, especially very active lymphomas, that is a very inflammatory type of condition and where the inflammation itself is probably a very major driver of fatigue and why people feel so tired. And that's just the cancer itself.

And then the treatments that we give people; the chemo, transplants, all these things – these definitely can exacerbate fatigue, at least in the short term and the long term probably also.

What I do most commonly, which is allo-transplant (allogeneic stem cell transplant), it's somewhat easy for me to prepare patients of, "There's a certain pattern of how you're going to feel through the transplant," meaning you come into the transplant and at the beginning, you feel okay. Even those first few days of chemo you feel okay. And there's this delayed effect where it's just the middle part of that experience when your blood counts fall and when your body is just highly, highly inflamed that you will feel the worst. And these are symptoms, again, like Mary said, it's a cluster. It's things like drowsiness, sleep disturbances, pain, nausea, fatigue, and flu-like symptoms, just feeling so beat up like you can't get out of bed.

It's not just transplant. Even if you're going through a chemo cycle, when you get to that tough week, that is probably inflammation driving all of that. We know that when your blood counts fall and when your body and tissues are damaged by the chemo and the radiation, that they respond to that by generating a lot of inflammation, a lot of cytokines, which are proteins that regulate inflammation, and we know that these cytokines and these proteins can cause tiredness, can cause that feeling of just being so beat up.

When that inflammation dies down and your body starts to recover and your blood counts are recovering, people will feel dramatically better compared to that tough part of a cycle or of the transplant or whatever it is. There's many different mechanisms. Treatment-wise, I would say inflammation probably underpins a lot of what we see in terms of our patients.

Elissa: Now do all cancer patients experience this type of fatigue or does it affect some patients more than others?

Mary: I think it definitely affects some patients more than others, but I don't think we have any statistics to prove but I would say all patients have some form of fatigue just for the treatments that we give them. So, I think that's pretty much a given that they have some form. Whether they bring it to us as a problem or concerning symptoms, maybe not always, which is why we have to always be vigilant and ask them how they're doing because it could be a problem that we just don't even know about.

Dr. Nawas: Yeah. It's also important to remember and I try to remind patients, "Don't compare your experience to someone else's." A lot of people-

Elissa: Right.

Dr. Nawas: -will listen to podcasts like this or be on the Internet seeking community among other patients who are going through the same thing; and just because someone might be going through what you think is a similar treatment and having a very different experience, that does not mean that your experience is abnormal or that it should be easier for you.

I remember a few months ago when I was taking care of patients in the hospital, I had two patients, similar age, same gender going through a very similar treatment. And they met up when they were in the hospital and they became kind of a support for each other. After a few days, it became very clear that the trajectory of symptoms was very different for these two people. And the person that was having a harder time really kind of beat herself up about it even more saying, like, "This other person is doing so well. They're eating, they feel fine, why do I feel this way?" You don't know what the other person's circumstances are. You don't know specifically what treatment, what dosages, where they are in their disease journey. There's truly no comparison and no experience is going to be the same as someone else's and so it's okay that you're not having what someone else has experienced. And that's not something to beat yourself up about like you should be doing better. It's tough. It's tough for everyone, and it can be tough in different ways.

Mary: Yeah. And I think that's also important for us as the healthcare professionals to remember. I always take the approach that fatigue is like pain, it is what my patient tells me. That is not for me to judge, so whether they have pain or whether they have fatigue, that is mine to help them get through.

Dr. Nawas: Exactly.

Elissa: Now how long does cancer-related fatigue usually last? You mentioned a little bit about the treatments, but then you also mentioned earlier about post-treatment survivorship.

Dr. Nawas: For the kind of patient that is going through this treatment regimen, let's say like six cycles of chemotherapy, six cycles of R-CHOP. With every cycle, which is roughly four weeks, again, there's this pattern of like the beginning is okay, the middle is the tough part, and then by the end you feel okay again. But you're going through six cycles of it and I tell people, "It's cumulative. At the start of the second cycle and the third cycle, you're not the same person you were at the start at the beginning. Your reserve has diminished and that's normal."

Part of that is just going to carry over and carry over and that'll stay with you through the cycle and a little bit after. And when you're done with chemo, it's not like you snap your fingers and go back to being the same person that you were. It takes months, and for some people years, to recover and go back. There's been surveys of cancer survivors and like a third of patients will tell you years out they still have fatigue beyond what they think that they should expect.

It's, unfortunately, not an uncommon experience for that to stay with you, but there's different mechanisms and causes and some of these causes for fatigue are reversible and are things that we can address. For example, after cancer therapies, people can have abnormalities in their thyroid function or maybe they're on a medication that causes fatigue. So, it's important to just continue to talk about it to make sure that there's maybe something that we could do to address it or reverse it or make it better.

But, nonetheless, even with everything addressed, I think it's not an unusual experience for fatigue to stay with people for a long time.

Mary: And I think in the survivorship mode it's, once again, more important for us as the healthcare professionals to ask about it. And I do feel as though we've sort of gotten away from asking them about it, but that's when it's so important because I think there's a couple of things. There's the caregiver fatigue that I think we many times do not address. People have been bringing them to their appointments for three years and doing things for them and maybe being the only breadwinner in the family that we got to look at their fatigue. I think we really have to look at the whole family unit, the relationships and everything.

Dr. Nawas: A lot of things masquerade as fatigue. Like if you're depressed, which, again, is a very normal reaction to the trauma that people go through with diagnosis and with treatment, that can present itself as fatigue. If you have pain because physiologically your body is just now different and responds to triggers differently, that can manifest in different ways. So it's really a cluster of things that people go through and it's important for us to make sure that we talk to our patients about this and then patients should feel empowered to bring this up.

I think sometimes people feel like, I got through this, I'm in remission, I shouldn't ask for more. And it's okay to ask for more and to expect to have a good quality of life. I think it's not enough for us to think that remission is the final goal. I think quality of life is incredibly important to people, and we're starting to do a better job in terms of studying that and understanding how different treatments impact quality of life for patients, but we have a long way to go.

Margie: And I see that for the patients as well as the caregivers that it's through their expression that many times you are able to see if they're going through the fatigue. However, is there any test that is done or can be done to detect if a cancer patient is going through fatigue?

Dr. Nawas: Good question. If I were to be presented with a cancer patient, whether they're going through treatment or not, who is reporting fatigue out of proportion to what I think it is would be a typical experience, then you really, as a doctor or provider, have to step back and think about it very holistically in the same way as a primary care doctor would think about any patient who comes through the door complaining of fatigue. The first thing I naturally think about are blood counts.

If that's normal, then you think about iron levels or vitamin deficiencies. If those things are normal, we have to think about the thyroid, pituitary, neuroendocrine system. These are all things that are very important in terms of how our body regulates hormones and steroids. And these things definitely impact the feeling of fatigue and can be damaged through chemo, through radiation, whatever it is. And so there are blood tests to check the function of all of these things and we could check that.

And then medication review, that's a big one. We have our patients on tons of medications and certainly a lot of them can cause symptoms like fatigue, drowsiness, that kind of thing, and seeing if there's room for modification or trial and error. That is definitely the first check that you would do.

And then, if you have a patient who's in remission, with fatigue, then you do have to worry maybe this is a recurrence. Maybe there's some imaging or something that should be done. So, there are definitely tests and a workup that can be done as a first step.

And then not so much blood tests, but back to what we were talking about in terms of pain and depression and mood disorders masquerading as fatigue, there are also surveys that we can have patients fill out to give us an idea. Even if they don't recognize within themselves that maybe I'm depressed, these things have been validated and studied in populations to be able to detect depression and anxiety and

things along those lines. So, yeah, there is definitely a workup that, that should and can be done.

Margie: That's really good to know. Especially for those people that tend to internalize and not want to express because they're going through enough as is.

Dr. Nawas: Exactly.

Mary: If all those tests, hopefully do come back normal, then you can peel off another layer and see how is their nutrition? Are they eating healthy? What is their weight? What's their protein level to see how they're doing? Do they need a nutrition consult? Are they drinking enough water every day? And then, of course, exercise. What are they doing for activity? Just keep pulling off the layers to help them.

Dr. Nawas: There is, what I believe, like 80% of this dealing with things like fatigue is just the basics and the same thing that they would be for a noncancer patient is, are you sleeping well? Is your sleep good quality? Is it interrupted? Do you maybe have sleep apnea? If you are sleeping well, are you eating well, like Mary said, Are you eating nutritionally? Are you exercising? Are you maintaining your muscle mass? So just sleep, nutrition, and exercise is probably 80% of it for everyone.

And then, beyond that, after you've gone through cancer treatment, you are just physiologically different. You're different from how you were before, and some of those things may not be as easily addressable. But I do think the basics can get you a very, very long way.

Lizette: Right, so is it that conversation that occurs once you recognize that somebody has that cancer-related fatigue? Is that how you as healthcare professionals help patients through this?

Dr. Nawas: Yeah. That's where survivorship programs come in and different cancer centers are at different points in terms of how much survivorship we offer patients. It's a goal for all of us, and we're not exactly where we should be across the board,

but we're getting there. But, yeah, that's a huge part of survivorship. It's not just fatigue. It's your mood, it's all of the things that took a backseat when you were just trying to get through treatment. And now that you're done and trying to get back to normal life, it's the same things that any doctor would address with their patients. Making sure that you're up to date on all the usual things. There's a lot of work to be done on the other side of the diagnosis.

Lizette: And are there any medications or like you alluded to before, maybe the possibility of changing or adjusting some of the patient's current medications?

Dr. Nawas: Trial and error with certain meds. Some meds are not things we can easily change, depending on where you are in your treatment course or even post-treatment. Some meds, there is some room for changing things around.

In terms of actually using a medicine to target fatigue, there's not one pill that's going to turn things around. If there's a sleep issue, there may be medications that help you with sleep. If it's a depression issue, there are medications that have stimulating side effects that can be helpful and can manage the depression or the mood disorder. But there's not any stimulants necessarily that are recommended that are just going to give you like this energy boost. But there's still a lot from the medication standpoint that can be optimized to try to help.

Back to the acute phase of things, remember the phase of where you go through the symptoms of pain and nausea and fatigue or that tough week of chemo, the way we currently treat it is we just treat each symptom in isolation. But we do have a better understanding now that it's probably inflammation driving this cluster of symptoms.

And there are some studies that are targeting these inflammatory proteins or cytokines that have been studied, in the transplant setting and even outside of the transplant setting, that have some utility where if you can block one of these inflammatory proteins, you can really rid people of a lot of these symptoms that they struggle with

through the acute phase. None of that is approved yet, but it is a very exciting area of research and then, hopefully, something that we can improve upon.

Elissa: That's great. You had mentioned earlier some of the things that patients can do at home, so the basics of sleep, nutrition, maybe therapy for depression, but also exercise.

Now speaking of exercise, I'm an acute myeloid leukemia survivor; and when I had fatigue, the biggest recommendation from my doctor was to exercise, which seemed very counterintuitive that I should exercise when I'm feeling so tired. But it somehow worked.

Dr. Nawas: Good. I'm happy to hear it worked. I'm happy it's not just something we tell people.

Elissa: I was like, "You want me to go for a run when I am just barely getting out of bed?" And yes, that was the answer; and it actually helped. So why is that? Why is exercise so beneficial to cancer-related fatigue?

Dr. Nawas: I think it starts several steps even before that. Like if we can preempt that. What I tell my patients if they're about to go through some kind of an acute stressor, like a transplant, is exercise now before it starts. Make sure you're in shape now. The best shape that you go into this, the better shape you're going to be coming out of it. It's inevitable that you're going to take a dip through this process; but if you can build up your muscle mass and you're conditioning in a very good way, then you have some room to drop. And it's easier to then recover on the other end.

Mary: I see a lot of patients that go through autologous stem cell transplant. And we try to get them in shape as much as possible. But I always try to meet them where they're at. I think you said, "I can't even get out of bed." So, then those should be your goals for the patient.

Okay, "So today you're going to get out of bed and you're going to spend most of your day out of the bed; and let's make a goal of walk the halls or walk outside twice a day. Also, you can bring in friends or family, people that want to help you. Make it a little bit more social. Have them come over and walk outside with you. Being in nature is good.

A lot of my patients that are maybe elderly and pretty weak to start out with post-transplant. Are you watching TV? Are you sitting in a chair? Most of those answers are yes.

So, then I'm like, "Well, with every commercial, I want you to stand up ever so slowly. Gain your balance. Bring your belly button to the spine, stand up straight, and then sit back down. And then keep repeating that throughout every commercial.

And then the next commercial, have some free weights by your chair and do some bicep curls. The next commercial, stand up again. And the next one, triceps." So, we start very slowly, but it does work.

Elissa: Yes, yes. And it's hard for patients too. They kind of have to give themselves grace, especially if they were very active prior to their treatment; and all of a sudden, they can't do anything.

I think my only goals were to walk downstairs and cook for myself and then eventually got to walking outside a little bit with my dog. But then, when it was post-treatment survivorship and trying to get back to activity, I was just still experiencing fatigue; and really that exercise was so helpful to me.

Mary: Well, and then, once again, asking the patients what their goal is; and if we're not asking, tell us what your goal is. I had one lady; her goal was she loved to bake. So, I remember working with her and like, have other people gather the ingredients and put them there, but you can stand, and you can knead the bread and all of that. But have people help you with those things.

If you have something special that you want to do tonight and you don't want to use all your energy, but you have a clinic appointment, then use a wheelchair to come to clinic. So really just managing the goal, but every day make a goal.

Dr. Nawas: There's also this kind of mixed messaging that I think we send patients. When I'm preparing someone to go into the hospital for a month for a transplant, I tell them, "You're going to enter your hospital room, and the bed is going to be the center of the room, and someone's going to tell you to put on a gown", and then people sort of internalize that "I'm a patient. I'm going to put this on, and I'm going to sit in bed." And the bed becomes where you spend most of your time, where you get your infusions, where you eat your meals, which is not at all how any of us live at home. Right? You get up in the morning. You get dressed. You shower. You do some things around your room. You definitely sit up for all of your meals.

And by changing that fundamental way of how you live day in and day out, you really put people at a disadvantage; and that's why people get deconditioned and get behind. So, there's a lot that we have to do as healthcare providers to fix the messaging and give people the advantage of not falling behind when they're in a hospital for a long time.

Mary: And when they go home, I like to try to educate my patients of what to use the bed for. I don't even encourage them to use it for a nap. I say, use your bed to sleep and sexual relations; and beyond that, be up. If you take a nap on the couch or in a La-Z-Boy®, that's fine. And then, get yourself ready for bed so that you can really maximize that sleep. Make a routine, whether it be a half a cup of tea every night, shut off the devices, some quiet music. Try to have a routine so that your body knows it's going to bed and go to bed at the same time. Try to get up at the same time. You just want to get those sleep rhythms back to normal.

I also have had the great privilege of working with a lot of young cancer survivors that have gone through transplant. And especially the young women. Their hormones are

off; and oftentimes at night, they are awoken by hot flashes. Well, share that information; and I try to be vigilant and ask them about it because there are things maybe we can do for that while their cycle is returning.

Dr. Nawas: We don't always do the best job of asking, but people should feel empowered to tell us even when we neglect to ask. Like you're allowed to ask for quality of life. You're allowed to ask for something beyond just being cured or being in remission. Your experience is important. And it's important to us.

Mary: Quite a few years back there was, through the Oncology Nursing Society (ONS), a big push to really improve patients' quality of life as far as fatigue. Back then it was dubbed as the sixth vital sign. So, we were really very vigilant about it at that time, asking about fatigue. I've tried to ask more about their fatigue level because it is such a bother to the patients.

Now we have eight vital signs; and fatigue isn't even on there. So, it like has fallen off everybody's radar, but to Dr. Nawas's point, don't let it fall off our radar. Bring it up to us. Have us try to help.

Elissa: Our final question today, on our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." What would each of you say to patients to give them hope if they are experiencing cancer-related fatigue?

Mary: I would just say that the healthcare professionals, in my opinion, that are in this want to help. But we can't help if we don't know. So, if we've failed to ask, then bring it up to us. We are willing to listen. Tell us if it bothers you. We want to help.

Dr. Nawas: I completely agree. It matters to us, I promise, as much as it matters to you. And if we don't express that, then please bring it up to us.

When I have a patient, my goal is to get them back to what they were doing before they ever met me, before this cancer ever happened.



And we may not get 100% of the way there, but our goal is to get as close as possible. And so if we're not close, then there's work to do; and there are solutions.

Elissa: Well thank you so very much, Mary and Dr. Nawas for joining us today. I love this great discussion on cancer-related fatigue. I think a lot of people will relate to this and a couple things that I'm so glad that you mentioned. One is empowering patients to speak up and share their side effects, share their concerns, their questions with their doctor. But then two, also you mentioned the whole family and relationships and caregivers and then maybe in support as well. And at LLS, we do have caregiver support and information, so we'll put those in the Show Notes.

But thank you both so, so very much for being here with us today and talking all about fatigue.

Dr. Nawas: Thank you so much for having us.

Mary: Thank you for having me.

Elissa: We would like to give a special thank you to University of Chicago Medicine for supporting this episode.

And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

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We would also like to know about you and how we can serve you better. This survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact LLS staff, please email TheBloodline@LLS.org. We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

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