

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Coping with the Challenges of Living in Isolation'

Description:

May is Mental Health Awareness Month. The Leukemia & Lymphoma Society (LLS) recognizes the unique issues faced by blood cancer patients and caregivers from the moment of diagnosis throughout survivorship. These include psychosocial and emotional effects such as relationship stress, anxiety, depression, survivor guilt and more, which are further compounded by current events. Increased awareness about mental health and cancer can help patients and caregivers best advocate for treatment that meets the breadth of needs during the cancer journey and beyond. LLS provides education, support and resources that can help.

On this episode, Alicia, Edith and Lizette speak with Dr. Marni Amsellem, a clinical psychologist in private practice, specializing in health psychology, stress, and coping. Join the conversation as Dr. Amsellem explains the effects that social isolation caused by forced change, can have on a person's mental health and ways to cope with them. She shares the challenges that many face as a patient and as someone living through today's coronavirus (COVID-19) pandemic. She suggests helpful ways to shift perspective as well as shares additional resources that address the emotional impact of isolation.

Transcript:

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

Edith: I'm Edith.

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

Alicia: Today we will be speaking with Dr. Marni Amsellem. Dr. Amsellem is a clinical psychologist in private practice, specializing in health psychology, stress, and coping. Additionally, she consults on and writes about a variety of mental health relationship and prevention-focused topics, which she shares on her website, www.smarthealthpsych.com. Welcome back, Dr. Amsellem.

Marni Amsellem, PhD: It's lovely to be back. Thank you for having me back.

Alicia: Of course. We're excited for our conversation today. Dr. Amsellem has been a guest on *The Bloodline with LLS* before in which we spoke to her about "Cancer and Mental Health." And for those who would like to listen to that episode, you can find it below in the "Survivorship" episode listing.

Now, on today's episode titled, "Coping with the Challenges of Living in Isolation," we will discuss the effects of social isolation and ways to help people cope with them. And as we all know, human beings, we are social beings; and the level to which we're social may vary, but the overall statement is certain, that we definitely need each other. So, depending on your situation, of course, isolation can impact anyone in different ways. But Dr. Amsellem, to begin the conversation, what is isolation?

Dr. Amsellem: Isolation has taken on a new meaning as we are living through a pandemic right now. But, you know, what that typically means is taking the precautions that we need to keep us a safe distance for whatever our vulnerabilities are. Certainly, when we're immunocompromised or living with people who are or have other health conditions that are requiring distance that all contributes to isolation from the, physical sense; and, of course, there is other types of isolation as well.

I'm speaking mostly of social isolation on the emotional end as well. Right, all of the aspects of being around others related to emotional connectivity. That's a big component to all of this as well.

Alicia: Absolutely. And when it comes to a cancer diagnosis or maybe even a pandemic, which is what we are all living through right now, and for those listening, are living through both of those things, social distancing-

Dr. Amsellem: Right.

Alicia: -is necessary for those who are immunocompromised and also, of course, to help flatten the curve, the pandemic curve. How does forced change in social behavior impact a person's overall health and mental health, like you said, the emotional side of it?

Dr. Amsellem: Well, a lot of it is what you're referring to as forced change. This is beyond, a lot of this is beyond our control right now. We are needing to do this in order to, you know, protect the public, basically, right, to keep the numbers down, to reduce the spread, to keep the pandemic as manageable as possible right now until there are better treatments, until there's a cure, until there's a vaccine, etc.

So it is something where we are needing to adjust, make huge adjustments to our lifestyles globally and accept that there are things that we have to do that are beyond what we would choose to do right now. So that is something, of course, that a lot of people who are or have gone through cancer treatment have had to grapple with on a, much smaller level, on an individual level, right, on how that has affected their own lifestyle, you know, things that they've needed to do to make adjustments, again, beyond their own choice.

Alicia: Right, and social isolation, does the effects of that differ by ages? Because, you know, for older adults, they're more likely to experience bereavement and encounter health problems that increase their need for social support and companionship. So, assuming that the health-damaging aspects of social isolation can be particularly harmful at older ages, would that be correct? Would you agree with that?

Dr. Amsellem: I think this is an issue that spans all ages and we know that social connection, both physical as well as emotional, is hugely important for our emotional health as well as our physical health.

What's different about this right now is that every age is affected by this. The young, very young who are not seeing anyone other than the people that they are living with right now. So, they might typically be nurtured by, grandparents, professional caregivers, and now it is really just the individuals who they are quarantining with.

And, of course, all of this is very tied into the moment. As things continue to evolve, that will change, of course. But the point being that all ages are affected. Certainly, students who do not see their friends anymore when they had seen them, you know, throughout the day in school, college students who had their final semester of the year perhaps out of their bedroom from their home when they had been in dorms before, up until mid-March. So, there's a lot of adjustment across the age span.

Alicia: Right, and you bring up a really great term is adjustment. Especially, again, and putting this in the context of a cancer diagnosis when that's also a forced change where they now have to navigate this new lifestyle or, like they say, "new normal." It's definitely an adjustment period.

Dr. Amsellem: Absolutely, and it will continue to be. We are in flux. This can be a conversation that we're having mid-April, mid-May, mid-June, and the circumstances will be different, will likely be different throughout an endpoint that we're listening to this conversation.

So it is evolving, and it's something that we need to continue to be open to rolling with whatever changes and adjustments we need to, to be living with and recognizing that things might not look the way that we had envisioned that they might look for us, for the world, and as it relates, of course, to individuals who are in treatment right now, finding a place where there is some comfort and the rest of the world moving as it will and as it is right now, it, it's continuing to do where that person, you know, where somebody who is immunocompromised, who is going through treatment, or who does have another, you know, complicating medical situation which can be a whole gamut of things, or living with someone who does, you know, how to incorporate how the world is moving with their own lifestyle and necessities.

Alicia: Um-hmm.

Dr. Amsellem: So, this is something that a lot of people are grappling with right now.

Lizette: Right. And since, you know, most people are dealing with this at this point, isn't it kind of different for cancer patients that have had some type of isolation? And they were feeling that maybe they're alone in that isolation because they were immunocompromised whereas, you know, their caregivers, their loved ones were still going out and, and didn't have isolation themselves. But now since everybody is joining and we are all social distancing or really physical distancing, hopefully not social distancing, isn't that, could that be a different dynamic for a cancer patient?

Dr. Amsellem: Absolutely. And that's something where I think normalizing that experience, that "it feels different for me than the rest of the world," that is something that I'm hearing from everyone whom I speak with actually, right, who is in this situation right now. Either they themselves are going through treatment or someone that they're living with is and how to navigate that and all of the changes that we are going through right now and are projected to in the future what that looks like, what that means.

And something that I've heard also, at least early on, was, "Huh, now everyone else gets it. They understand what it's like to have to take precautions and to, you know, really think about life a little bit on, more of a defensive stance of, okay, you know, what are the possible vectors out there? What, you know, what are the risks, and be thinking about approaching the outside world that way? So, I've heard from a lot of people that their friends are turning to them and say, "how do you live this way or how did you get used to this?" And so, they're now, you know, they had become the sources of offering advice and coping. Right, coping strategies.

Alicia: Right.

Dr. Amsellem: So that had been something that had been adaptive; but, as the outside world moves forward, however it will, and be a more physically engaged again, whatever that looks like, whether wearing various protective equipment or, the sizes of how we're going to be gathering, at least in the short term, will certainly look different. How does that mesh with what feels comfortable? Particularly because when we follow medical advice, and this has been true throughout this, you know, this pandemic, when we follow medical advice, it is usually based on the research and the experience of medical professionals, right? And this has been brand new. So, really, the only research that we have had accessible has been very new research or has been drawn from previous pandemics where there are parallels.

That's very different. So when you're asking your medical team for their advice on a situation where you don't know what to do about having contact with this person who might have been exposed, all of the various scenarios that we're all facing, your physician, your nurse, whomever you speak to might just not really know right now. And again, I think we're learning every day. We are living this and learning a lot. Our growth curve is really, it's substantial right now.

Every day, of course, there's new information to guide our decision-making. But in the absence of that information, it's really going off of best hunches based on the limited experience as well as converging data from other similar type viruses or similarities, from other things.

So it's really hard, you know, to take home, I guess what I'm saying is it's really hard to make sound decisions in the absence of concrete information; and that is something that, certainly, everyone has been trying to grapple with. But for those who are at higher risk groups or who have already been affected with the virus these are very challenging decisions.

Lizette: Right, and also just coping with isolation in a time where-

Dr. Amsellem: Yes.

Lizette: -you have more of that uncertainty to deal with. You already have the uncertainty-

Dr. Amsellem: Right.

Lizette: -about your diagnosis and what lies ahead. And now to have even more uncertainty.

Dr. Amsellem: Yes, going through cancer never happens in a vacuum. So however, it might have been unfolding in your life, you know, other outside stresses or, other dynamics happening, that would have been enough, right? But now you have, you know, there's so many unknowns, and how to incorporate all of these things together and make sense and plan for the future. Certainly, that is one of the most challenging things from the experience of going through cancer, whether it is your own diagnosis or someone who is close to you, of just knowing, or finding some comfort in not knowing what the future will bring.

Right, of course we never know what lies around the corner. That is true no matter the day or the circumstance. However, with, you know, cancer, of course, brings a whole new set of things that are a reality to that equation, right? Well, it's happened before.

What does that mean for my future? And then you have the, "Okay, what is the world going to look like X months from now?" It's adding a lot more to, you know, to the recipe, so that the final equation is, it's one of those really challenging math equations that, nobody can really figure out, I think might be the analogy there.

Lizette: Good analogy.

Alicia: That is.

Dr. Amsellem: Yes, with lots of algebraic terms and lots of Xs and Ys and all sorts of numbers and letters, right.

Lizette: Right. So, what type of coping mechanisms do you think would benefit patients, caregivers, really all of us at this point, with-

Dr. Amsellem: Yeah.

Lizette: -the isolation we may be feeling?

Dr. Amsellem: Yeah, yes. I think the best advice, generally speaking, is to tap into what has worked for you in the past, both generally, as well as coping with isolation or having some regular distance or just, you know, less physical engagement with the outside world. So, what had been useful for you before and tapping into that. You know, how have you found some peace with the time that is resting, that is time away

from others, as well as new strategies that you might have, sort of jumped on board with, throughout the cancer journey or throughout this journey into the whole world happens over technology now, right, over Zoom or whatever the interface is.

So, what is working? Making adjustments based on your own needs at that time. If you are maxing out on having calls with multiple people on, over a screen, maybe taking a little break from that and instead picking up the phone and, engaging that way or getting creative.

I've also been talking a lot about writing letters right now too. Right, actually putting them into the mail and sort of like what we used to do a long time ago. So just varying it up a little bit and trying something new. Being, open to things and constantly readjusting and shifting as, as works for you as you need to. So, when you're noticing you're, fatiguing on something, varying it up a little bit.

And another huge thing is reframing the situation. So that is so important. So, all of us right now I think are a little more in-tuned to the weather, for example, than we might have been before. Right, whenever, so many other variables going on in our day. Yeah, the weather was still happening. And certainly, many people are very sensitive to the weather and might have always noticed that, yes, a rainy day means this adjustment to my mood, sunny day means this. But now if you're in an environment where there's been several days of gray or rain in a row, there seems to be that cloud over everyone right now. And that sunny day seems, right. There's some variability there, but it really is affecting us; and we're noticing things. We're noticing the leaves blooming on trees perhaps more so than we might have in springs past, right?

So, there's shifting our mindset to notice those things and things that we see as positives, too is incredibly important. Whether or not we're in a pandemic, whether or not this is related directly to cancer, taking a look at your mindset and making any adjustments to notice something that is feeling good, that is a positive in a situation is a wonderful thing for us, regardless of the circumstances.

Lizette: Sure.

Dr. Amsellem: Those would be my, off the top of my head recommendations for coping.

Alicia: Dr. Amsellem, I think it's such a great point that you mention each person finding out for themselves how much social interaction they can kind of deal with-

Dr. Amsellem: Right.

Alicia: -making sure that we are able to gauge that for ourselves. I kind of have the thought that you don't have a normal for Zoom when it's just used as a conversation. We have a meetings mental mode which suggests meetings. And you can't read body language that well in a Zoom meeting. And I think for me I have to really say, "I can't do Zoom all the time, I think of it as a meeting." And when there's more of them, it's just overwhelming.

Dr. Amsellem: Right. So much of life is happening over those types of interfaces so how do you distinguish the difference between what feels like work and what feels like connection to, in a nonwork setting. And by the way, work connection is also very important, too, and, and might be felt even more pronounced when we are distant than when we are, you know, might take for granted, that physical connection.

But one thing to do, of course, might be to if you're tech savvy enough to change the background in your photos to something that looks, you know, that feels festive or finding an activity to do together with someone over Zoom, whether it's, you know, a word game or Bingo.

Alicia: Yes.

Dr. Amsellem: So, yeah, everybody's cooking over Zoom.

Alicia: Sour dough bread.

Dr. Amsellem: Right. Pretend like you now have your own cooking show on a cooking network, and you are talking about what you're making and now you have the audience of whoever you're talking to, right. Things that might not have been a part of your routine before now it can be. There's, you know, the, the possibilities are limitless. Now, of course, they're limitless but they're also limited by the fact that we are two-dimensional, that we only have that part of our body that is in the camera at that moment. So, it's also just accepting, you know, to the point about mindset. It's, it's accepting, okay, here are our limitations right now, and until things do feel more comfortable where we can get together because, again, as, as things open up, we might be allowed to, but what, what feels comfortable, what feels safe, what is taking into account the best information that we have, the most accurate information to make judgements for yourself about how to engage with the world.

And, also, it's okay for some time to not engage too, right, to take a take a break from engaging, you know, to really appreciate the positive of the fact that we are not

needed to be on all the time. Right, as long as you feel like it is not a lonely feeling that is, drawing you away, or certainly, you know, a more negative emotions which are driving you away. But if it just feels exhausting, particularly if there are reasons why your energy is low or there, you know, or there is a lot of fatigue present it's okay to step away. It's okay to, just turn off the technology for a little bit, you know, sit by yourself and notice those leaves blooming, or sit by yourself and open up a book or listen to music or do something that is nourishing for you. Or just connect if you are living with other, if you are quarantining with others, to just engage, just engage there.

Lizette: Yeah. I think that's even more important just because now so many people are working remotely and, you know, that work-life balance too is, also coming into focus for many people.

Dr. Amsellem: Absolutely. And just like we were talking about with the difference between a social call and something that might seem more like a business call, our workspace it is literally our home space right now too. So thinking about how that looks for you and if you can, you know, physically, if you have the ability to physically have space that is just set aside for work, everyone's circumstances are different, right. However many people are living under your roof or whether you're, in a spacious place or a place that is not as spacious, trying your best to, you know, create the physical environment that works best for you so that you know that this is your workspace. And then when you're not working, you know, you've relocated to a different set of four walls.

Lizette: Right. We have an LLS online community where patients and caregivers alike take part and are able to talk to each other online. And we had several caregivers as well as patients partake in a more formalized journaling project where people were able to journal, and we did provide some instruction. And many patients and caregivers really said that the journaling really assisted them throughout their journey. And I know that you've also have a resource and have journals. Can you—

Dr. Amsellem: Yes.

Lizette: -talk a little bit about that?

Dr. Amsellem: Absolutely. This is a very appropriate topic to be talking about right now, too, as we're talking about isolation, as we're talking about coping, as we're talking about navigating all of this uncertainty of everything. One of the greatest resources that we can draw upon would be journaling. All of my experience, which

has now been 20 years working in psychosocial oncology, it's brought me to incorporate more journaling into the work that I do with patients, with caregivers, with those who are posttreatment. And I have recently published my first journal that is for the cancer experience and that is called *Reflections: A Journal Companion for the Cancer Journey*.

So that was something that came out of some workshops that I had run over in the office where I work, and I created a set of workshops around it and then turned some of the activities into a journal that I wanted to, make available to the world. So it is available right now. And, of course, I published it right as all of this was unfolding, so and it's all mindset. It's all how you're looking at it. It's a great thing because the resource is there and now, we can use it. You can find a link from my website as well as it is on Amazon.

Alicia: That's a great resource.

Dr. Amsellem: And it can be searched through my name as well if it's hard to find.

Edith: In addition to your book, what other helpful resources or organizations would you recommend for those seeking ways to cope with their isolation?

Dr. Amsellem: As we are recording this right now, it is mental health awareness month, and the world has really jumped on board with us and recognized the role of our mental health and in everything, really. And so a lot of organizations are making this a priority and putting forth resources. So, if there is an organization, you know, a cancer-focused organization that you tend to turn to, know that right now there are some resources that they are promoting.

I would also promote the resources that are available through the American Psychological Association. They have put together a resource of updated, you know, really up-to-date tools for providers, practitioners, as well as, the general public on the latest knowledge, which really is evolving daily and that, you know, related to COVID, related to isolation, and related to challenges that are unique to the times that we're living in right now in addition to, you know, to general resources.

And that point of general coping resources coping is not new. Even living through pandemics is not new or living through really challenging times. So, there's a lot of information that we have gathered from other things and a lot of resources that have been developed previously.

So going to reading a, a more general book or website or article on coping might yield a lot of useful insights that might not be specific to the current challenges but you know, might have something that really resonates with you. A lot of organizations really are doing some incredible things right now. So just being open and recognizing that it's a challenging time for everyone and everyone is pretty on board with recognizing that. So, it's okay to ask for help, checking in with others as well, so putting that in the forefront. And you might find that someone in your own network has some great advice and recommendations for resources as well.

Alicia: And, like you said, May, being mental health month, would you say that the conversations or those seeking help for the mental health is improving? Are you seeing that people are now being more open about getting the help that they need?

Dr. Amsellem: Yeah. I think that there have been shifts over time, and we will see again, we're living through this right now. We'll see what the shift ends up leaving in its wake from, from all of this from the spring, in particular, of that initial adjustment. But I think that awareness has certainly increased and has been increasing, actually, for some time for, the fairly not uncommon issues, you know, related things that are, you know, focused on anxiety and depression and things that are fairly prevalent in the population and where it's okay to acknowledge, it's okay to seek help.

You know, there's been a lot of public figures that have come out advocating for it's okay to ask for help, you know, in seeking treatment and that has had a huge impact on the public that very generally is breaking it down into different demographics. There's a lot more acceptance among, younger ages, amongst certain demographics than others. It's moving toward that way amongst certain age groups and the distinction between more common and prevalent mental health issues versus things that are a lot more debilitating and seen as a little more frightening perhaps by the public and how there's still a lot of challenges and barriers to overcome around stigma and acceptance and services and understanding too.

Alicia: Right. When I think about mental health and kind of, like you said, the shift is definitely happening, and thank God for that, but I think about the cancer-

Dr. Amsellem: Yes.

Alicia: -patients who have told us, actually, that just because I look fine doesn't mean I'm fine. Or someone might say, "You look-

Dr. Amsellem: Right.

Alicia: -great!" And they're not having the best day or they're not feeling great. And when I think about-

Dr. Amsellem: Yes.

Alicia: -mental health, I think about it in the same way in that someone might see someone-

Dr. Amsellem: Right.

Alicia: -and assume that they're fine or that they'll get over something, and that's not necessarily the case.

Dr. Amsellem: Yeah, that, really is. Not every wound, not every illness, not every disability is something that is visible, so that, that is a, you know, a regular struggle for individuals who are feeling the strain of whatever's affecting them, whether it be something emotional, whether it be something physical. And I'm just thinking about right now we're all interacting, you know, pretty much in the same way over, you know, at this point in, in time, in May, over a Web interface basically. So, we all might look we all might look actually quite a bit the same, right, with hair not-

Alicia: Right.

Dr. Amsellem: -really being like it was before or something like that. So I'm wondering how that has shifted, but, yes, that is something I hear frequently from individuals that it's really hard to hear that from others that you look great, right, but it feels very loaded. And although they might know that it's meant as a compliment and no doubt it is, it feels very loaded for them of, you know, how do I respond to that and wow, that's really challenging to hear, right.

Edith: Is there anything else you would like to share with our listeners?

Dr. Amsellem: I really want to acknowledge that doing everything that you can do for yourself, for your loved ones right now is a good thing, and it's okay if it's not everything. Right. There might be a lot of things that you feel like you could do that you could be listening to, that you could be, you know, things that you could be doing with this time, right, in isolation, again, regardless of whether it's because of a pandemic or because of needing to stay away for your own health, but it's okay to be doing what you are doing. And everything you are doing that you know is, you know something for yourself is a good thing.



So, you know, taking the time to listen to a program like this is doing something for yourself and acknowledging that for what it is very important, and acknowledging all of the little things, all of the big things and know that all of these things really do have an effect on you.

Edith: Very well said. Thank you.

Alicia: Dr. Amsellem, thank you so much for joining us today to speak about such an important topic and shining light on emotional effects of isolation and mental health overall. And a huge thank you for all you continue to do for patients and their families each and every day.

Dr. Amsellem: Well, thank you, again, for having me here today. And I'd like to throw that gratitude back to you for everything that you and the organization do.

Alicia: Thank you. And for those listening who would like to learn more about Dr. Amsellem and her publications, please visit www.smarthealthpsych.com, and the link will be listed below this episode.