

### Operator:

Greeting and welcome to **Common Anxiety and Fear: Coronavirus (COVID-19)**, a live telephone and web education program. It is now my pleasure to introduce your moderator, Lizette Figueroa-Rivera. Thank you, Ms. Figueroa-Rivera. You may begin.

### Lizette Figueroa-Rivera:

I want to take the time to thank everyone for participating in today's program. All of us have unanswered questions and concerns about the coronavirus or the COVID-19 pandemic. There are still many unknowns. But at LLS and in your treatment centers, there are many health care professionals that are working diligently to make sure that your needs are addressed. You've already been through adjusting to a new normal after hearing that you, or your loved one, was diagnosed with cancer, and now you have to adjust once again, another uncertainty for you.

LLS wants to help in providing you with support at this time. All of our support services and information regarding COVID-19, including information about our new COVID-19 financial assistance program, are on our website at [lls.org/Coronavirus](https://lls.org/Coronavirus). If you want to speak to us directly, please call 1-800-955-4572. Please let us be here for you.

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I'm now pleased to introduce Ms. Julie Larson, LCSW, psychotherapist and speaker-educator. Ms. Larson is a licensed clinical social worker who has spent her career working in oncology supportive care. Ms. Larson is a frequent speaker for LLS and has been a keynote speaker in a number of LLS's Blood Cancer Conferences, as well as other organizations--and an educator to both survivors and professional audiences--where she has presented about the impact of a serious illness, living fully after a cancer diagnosis, and resilience.

We're always honored to have Ms. Larson as a speaker, as she continues to motivate us and bring some peace into our lives every time we hear her speak. On behalf of The Leukemia & Lymphoma Society, thank you for volunteering your time and expertise, Ms. Larson. I'm now privileged to turn the program over to you.

### Julie Larson LCSW:

Thank you, Lizette, and hello to everybody that has joined us today. And hopefully this time together could be a bit of a sanity break for you, and that we can talk together about everything that's going on. I want to just begin by saying that I'm glad you're here. And this is hard. There are no two ways about it. This is uncharted territory, and we are all working to find how we get through each day.

There are some scary times right now and uncertain. And a lot of that is not in your mind. Some of that's very real. There are health concerns, financial instability, job fragility, mental health vulnerabilities, relationship stress. However, at the same time, there are some of that worry does live only in our minds, and I think that's what we're going to focus on today.

So wherever you're joining us from, however I find you today, hopefully we can kind of sit back and think, "What's going on for me," because finding calm doesn't just help us feel better. Finding calm can help you act smarter. And in those moments when we're able to kind of find a reservoir where we can feel stable, where we can feel grounded, we're better able to make decisions, to take care of ourselves, and to take care of those that we love.

So, let's begin. I said that I know that there are a number of different people who might be listening in today. Some of you might be in active treatments right now and navigating what it's like to enter the health care system. Others of you are care giving for someone that you love and figuring out the best way to take care of yourself at the same time that you're taking care of someone else.

And still others might be health care professionals, or even just the general public, that have tuned in today. So, I want wherever you are, I want you to think just for a moment. Sit back in your chair and think about where you are in this journey and do this work right now. Let my voice guide you and to check in with yourself because the stress shows up for each of us in unique and different ways. And when we think about mindfulness and when we think about taking self-care, I as a therapist kind of parse this out into two pieces. Step 1 is kind of quieting the mind or beginning to pay attention with purpose. What's happening? Checking in with myself, what's going on here? How is it showing up? And then the second part of that, after we get a little quieter, after we get a little more grounded, is then kind of insight. What's driving this, or why am I feeling this way, or what is that unmet need that's underneath this difficult or heavy feeling?

So, when you're at that first step of relaxing and quieting your mind, it's for the purpose so that you can see more clearly. And yet when we're extremely anxious, you may want to spend more time finding calm rather than investigating what's driving this worry. And, in fact, investigating or getting curious, exploring that today, could be counterproductive while you're working to build a state of calm.

So for the purpose of today and right now, I want to just begin by thinking about, when all of this begins to fly and begins to overcome me, how do I do this work of finding calm. So the first piece of developing a habit of checking in with yourself. And this habit formation can begin today. I hope that you carry it forward after our call. But whether you're at the bedside of somebody that you love, whether you're entering the hospital, whether you're just at the end of your day and sitting on your couch, or whether you're in your kitchen making breakfast, and you begin to feel something that does not feel completely comfortable, can you name the feeling that you're having? Can you begin to put a label on it? When we are able to do that, we can separate ourselves just a little bit from the feeling that we're experiencing versus being completely consumed by that feeling. We give ourselves a bit of a break, a pause. And in that pause, in that space, that's where you can make a choice and plug in self-care.

So, I'm going to leave you with that, or like put that out there for you, that when you feel that, can you begin, begin just by naming the feeling? It might be feeling overwhelmed, vulnerable, disconnected, irritable, impulsive, frantic, pressured, scared, neglected, panicked, helpless. All of those are things that I'm hearing right now in my practice. And then secondly, if you're not necessarily feeling nothing, what is showing up in your body that's another clue? Can you begin to fine-tune that self-awareness of how is this stress, how is this comfort showing up for me? Is it showing up as a headache? Is it showing up as my shoulders are tense, and muscles and an increased heart rate? Sometimes it happens when we're nervous or anxious or panicking or feeling a lot of pressure, shortness of breath, which is very confusing right now. I've had a number of people that I'm working with feeling that sense of shortness of breath, which is scary when we think about the symptoms of COVID-19. But, the shortness of breath and headaches and shoulder aches are often sides of tension and stress. Butterflies in your stomach, digestive issues, fatigue or weakness. So just taking it again, taking inventory, checking in with yourself.

And then if we take it a step further, what are you doing that's helpful? What are you doing as far as maybe a regular bedtime, drinking water, getting outside, connecting with other people? What is working for you? How are you getting here? How are you in front of me today? What's working? How are you getting from the top of the morning to the end of the day? And then, conversely, what are you doing that's not working so well for you? And as I've sat with people over the last few weeks, I'm hearing common themes to that of, "Oh, gosh, I'm checking the news," or, "I'm looking at my social media so much. I'm feeling that pull. I'm both terrified and overwhelmed by it all and also strangely addicted to continuing to feed--feed it to myself," so continuing to find what you're needing or what's not working for you. And sometimes that takes that moment and that habit of checking in, going to bed. Maybe you're staying up too late.

Do you recognize thought cycles that may not be working for you, like things like fortune telling, making predictions about the next few weeks or the months? I'm listening a lot in my in my sessions to people talking about this feeling of uncertainty. And yet at the same time, they're talking about uncertainty, people are also beginning to tell me, "Oh, my gosh, and then this is going to happen over the summer, and this is going to happen in the next few months, and then we're all going to be in our homes until the end of the year," all of these predictions which is not nothing that

you--which is, in fact, not uncertain. You're making a plan or making a prediction. And it might be helpful to kind of fall back on the fact that we don't know. Maybe there's relief in that. All of these things that I'm telling myself or these predictions I'm making, I actually don't know. Maybe there's a breath or a pause in that.

Comparing to others. I don't know about you, I'm hearing that in some of my clients, I'm hearing it in my friends. I certainly recognize it even sometimes in myself, for heaven's sake. How are all these other people finding silver linings and getting all these projects done in their home and embracing new things, and I'm just sitting here trying to make it through the day and overwhelmed and at times frozen? So, when we begin to do that, and we're always landing on the bottom of the heap, then that's not working for us. So, that's not helping; expectations, similarly, or personalizing, "Goodness, her tone with me implies that she's frustrated and irritated with me," and the way that sometimes we can personalize things.

So, my challenge in this slide today in saying all of this is to begin to pay attention with purpose, to begin to watch, "Oof, there's that heavy feeling, this is what doesn't feel comfortable." What's going on for me? What is that feeling? Can I take a break? And maybe what's going on, what's happening? And then, this note that I have of going to the mental gym. In that work, how do you redirect your focus back to the present moment? Let go, relax, return, and gently start again? I've got a couple of different strategies and that kind of leads me right into the first one. Strategy 1, the here and the now, that wherever you might be when these moments of anxiety or fear overcome you, how can you ground yourself back to the here and the now where you're safe, where you're okay?

One of the strategies that can get you there is using your five senses. So, are there five things that you see, four things that you hear, three things that you feel, two that you smell, one that you taste? And if you kind of have to go through that mental gymnastics of coming up with that inventory, it turns the attention away from that ruminating or fearful or anxious thought, and it brings you back to the task of getting very grounded in the here and the now.

Another thing that can help you to kind of slip away from that feeling of the overwhelmed, all-encompassing vastness of unknown, is to break your time down into manageable chunks. Sometimes I find myself telling my clients, "Let's just worry about from the time you wake up until the time you get to lunch, and then from the time you get to lunch until the end of the--until like 2:00 or 3:00 in the afternoon, and then the evening, and then right before you go to bed."

And every time your mind starts to wander or starts to shift off into the future, can you yank it back, pull it back to what's right in front of you, come back to this now, come back to this present. It can be irresistible, honestly, to get caught up in anxiety. And the stories that we're all telling ourselves and that we're also reading about and hearing with regard to worry and fear, that pull is strong right now, and you need an anchor. And the good news is, is that your body is a very, very solid and present anchor for you. So how we can use our body, our breath, our senses to anchor back into right now? I say a lot that it's useless in many ways to tie a thought to a thought.

It's like tying two helium balloons together. You can't tie a thought to a thought. So, how can you tie a thought or take that spinning mind, that busy mind that we might all have, and anchor it back to the weight of your body on a chair, the feeling in the bottom of your feet, your hands clap, grasp and ungrasp your hands to kind of get back into your senses and to your body? And then it might even be helpful and I know that I've even begun to practice this habit myself and I've been sharing it with clients of when those thoughts keep coming, keep intruding, keep pushing at you, that you gently just say, "Not now, later, please," because right now you're focusing on being calm. So not now and so just kind of dismissing, gently dismissing. Not judging, but gently just saying, "Not today or not right at this moment."

Fear and anxiety, if you think about it, are generally about the future, and our body is always in the present. So get there, begin there. Sit comfortably, take a few grounding breaths. One trick or a strategy is that sometimes when we feel that hijack of intense emotions, maybe the first and only thing you can do in that heated moment or that intense moment is just take a breath and if you can only remind yourself, "All I can do right now is to take a breath." But in taking that good breath, it buys you time, and it begins to give you some beginning clarity, so that you can drop into the solidity of your body and rest there rather than your mind in the spinning anxieties of the future.

This final bullet point that I've got here is sort your thoughts. So, if you're--if you're able to kind of thought watch and I don't know if that phrase makes sense to you, kind of thought watch and pay attention. Can you begin to sort those thoughts into buckets, "Oof, I should have been doing this earlier, I should have, I should have done that last night, I should have called somebody." I should have, that's a thought for the past. Put that in the bucket of past.

Or, "I don't know where things are going to land, I don't know how I'm going to go in tomorrow when I get to the doctor, I don't know how I'm going to get with my follow-up care, I don't know what's going to happen." That's a future thought. We're going to put that in the future bucket. And then, we get right back into what's right in front of you and leave all of those future worries and those future anxieties, leave those to the efficacy, the ability, the capabilities of your future self. So right now, you are only responsible for what you are doing right in this exact moment, and we're going to trust in our future self to worry about those things down the road.

This leads me into strategy number 2. So, that can be work to kind of get into that state of calm and to get grounded. Like I said in the very beginning of this webcast, this fear and coronavirus is, in fact, very real. It is scary, and there is uncertainty going on right now. And therefore it may be unrealistic, honestly, to think about completely washing away what doesn't feel comfortable, and we might have to begin to learn what it's like to tolerate or to live with and to live alongside some of this uncomfortable feeling.

So begin by just acknowledging that fear or worry, and it may not completely go away. But then in that, do you get a little bit more flexibility? So, when we can separate, and when we can begin to recognize the feeling, we've got a little bit of super power, we've got a little bit of flexibility to then say, "I see you, I know that that fear is there." And I'm also at the same time going to redirect my attention over to maybe my children and my home, maybe this conversation or the list of questions I want to ask the doctor for later today. I'm going to redirect to sitting at the bedside and being just close and present with my loved one. I'm going to redirect to making lunch and making choices that feel right and feel good for me. I'm going to redirect to working on this puzzle, working on this project. I'm going to focus there. I'm going to say, "Hello, that fear and that worry is there. I see you, I feel you. You can sit quietly alongside me while at the same time I work on what's right in front of me." And when we strengthen our ability to tolerate difficult emotions, as opposed to fighting them and running from them, then we become more skilled at allowing them to coexist in the background as we attend to other things, and that makes us better able to function. That allows us to still stay connected and still stay kind of responsive to what's going on as opposed to reactive. That if we're caught in all of the feeling, or that we're busy, engaged in a struggle with what doesn't feel right.

And that's really all that we're able to kind of spend our energy and our attention on. But as you begin to build the sense of calm compassion and self-awareness, it helps us to do our best under stress and lowers our chance of reacting from fear and panic. So, there is a skill, there is kind of a muscle building in learning to just be able to feel and allow that feeling to sit there at the same time as other things. Learning, and learning the nature of what gets us revved up. So, you might begin to recognize, what is it that spins me down a train of terribles? I think again, I mentioned the news. But even more specifically I think in some ways we have a little bit of a social responsibility to stay reformed right now and to know what's going on, right. But when do you hit that mark of like, "Woo, too much, I've kind of jumped over the catalyst--or jumped over the tipping point, and now I'm not feeling as good as I was when I first began to read today."

I know that I was talking to a client last night. She's a nurse in a major hospital system in New York City. And for her, reading a lot of the news or getting information is in many ways helpful and grounding. But as she begins to read personal stories, diaries of somebody that's in an ER, that's the stuff that she's beginning to recognize that takes some time to learn and to understand, "Woo, now I understand what my trigger is," or, "Now I understand where I'm particularly tender or vulnerable." But, when you recognize it, then you've got the work of kind of saying, "There's where I'm going to draw a boundary, there's where I am recognizing I need to set a limit, because that doesn't ultimately work for me." So, recognizing what revs us up is a gift. And when I say that it gives us a gift because you can say that you're lost in that feeling, and you can just experience it as opposed to problem-solve it. And it's rarely just one thing- helplessness, underlying fear, uncertainty, underlying anger. Self-awareness helps us to discern the

various strands of what's going on for us and to better understand what the feeling is and what the need is underneath that. So kind of letting it be helps you to kind of understand more about what's going on for you, as opposed to fighting it or running from it. It might calm and settle that feeling a little bit.

Strategy number 3, so I've been talking to a number of people about this, too--so letting it be might feel like a lot. Getting in the here and now might feel like a lot of effort, a lot of work. And I vividly remember a session just a few weeks ago when a gentleman that I'm working with said to me, "Julie, I can't do that. I'm trying, but my mind keeps going to the worst-case scenario--keeps going to the worst-case scenario." And I said, "Well, then, what?" And so, can there also be a strategy in this, that if it's really hard, that you might just need to play this worst-case scenario out? And, in fact, is there something that could be settling and calming to letting your mind come up with a concrete plan for "what if?" So, if it's hard to get in the here and the now, if tolerating the feeling is taking a lot of work, well, then, maybe try, experiment, or consider your biggest "what if?" What if I get sick, what if my caregiver gets sick, what if one of us has to be admitted into the hospital, and then ask, then what? Well, then, what? Well, what you do? Who would you call? Where would you go? Where would dependents go? What if we couldn't get a delivery of a certain thing that we needed, then what? That's a good question for your doctor. We would come up with a strategy. Sometimes if we create that concrete plan around your "what if" fears, like I said, it settles that anxiety, and it helps you to know, "You know what? This isn't the end of the road. There isn't a hard stop." I've come to discover that when I shine the light on that, there's more there that will help me to kind of piece that together. Fleshing out a plan for your fears and that worst-case scenario might also help illuminate the disparity between that worst-case scenario, between that ultimate fear, and your present reality.

So, I was working with somebody who is going through treatment, and she's very concerned and feeling very vulnerable medically. And so, we went down that, "what if, then what, what if, then what" strategy to, because she was really, really compromised and very helpless and in the hospital alone. And when we finally got to that picture, it brought so much clarity and light to the fact that she's in her home right now and not at all feeling that sick or fragile or unhealthy. And it was so different. So, the disparity between the two pictures was so much more clear once we traveled that road. And it helped her get grounded, and it helped her kind of challenge, "OK, I'm not there, that is not at all where I am today, and, in fact, that's helping me get a little bit more grounded and anchor back to my here and my now," something to kind of think about or to play through for yourself. And sometimes that's hard to do. Again, back to that idea that I said about it's hard to tie a thought to a thought. If all of that thinking that you're doing and creating and asking "what if, then what" is in your head, that might balloon and get even bigger. So, do you have a trusted someone else, a trusted loved one, that maybe you talk about "what if" with? Come up with that concrete plan, bounce ideas off of one another, hear their rationale, hear their logic and practicality, and allow that to be part of that story for you.

Strategy number 4, thinking about all of this, too, calming anxiety—control/alt/delete. So, I think on your computer and we all are on our computers more than we ever thought we would be these days and things just go buggy and, as my kids call it, glitchy. Everything is glitchy, that sometimes it helps when it all gets glitchy to just take control/alt/delete and just, "Whoof," start afresh, break it up, kind of that act of just kind of shaking--shaking free. And how do we all in these times find an anchor outside of the worry? So get outside of it. Get outside of the worry by perhaps getting outside if you're able to, going for a walk. There is a lot of evidence that nature and even seeing the sky and breathing in the air and feeling the different temperature on your skin, that has an incredibly calming effect physiologically, so if you're able to get outside and kind of control/alt/delete this bubble that we can get stuck in. If you can't get outside, can you open a window? Can you even just open a window and be able to hear the sounds of what's going on out there, the difference in the noise and the static and people's voices or birds or something. A creative project, cooking, building, writing, something that might fully consume your attention. Sometimes a good book, people can get lost in that, and that's a way to anchor outside of all of all of coronavirus and everything that's going on and the social isolation and the being stuck inside--building and cooking. I know a lot of people are doing a lot of physical activities and YouTube classes and yoga and walking and just running up and down their stairs, whatever it is. That that's a way to control/alt/delete. And you might need to say, "Oh, my gosh, I'm stuck, I am spinning, I need to do something dramatic, I need to shift gears, I need to control, alt, delete. I'm going to run up and

down the stairs, I'm going to just kind of either go back and forth in my apartment, I'm going to get into a project, I'm going to sit down with a coloring book or a paint-by-number."

Connecting with others. Call a good friend. Resist the urge in connecting with others to completely indulge only in coronavirus storytelling. So, sure, that might be natural, and it might be understandable to touch base, "How are you doing, what's going on for you, what's new, where's your head today?" That might begin the conversation. But then, make a point and make a concerted effort to turn the conversation and turn the attention of that call away from coronavirus, away from all of this to. Maybe you can talk about a TV show that you're watching, maybe you can talk about a silly video that you watched online or a book that maybe you're reading or your recommendations for other people, a new something that you're cooking or a project that you're doing. Turn on music. Boy, that will change a room. I know in my house, I can't say that I was always a giant--I don't know that I always kind of turned to disco music, but for some reason right now, it's the music that is working in our home. And when we turn on some crazy disco music, the whole energy of the house changes, and it feels different in here. Similarly, but in a very different way, when things are a little crazy, and it's too loud, or it's too just monotonous, and I'm feeling kind of heavy, just put on classical music and--just to feel the energy in the room could get quieter and more still. So using those external things that might help to direct and change the energy of the room. Allow yourself to pull on those right now as a tool.

I have this slide here, and I do think all of these things have validity and are important. I don't know about you and how this hits you today, but I am also hearing a lot in my sessions now that people are feeling bored, just bored, that a lot of the novelty of this in the beginning, diving into all those new recipes that you wanted to cook and pulling out the 1,000-piece puzzle--all of that is getting pretty boring. People are even sick and tired of sitting on the couch and watching TV. So we're being called, yet again, to get pretty creative and to figure out and to dig deep and to look a little closer at what we can do. I will remind you in that challenge that a month ago, you were doing the same thing when your lives were so busy, external and outside of your homes, and you were like, "Oh, my gosh, I've just got to be at home." Somehow in that moment, you found a way to make that work. And so, here we are again at another hurdle of, "OK, I'm suddenly feeling all of that boredom and monotony again." I've got to plug that same resilience in to figure out, "Now what?"

I am going to say this through the lens of a cancer survivor. So, as a cancer survivor, and these might be questions that you might be feeling that are unique to cancer survivors and caregivers right now and how we might address and talk about this. As a cancer survivor, I feel very vulnerable and scared about getting the virus. And I'm hearing that. That's a message that's coming up. And I think that's a common one. It's a very, very understandable feeling. Where do you have control? So again, I'm going to go back to that thing, that idea of placing those thoughts in buckets. What's a future thought, what's a past thought, what's right now? That also is very similar to, where is it that I do have control, and what is outside of my control? That, gain knowledge. What is unique about your specific trajectory on a treatment protocol? What is happening with your particularly clinical trial? Have you talked to the clinical trial coordinator? Gain knowledge, connect with your oncology team to know, if I go in for treatment, do I go to the same door, do I go to the same drop-off, do I use the same driveway that I've always used? Or are things changing, am I going to a satellite location? Am I entering in a different door, a different place? Am I connecting with someone before I go to my treatment floor? So that you know everything, where you have control, and you feel a little bit more-kind of you have some sense of grounding of I know exactly what to do?

And then, the contrast of that, where you don't have control. What's outside of your control and being able to let that go and refocus on where you do. We know that health and preventative-wise, the things that cancer survivors can do to protect themselves are the same, exact things that we're recommending to the general public but just to be incredibly diligent, so practice consistent hygiene recommendations, hand washing, social distancing, not touching your face. That those are very, very important, and especially if this isn't a one-size-fits-all. Everybody is a bit different. Just because you're a cancer survivor does not necessarily mean you're at a higher risk, but we know that when you're in treatment you know that treatments do put immune systems at different places of vulnerability. So, that's where you need to talk about it with your medical team, where you need to fall in that awareness of kind of diligence and taking care of yourself.

Sharpen yourself around awareness, around how your anxiety is triggered to you--so that is 100 percent a place where you have control. So, ok what's happening for me, what's going on in my body, what can I do to calm that anxiety, how can I get grounded, what can I do to help myself set myself up for a stronger day, getting to bed on time, eating meals, drinking water, practicing self-care, connecting with others? These are all things that you have control over. Watching how you react to feelings and the level and the intensity with which you react. I've been saying to some of my clients that it's understandable to feel fear and to feel worry, but to be mindful even of our language in that. So, sometimes the words that we use to describe how we're feeling can amp up, fuel, or even further trigger the feeling because fear and worry fuel more fear and worry. So when we use words, really activated words, like "I'm terrified," or, "It was miserable," or "I'm horrified," or, "I am so devastated," those are pretty intense and activated words, so even just being--watching the words that we're using to describe our own experience, that I'm uncomfortable, that this is really challenging, this is heavy. Those feelings sound maybe a little bit softer than terrified and miserable. So just watching that, too, and how that might continue to direct or fuel how you're feeling. That is a place where you could have some control.

This is reminding me of when I was really sick and stuck at home. I don't know if that's happening for any of you who are listening. And those feelings are hard to experience again, and I would say, yes, that makes sense, that's understandable. And I'm hearing that from some of my clients, and it's kind of pulling them back in somewhat a PTSD kind of manner and triggering back to when they were isolated and when they were sick.

My work in those sessions, and what I would say to you, is can you find all of the ways that today is different than that time? For some of my clients that I'm working with who are post-treatment and beyond that care, they're thinking back to times when they were recovering from a transplant or in the midst of every other week or weekly chemotherapy. Their bodies feel different today. They feel stronger, they don't feel as sick. So, yes, they're isolated, they're alone, they're just with a few loved ones, which feels very similar to stuck in your home. But their body is still stronger, they don't feel the same level of fatigue or sickness--illness.

Another thing that I've heard a lot of cancer survivors saying to me is, "Back when I was isolated, going through treatment, I was the only one, it was just me. And all of life kept continuing. And that was one of the hardest things, that people continued to get married, and people continued to celebrate birthdays and have parties and go out to dinner. And I was at home in my room, worried and fearful, alone." And at this point today, despite how this is hard, that our whole world is struggling with this, there's something unifying about that, that we're all together in this, in sharing the suffering. Maybe you feel stronger, and maybe it's easier for you that everyone is home. Maybe you could add to that list. What else would you be able to recognize or think about that makes this time feel a bit different, not that it's easier? I'm not saying that it's easier or harder. I'm not judging it or ranking it. But, I'm just saying, could it be different?

"I'm really nervous about entering the hospital system, despite wanting to continue treatment." Keep stating and remind yourself, do the work of kind of reminding yourself that cancer centers, hospital systems, experts across the oncology field, are all working hard to assess risk versus benefit of treatment and follow-up care for all cancer survivors. So really thinking about, what is the risk to not having you continue your treatment, what cancers are faster growing? And we need to maintain treatment, we need to keep people on protocols. And what other diagnoses or treatments can we maybe slow down or stop or administer in different ways?

Follow-up care. When do we really need to monitor and check, and when can we say, "OK, at this point, we can push this back for a few months and re-evaluate and re-assess then?" I know for some of my clients--I have clients that are on both sides of that spectrum, so I can say that those--so just even that awareness for me, sitting at this and looking at that bigger picture, it tells me that these decisions are being made in a very case-by-case, very individualized basis. I have clients who have follow-up cares that have been rescheduled to middle or later this summer, and yet they're still going to connect with their oncologist on--through telehealth on the day they were supposed to get a scan. They're going to change that to a phone call or a telehealth appointment. And then they're going to have their scan later this summer or into the fall, wherever we can push it, when it feels right to do. That feels reassuring to be able to connect and to still have that anchor--but also really hard to not get that news of a scan that we long for and that we

hope to--that helps to kind of keep us going. And so, even acknowledging, right there acknowledging, that feeling of disappointment, frustration, sadness and saying that feeling, allowing it to be there--and then getting re-grounded into, "Well, despite the fact I can't get that, that feeling is there. What do I have--what do I have control over as I talk to my doctor, what questions might I ask, what can he maybe suggest for me? "

And then, I have clients who are continuing to go in, and clients who were paused for a period of time, but now that we're months into this, they need to go again, so they're going now and how they're beginning to learn, "Ok, what does this look like for me, how do things change, and how are the doctors continuing to take good care of me and keep me safe, despite the fact I need to enter the system." So, remembering that there's a whole team. No, you're not alone, there's a whole team of people that are really looking out to keep you safe. I feel frustrated when others are not taking coronavirus or COVID-19 precautions seriously. I'm hearing that, too. And you know, for some of my clients, they're like, "You know Julie, I feel safe by myself, and I feel like actually I'm coping pretty well in the social isolation. There are things I feel like I'm dealing with pretty well. But gosh, do you know what's really working at me is this judgment that I'm feeling, this frustration I'm experiencing with others who are just not taking care?" And I am that vulnerable population, and I don't know what to do. So, I think, again, I'm going to go back to, notice the feeling, that self-awareness, let's name it for what it is. It's frustration, its anger, its irritation. Notice, that it's desperate, feeling frantic, vulnerable. Notice the feeling, see what it is. And then, what's driving--what's underneath that feeling? Well, that you have a need. You have a need to keep yourself safe. Maybe you have a need to be respected, maybe you have a need to be considered. And how do you address and say that, "I'm feeling frustrated when you're not wearing a mask or when you're not social distant when you're coming over or you keep wanting to be in our--be in our home. That's making me feel frustrated. I need my space to feel really safe right now in order to help me feel calm. Would you mind calling before you come or stopping at the front door, or would you mind wearing a mask when we go out, so that I know that when you enter back into the house, you're safe." So making those requests and helping people really know what's underneath this--not just wanting to make your life miserable or have a power--power struggle, but this is where this is coming from.

Be clear about your needs, set boundaries, make those requests. And when I say set those boundaries, I'm going to go back. That might also mean that if it's not somebody that you're having to deal with day in and day out, that recognizing I can't. That is a relationship that I'm going to need to let go of in some way right now. I'm going to need to create a little distance because it's anxiety-provoking for me, because it's stirring up so much intense emotion. So, I'm just going to create a little healthy distance for myself today. That's not always, but for today, that's what's helpful.

Last night I had a session. And that client was really struggling with going outside with her young son. And she felt like the entire time they were out on a walk or the entire time she was out, she was screaming and yelling, "Don't touch, don't touch, don't touch your face, don't do this!" And even the effort of getting outside, which was originally for the purpose of mental health, was becoming so anxiety-provoking that we just decided, maybe for you, staying inside is actually better--or going out alone without your son at a certain point in the day when somebody can take over--your husband.

So, what we might feel like social connecting is what's really good for us and that we ought to/should be doing that. But then paying attention, recognizing, "How is this working for me? Is it?" And if it's not--creating some boundaries and finding a different way.

Survivor narrative. I am listening closely to the survivors that I am working with and the caregivers and hearing them tell me some pretty powerful things about recognizing the strengths and the resilience that got them through their cancer experience, "Oh, all of those muscles are at work today," what they've learned and how they've done that. They're able to employ that and feel proud of that and recognize the value. In fact, I had a client say to me, "I know exactly how to do this. I've been managing the fear of recurrence since the day I got my diagnosis." This is the same. This is managing a feeling that doesn't completely go away and still focusing on living your life, "I know exactly how to do this. And those around me are struggling with being isolated and alone, and I've been here before, and I know what to do to care for myself." So, I want to just take a moment to say there's a part of you that may know intuitively and maybe exactly how to do this. Lean back on that. What is it that got you from your diagnosis to now? Maybe



that's a new-found skill in the ability to gather information that's helpful to you or reach out to others that are supportive, help you stay organized.

**Humor.** Goodness, who is living for the COVID-19 memes that are floating all around right now, right? Thank goodness for the funny people. The humor is a trait of resilience, and it is something that helps us to find levity and lightness in the presence of hard times.

**Flexibility.** Maybe that was something that you had to really employ before in your life, in that things don't go the way that you want them to. And sometimes you have to look up, radically accept what is, and then begin to shift and to move and to be flexible about trying a new way. And if that's something that you've become very good at, use that and remember that now. And asking for help. I had a client just this week say to me, "I hate to feel so needy and helpless." And my response to her was the ability to ask for help and the ability to share what struggle and what your suffering is, is often one of the most courageous and one of the hardest things to do. It takes quite a bit of strength. So to be able to ask for what you need and to reach for those that can stand alongside you--not maybe physically but at least emotionally in their presence remotely.

What has helped you to feel grounded or prepared in the past through your cancer experience or at other times in your life when you felt worried or overwhelmed? Because sometimes our best resource for knowing what to do when we don't feel good is ourselves. So in other times, when you have felt unsure or overwhelmed, what have you done, and how have you cared for yourself. Talking through worry with a loved one, going for a walk, listening to music, journaling, moving your body. And what would a close--and if this is all hard to do, if it's all hard to come up with these things--I don't know what my skills are, I don't know what my resilience is. Well, then, can you borrow a good friend or someone who cares for you and loves you and has watched you? And what would they say to me or to you about you? You know, what has helped you find your way? Can that be some place where you can gather that information?

All of this is to acknowledge and to say to you that self-care takes effort. This is work. Clients of mine are telling me, "I feel so tired. I don't feel like I'm doing anything in the day, but yet I'm so tired." And this mental gymnastics and this heavy lifting is work. It takes a lot of effort and energy to redirect our mind and to get calm so to feel tired is understandable. There's energy involved in mental monitoring. So, be gentle with yourself. Acknowledge that, practice that self-compassion. Observe and note how much time you need to recharge and feel different, and you might be surprised. So, recognize, "Ok, I'm feeling irritable. What am I needing? I'm needing some stillness or I'm needing some activity, I'm needing some stimulation."

And then, when you plug that in, if you're able to, how long is it before you start to feel different? And you may, when you're in the midst of that heavy feeling, feel like, "Oh, my gosh, it's never going to get there. I'm never, I'm all consumed by it." And then, it might take long--take a shorter--it might not take as much as you think, maybe a good conversation with a friend, and an hour later, you feel very different. So, watch for the upswing these days, too. Give thought to how you end each day. So, how we end each day is kind of how we fall asleep at night. Reflect on what was working. Gratitude is an amazing antidote to worry and to fear. Connection, escape--so escape. If you just need to plug in the TV or put on music or a book and just escape from it all for a bit. Allow yourself that comfort and that--that chance to kind of just end your day like you mean it.

And remember this is something that I'm leaning on myself and saying a lot, too, impermanence can be your best friend. So, each hard moment changes. And watch for that. So, if we're only looking for what's not working, if we're only looking for what's hard, or if we're only looking for where things are lost, you will 100 percent find it. You will not be disappointed. So, we also have to take some effort and some time to look for what is working, what's helping us, what brings some sense of comfort, maybe even joy, how were we tolerating this time, who was around us that is meeting our needs, how are we doing this day in and day out?

So, that's what I have for you today. I know there are maybe a couple of questions that we can kind of end with. Thank you! Thank you for sitting with me and for joining, and good luck out there. I know this is hard work,

and I hope that some of this message has given you something, a little nugget or two, that you can take and use as you continue to navigate the road ahead.

**Lizette Figueroa-Rivera:**

Thank you so much, Ms. Larson, for your very supportive presentation. It's now time for our question-and-answer portion of our program.

Julie, our first question comes from Rose. Rose is asking, do you have any recommendations on calming anxiety and fear while caring for young children when it may be harder to pause?

**Julie Larson, LCSW:**

Yes. So, caring for young children adds a whole other level of stress and busyness and activity, right? There's constant movement, there's constant need from them. I would begin by saying take a moment at the beginning of your day. So, if you are able, and this might be effort and discipline, but can you begin your day in some way that allows you a moment, a pause, to take a deep breath, to set an intention because then at least you go into this, this race with some reserve and with some grounding? So, begin your day, so it's not like shot out of a cannon. How do you begin your day? That's step 1. And then, too, with little ones that are constantly needing you, constantly there, begin to manage your expectation with how much you're able to be there for them. And I know that what are the things that you can do where they can be on their own? I know that there are a lot of guidelines around devices and screen time. And I know parents are feeling a lot of guilt for using that more than they typically would. On the other hand, I think that mothers and fathers need time for themselves. So, this time is unprecedented. It's not unlike the other--so, if you're needing to kind of turn to things like devices, shows, apps, games to kind of give your child a break--and yourself a break--that that's okay, so that you get sips of self-care through the day.

The other thing I would say is just to accept that this is what this is. That right now you might not be able to do four to five things in an hour, right, that you might just need to be sitting on the ground and reading a book with your child, that you might just need to pull them onto your lap and take a time. That when we fight it, when we try to do more than we can, that it makes it worse. And sometimes just by giving into it, expecting it, and getting down on the ground, it feels a little easier.

**Lizette Figueroa-Rivera:**

Thank you. And our next question comes from Amy. Amy is asking, is there an anxiety medication that is low dose and can be taken on an as-needed basis?

**Julie Larson, LCSW:**

Many anxiety medications are able--they come in and out of your system. There's something that you can take that when you're headed into a stressful moment, you can take like certain medicines

that will help you to kind of stop that ruminating, spinning feeling. And then it leaves your system that day, unlike antidepressants or other things that can also help with anxiety, certainly, but are longer acting in your system for a longer term.

That is an excellent question for your oncologist and your medical team to say, "I am needing something to help combat this anxiety. I'm feeling it more than normal. I think maybe taking a medicine would help me to employ and to flex my own coping skills." And that would be understandable. I think that dealing with anxiety and depression right now is very valid, and your doctors would be the best people to talk that over with.

### Lizette Figueroa-Rivera:

Thank you. And the next question comes from Stephanie. Stephanie is asking, how do you handle people who say, "You don't look sick?" How do I explain to others that I do have a blood cancer and that this pandemic may affect me differently?

### Julie Larson, LCSW:

Yes, that is a great question! One that you might even be dealing with outside of coronavirus, COVID-19, right. That how do people understand that this still affects me, but you might not recognize it or see it, it's not as obvious. I think for that there are those in our lives who can hear that message and can work to understand. And then, there are those who just never completely understand and get it, right?

So, the first step in that is beginning to recognize, who are those people in your life. That you feel like you can be honest with and share with them, "You know, I am in many ways healing, and my hair is growing back," or, "I don't look sick, but I still have side effects of long-term effects that I feel? My blood count is lower, or I feel fatigued, and these things make me more vulnerable, make my immune system compromised in some ways," how you can begin to share and educate some people. And then, "When people are wearing masks and social distancing, that's really helpful to me because it makes me feel safer."

So, there are those that you're going to be able to have that conversation with and educate and share and to talk with them, and then there are others who are just unable to hear that. And that's where we begin to set boundaries--clear boundaries--and know this might be a relationship where I've got to put a little distance right now or I've got to talk about other things. They're not able to understand this for me, so I've got to kind of turn my attention and talk about other things because it protects you.

### Lizette Figueroa-Rivera:

Thank you. The next question comes from Brooke. Brooke is asking, how do we manage familial stress during this time? In our family, the challenge is disagreements between adult siblings on how to proceed with their father's care.

### Julie Larson, LCSW:

Family stress is in many ways at an all-time high, too. And that was on my first slide, that we're dealing with COVID-19, we're dealing with financial concerns, we're dealing with a lot of relationship stress because we're all stuck in a home together or close quarters or having to make new decisions.

When you're dealing in relationships, I would say--again, I'm going to go back to step 1 of all that I've been saying--is awareness. What's happening for you, first and foremost? What are you feeling, what are you needing, what's going on for you? So, you're feeling frustrated, you're feeling a level of, maybe feeling irritated and concerned and desperate or frantic. Maybe that's because they're not--you're needing to be respected, you're needing to be considered. What are you needing under there? And then second, getting curious, so awareness and then curiosity. So, what is, what could be going on for that other person? Can you do that work? That's hard. And wouldn't it be great if other people began to get curious about you, right, if you're kind of wanting that relationship to have both sides? So, you're going to get curious about, "What is driving this," or, "What's behind that for them? Why are they--why do feel adamant about this?" I've got to get curious, I've got to get a little investigative about that. But, as you begin to do that work of getting curious and working to understand, being genuinely interested, and why is that--why is that mattering to you, why is that important? Then it might, then allow it, soften it a bit and allow them to be able to listen more to where you're coming from, so that together you're able to kind of put that in the middle.

So first and foremost, figure out where you stand. What's happening for you? And if you need to turn down that emotion and put in some calm first--because if we're feeling activated, we can't really go into a conversation where we're hot and angry and irritated--so if we kind of calm that, soothe that feeling, understand it more, and then work to

get curious, and then see if together we can kind of find the middle ground or find a place to be able to at least talk about it as opposed to ping-pong blame, the back and forth.

**Lizette Figueroa-Rivera:**

Thank you. And Eldon is asking, how often should we be seeing a counselor? Is every other week a standard? And I know others on the call are asking how to actually locate a therapist in their area.

**Julie Larson, LCSW:**

Yeah. So, that's a great question, and I hear that all the time, "How do I find somebody?" And your medical team, again, a therapist is considered a medical professional, too, so your oncology team might have great references and great people that they can be able to turn you to. And you can talk to them. And that might open another door. So just kind of consider thinking that that first person you call may not be the one. Like dating, it may not be the one, but it might open the door to other resources or other places, and you kind of continue the journey to find a good fit for you.

There are sites like *Psychology Today* where you can do like a therapist finder. It's kind of like a match.com of therapists where you can put in, you can do different filters. It's like zip code, insurance, things like that--to kind of begin to read profiles and see if there's somebody that feels like a match to you. There are organizations that provide support and ongoing care. So like even The Leukemia & Lymphoma Society's care line, they are available to begin to talk through things. Cancer Care has free supportive counseling. So, that can be a place to begin, and then those people might have more recommendations for where to turn.

I would also say that, the question was how often to meet. If you're working with a therapist who--that is a mutual conversation. That is not decided by either you or your therapist. It is a mutual, ongoing discussion about, "I'm feeling this, I'm hearing this in you, and I think there might be benefit in connecting again next week. What do you think?" Or somebody might say, conversely, "I want to talk to you next week." And the therapist might push back and say, "Let's push it. Let's try for two weeks. Let's see how we can go with that." There's benefit in both. There's benefit in connecting regularly because you might be actively doing work. There might be benefit in having a little time where you can flex your own muscles and watch yourself in a different way and then report back with little bit more space. So--but regardless, it's a mutual conversation between the therapist and the client.

**Lizette Figueroa-Rivera:**

Thank you. The next question comes from Monique. Monique states that her son just got off treatment, and, "We had a Make-A-Wish trip we were planning and getting excited about. Now, it seems that there's nothing to look forward to. How do we have something to look forward to?"

**Julie Larson:**

That is so hard, right? And it is so hard not to have things that are on our calendar or things that we do, even just during the week, let alone trips that we were looking forward weeks and months down the road. That's hard. And so, first, I think we've got to grieve that it's not there and just acknowledges it's hard, it's bad, it's disappointing. "I'm feeling it, too. We're together. What are we going to do about that, how are we going to make this work, how can we still have hope that that trip can happen at some point?" We don't know when, but still hold that hope that that can happen at some point.

But, what are some creative ideas that maybe we can do that we can look forward to today? And that might include creating structure. In this time that feels completely unstructured, how can we kind of come up with. You know, in our home, we have decided that we're not watching movies with the kids. They're watching shows, they're doing all kinds of things, but we're not watching movies until it's the weekend. And so, that kind of gives us like something to look forward. "On the weekends, Saturday, Sunday, we're going to pop popcorn, we're all going to snuggle, and

we're going to watch an actual movie." Now, during the week, we might be watching shows, they might be on their devices in different ways. But, that movie time as a family, that's not something we're doing until the weekend.

And that's very simple, but maybe it's even something like that. Maybe there's a night where you make it like a night where everybody can get dressed up or something that you can begin to look forward to. Work together on that. What would that be? For different children, it might look different ways. For some of my kids, they might really love the idea of getting dressed up for dinner and making it a big, fancy deal. And that's something that we can put on the calendar for the end of the week or later in the week and really look forward to. For other of my kids, that might sound like absolute the worst thing that they've ever heard, and so we've got to come up with another plan. I think kids love to do things as a family. So, even if there's a way that as parents we can carve out that space and that time where we're not multitasking, where we're not doing multiple things, and we all sit down together and play a board game, we all sit down together and play UNO--that sometimes those are moments that, if we plan for it, if we say, "We're going to do this at 4 o'clock on this day," then that in of itself can become something to look forward to.

### **Lizette Figueroa-Rivera:**

Well, thank you, Monique, for your question, and thank you all for your questions. We did receive so many questions, so thank you so much for your participation. I do want to give a special thanks to Julie Larson for sharing her knowledge with us and for her continued dedication and support for our cancer patients and their families.

If we weren't able to get to your question today, please contact an Information Specialist at The Leukemia & Lymphoma Society at 1-800-955-4572 from 9 a.m. to 9 p.m. Eastern Time or reach us by e-mail at [infocenter@LLS.org](mailto:infocenter@LLS.org). Information Specialists are available to answer your questions about COVID-19 as well as if you are in a clinical trial or considering a clinical trial at this time, our Clinical Trial Support Center (CTSC) Nurse Navigators can also assist you with more information about any changes in trials due to the coronavirus, and they could be found at [www.LLS.org/CTSC](http://www.LLS.org/CTSC). We did also produce another COVID-19 webcast that answered questions about any medical issues or immune system questions, and you can also find that on [www.LLS.org/Coronavirus](http://www.LLS.org/Coronavirus).

I did mention that we do have a new COVID-19 patient financial aid program that provides \$250 to eligible blood cancer patients experiencing financial hardship due to the pandemic. This will help patients offset non-medical expense, including rent, mortgage, utilities, and food. For more information, you may go to [www.LLS.org/Finances](http://www.LLS.org/Finances) or call 877-557-2672, and they are available Monday through Friday 8:30 a.m. to 5 p.m. Eastern Time.

We have added an online chat on Fridays in light of physical distancing, so to enable you to connect with others during this time. And you could find more information on [www.LLS.org/Chat](http://www.LLS.org/Chat), and you may also connect with others on our online Community, at [www.LLS.org/Community](http://www.LLS.org/Community).

Again, thanks to the supporters for this program, AbbVie Inc. and the Bristol-Myers Squibb Foundation. We really do appreciate you taking time out of your day to participate in this program. In these unusual times, please rest assured that we are all in this together. Stay well.