OPERATOR: Greetings, ladies and gentlemen, and welcome to the Living Beyond Breast Cancer webinar. At this time, all participants are in a listen-only mode. A brief question-and-answer session will follow the formal presentation.

If anyone should require operator or technical assistance during the conference, please press “star, zero” on your telephone keypad. As a reminder, this conference is being recorded.

It is now my pleasure to introduce your host, [Ms.] Elyse Spatz Caplan. Thank you.

ELYSE SPATZ CAPLAN, MA: Thank you, [operator], and welcome, everyone, to Living Beyond Breast Cancer's February webinar, “Getting Connected, Getting Support: African-Americans Living Beyond Breast Cancer.” This program is very important to the staff at Living Beyond Breast Cancer. ... For many, many years we have been doing targeted outreach, and [we have] created a very special publication called Getting Connected: African Americans Living Beyond Breast Cancer.

This month ... we are very pleased to host a webinar that’s culturally specific to African-American women and their loved ones, or their healthcare providers. ... We want our programs to be tailored, personalized and relevant to women's experiences, so we’re very proud to bring you a program today that will be a little bit different. ... At the conclusion of our speaker presentation, we have an [additional speaker, Sharon Register,] who participated in focus groups that Living Beyond Breast Cancer conducted a couple of years ago. [In] an effort to repeat and update the research that we did back in the 1990s, [when we] ... originally created Getting Connected.

My hope is that all of you who registered [for this webinar] ... [will] order your free copy [of Getting Connected, available on lbbc.org]. We hope that you will get [a version of this webinar] into the hands of [other people you may be] ... supporting. ... [We also hope you will use] ... it with your family, your friends and others in your community.

My name is Elyse Spatz Caplan, and I'm the director of programs and partnerships here at Living Beyond Breast Cancer. I will be moderating today's program, which will be interactive in nature. Again, just to repeat, we will start with a speaker presentation and then we will have a survivor's story and some feedback and comments from a woman that you'll meet a little later: Sharon [Register], who participated in our Chicago focus groups. Many of you will learn more today about how to connect to your faith, family, friends, care providers and other survivors, [as well as] how to enhance your learning and gain additional support through your journey.

I'd just like [to mention] a couple of save-the-dates. ... In March, we'll be doing a webinar on long-term survivorship, focusing on maintaining weight; and in April, we will have a webinar that we do every year on triple-negative breast cancer. We certainly know that triple-negative breast cancer seems to affect African-American women more [often] than other groups of women.

Our next large national conference will be our Conference for Young Women Affected by Breast Cancer, held in collaboration with Young Survival Coalition. That's ... February 22 to [February] 24. It will be held in Bellevue, Washington, which is outside Seattle, on the Eastside.
… Other housekeeping tips: … if for some reason you need to depart from the program a little early, or you know of others [who] might benefit from listening to the program, we will have a podcast available.

Lastly, for peer emotional support, we have a toll-free ... Survivors’ Helpline ... (888) 753-LBBC or 5222. ... We have women answering calls Monday through Friday, from 9 a.m. to 5 p.m. Eastern time. At all other times please leave a message. We will get back to you soon after.

Let me tell you a little bit about today’s featured speaker, Alisha Ellis. Alisha is a licensed social worker and coordinates a mental health program at Mental Health America of Greater Indianapolis. Alisha previously worked as an oncology social worker at Winthrop University Hospital’s breast health center, where she provided therapeutic, advocacy and programmatic support to people diagnosed with breast cancer, [as well as] their families and caregivers.

Alisha has also served as the clinical coordinator of the Women’s Cancer’s Program at CancerCare and the clinical coordinator of the L’Oreal Paris Ovarian Cancer Research Fund Hope Line. She has many other talents and credits to her name, but without further delay, I’m very pleased to welcome Alisha Ellis.

ALISHA ELLIS, LMSW, MA: Thank you, Elyse. And thank you for all the survivors on the line, along with the healthcare providers tuning in. This is an honor and a privilege to participate in this call today. What I really want to focus on is how we can get connected, stay connected, and support you through this process.

I want to start with a quote in honor of Black History Month, from Oprah Winfrey: “Every one of us gets through the tough times because someone is there, standing in the gap, to close it for us.” With that said, getting and staying connected is absolutely critical to the cancer journey. There’s often a need to be grounded in things that we know. For many of us, faith, a sense of spiritual connection, family, and friends offer a sense of grounding and stability. That allows us to make meaning in a circumstance that sometimes doesn’t feel like it makes sense at all.

It’s critical to hold onto the things that have been a source of support prior to learning about one’s cancer diagnosis, while [also] leveraging the benefits of science. The cancer journey is unlike any other experience, and it requires us to be connected. It doesn’t have to be a matter of choosing only to rely on one thing, at the expense of another.

How might one do that? Some things to consider: it may include involving sources of spiritual support along with your medical team. It may include reading and listening to the testimony of others who have gone through the process. It may involve gaining support from your faith community, while appropriately determining who you will share your diagnosis with, and when.

It’s talking about hope with family and friends. It’s staying connected. And staying connected can take on a variety of methods, whether it’s via telephone [or other methods]. Obviously, with Facebook, we have many survivors who are connected with loved ones and friends near and far. But it’s also finding ways to nurture your spirit and inviting others to support your efforts, so you can remain hopeful. Being open, and welcoming new and unexpected sources of support, is also critical. I encourage you to leverage people, including nurse navigators and social workers, along with your medical oncologists and radiation oncologist, all throughout this process.

Beyond getting and staying connected, one aspect of the cancer journey that is often overlooked is the need to speak your truth. Speaking one’s truth also means giving voice, and being heard and … validated. Sojourner Truth once said, “Truth is powerful and it prevails.” Finding your voice, and utilizing it to communicate with your treatment team is also critical. When you walk into your doctor’s office, you don’t have to check your “self” at the door. How many of you have truly taken the time to tell your treatment team who you are — outside of the information on your medical chart? Speaking your truth means telling your providers who you are. It means having them tune into the people, the events, or the values that matter to you, and make you unique.

For some, speaking your truth means identifying the events that are forthcoming — a wedding, an anniversary, a
graduation, a family reunion, or something that truly you want to be physically and emotionally present for. For others, identifying the people in your life, or the role that you have in their lives, is paramount to speaking your truth. Your roles as mother, sister, aunt, caregiver, or spouse all shape who you are. Lastly, for others, identifying the values that give you a sense of purpose — including your desire to serve, educate and nurture others — should all be a part of the dialogue about what makes you you.

During the treatment process, sometimes those events and those values must shift. But it’s critical that you find a way to “make present” those things that have sustained you prior to your diagnosis.

The last thing I’ll say about speaking your truth is that it also allows others to help you remain grounded in that truth. As you tell people the things that matter to you, in addition to fighting the cancer process, it also allows people to get on board, and support you through that.

Taking inventory: “One man can be a crucial ingredient on a team, but one man cannot make a team.” That’s a quote from Kareem Abdul-Jabbar. I thought [that quote was very] appropriate, because often, we [don’t] … assess all of the resources that are available to us. Who is on your team? You are not alone. You don’t have to figure out the many aspects of the cancer journey all by yourself.

Start by taking an inventory of who, in fact, is a resource to you. You might be surprised. There may be some people who step up in amazing ways that you never anticipated. There may be others who, unfortunately, may not be able to offer the support that you would have hoped. With that said, your care team includes you, your family, your friends, your medical team, but it should also include people who may have nothing to do with the cancer journey. [Some will be] subject-matter experts in particular areas, including financial matters, legal matters, which often is very intrinsic in the cancer journey process.

I encourage you to do a couple of things. Make a list of all of the resources that are available to you, big and small. Reach out to the people who may have gone through this cancer journey previously. Ask them who served on their team, who was helpful, what things did they gain from those individuals. Was it knowledge? Was it information? Was it contacts? Was it a list of websites? Begin to formulate your own list. You would be surprised how that list will grow, infinitely.

Second, make a list of the things that you think you might need help with. … I recognize that asking for help means different things for different people. … When you consider the word “help,” this is not about not being able to do for yourself. This is about how can you make or enhance what you already have, and make [it] better. For example, if you’re not feeling well, and you need someone to go to the grocery store, or walk your dog: is there a friend or family member you can call on? The value of making this list proactively is that before you actually truly need the help, you already have that inventory of people you can … reach out [to], at a moment’s notice. Most often, they’re waiting for you to call. They’re wanting you to allow them to help in some meaningful way. Task the people with things that you need.

One other critical step, I think, is identifying [someone] who you believe could serve as a spokesperson when you’re not feeling well. Very often, when we are not feeling well, it’s hard to ask for help or [hard to] galvanize your strength to ask. But if you have someone who is your spokesperson, [that person] can offer a summary of what’s going on, so that the people on your care team know what and how they can respond. Identify that person [who is willing] … to serve as your spokesperson.

I also encourage you to identify someone who will serve as a source of healthy distraction. [Maybe that] person … is your sister-girlfriend, who’s going to make you laugh, or … allow you to cry … [without triggering an emotional situation where you] have to take care of [her. You may have] … needed to allow yourself to have that release, [so make sure you know the right person to do that with]. Identify that person or persons, because truly they will come in handy.

Your team should include advocates. Often the cancer journey … includes many barriers. Some of those barriers
… will feel … impossible to scale. And so having advocates in your [corner] … to navigate the maze of paperwork and resources is also a critical step.

Last, in taking inventory, is assessing the way that you make decisions. Are you someone who needs to read or listen, or a combination of the two, before you make decisions? If that’s the case, as you receive information and you’re talking to your medical providers, it may mean that you have to … say, “I need time to take this in, and I need to process it.” But it starts with identifying the way that you best make decisions.

Educate your healthcare team on the way that you make decisions because, quite honestly, that’s going to allow them to determine how to best feed you the information. In return, it allows your healthcare providers to see that maybe your delay in making decisions isn’t about fear, isn’t about resistance, but really is about your desire to be actively engaged in the treatment process.

That brings me to the final point: nurturing yourself. Maya Angelou said, “I believe in living a poetic life, an art full life. Everything we do, from the way we raise our children to the way we welcome our friends, is part of a large canvas we are creating.” You, as cancer survivors, are nurturing yourselves. Part of that means that you are creating a canvas that allows you to have a full life. Your identity did not begin, nor does it end, with a cancer diagnosis. It’s a part of the canvas, but not the canvas [itself].

It’s important to take time to recharge, to rebound and to recover. That may mean different things for each of you. Case in point: When I think about the number of patients who talk to me about the loss of their hair, or the loss of a sense of beauty because there were changes in their bodies, or skin color, I think there’s a need for providers to allow people to give voice to that. The levels of loss will differ.

The topic of hair is particularly challenging, because each of us may assign different meanings to hair and to beauty. Whether your hair is long, straight, wavy, natural, braided locks, weaves, the cancer journey may challenge you to see yourselves differently. This process means sometimes redefining one’s style while mourning the loss of how we saw ourselves.

All of that matters. I encourage you to talk about it with people. No topic is silly. This process is infinitely personal. Leverage your social work team. Leverage your nurse navigators. Leverage your friends and family. Leverage the people who have sustained you in the past, and will hopefully continue to sustain you in the future. Allowing others to support you during this process is not just about the immediate issue. But it really also allows the people around you to receive the blessing of the gifts that they have to offer.

With that said, I want to thank you for your time and attention. If there are questions, I’m happy to answer them as well. Thank you.

ELYSE SPATZ CAPLAN, MA: Thank you so much, Alisha, for giving that wonderful presentation that I’m sure is resonating, whether the listeners are care providers, or women who’ve been diagnosed with breast cancer, or support people. I think there are so many practical aspects of your talk that will resonate for many others out there. I know that I’ve definitely taken away some things that I’m going to continue to think about.

… We will be taking questions by phone, or … online [participants can] … type them in [and] I will [relay those typed questions] … to our speakers.

I would like to now introduce Sharon Register, who came to LBBC in a number of different ways. But what I’d like to highlight for all of you is that Sharon volunteered to participate in one of our focus groups… and we were recreating our publication Getting Connected. I would like Sharon to share a little bit about her story, and also to have any comments or responses to what Alisha had to share.

Please welcome Sharon Register.

SHARON REGISTER: Thank you so much for that. Hello, everyone. Again, my name is Sharon Register, and I’m from Arkansas. I participated in the group in Little Rock, Arkansas. …I just wanted to let everyone know just how
important, just to piggyback off of what Alisha said, about being connected and having a good environment. I was diagnosed at 29 years old, in 2009, with stage III cancer. I’m just honored to be able to share briefly about the importance of your environment, the different people you have around you, [and] the type of support you have, whether it be family, friends, church members or some type of spiritual group.

Your medical team is so very important, because if you can’t trust and be open with your medical team, then you probably have the wrong team. ... I had an issue with my first doctor when I was initially diagnosed. I had to [replace] him, because he wasn’t right for me. He may have been OK for someone else, but you have to know what works for you, and ... just really, really emphasize making sure that you can be honest with yourself, your medical team.

What got me through my own process was I had to take notes a lot. I take a paper and pencil to all of my appointments. I would always have a family member with me as well, because you don’t hear everything ... [while] in this emotional state. Some things you hear and some things you don’t, and sometimes you just don’t remember. Having a pencil and paper with you as you go to each appointment is a very big help.

Doing your own research before you go [can also help]. It really gives you a better understanding of what the doctor is saying, before you go in, so that it creates an open dialogue. [Knowing some background for your questions will help you ask more specific, individualized questions of your doctor.] If you can ask questions [such as], “What does it mean to be triple-negative?” or “What does it mean to have your lymph nodes removed?” ... You would have a basic understanding by going on the Internet to look at those things.

... Sometimes it’s easy to talk, and at other times [it isn’t] ... because you have to be strong, because you don’t want to burden everyone with your big cancer diagnosis. You [end up wanting] ... to be strong for everybody. I did, anyway. I neglected my true feelings with my family. I had to go and find outside support a lot, which would be people that I talk with at my church. I had a very small group, but it was very good for me. My husband was good, too, but you don’t want to wear down your main caregiver, because [that person] can get overwhelmed as well. You want to have a broad but small group. It just depends what kind of person you are. But I really depended a lot on prayer.

In my own personal time I could cry, I could laugh, I could be mad, I could be sad. I could do all those things, and it was OK for that moment. But then you still want to make sure there’s no negativity constantly around you, sadness all the time. You don’t want to deal with that. That’s not good for you. You want to rid your environment of all that negativity.

Talk with some other people who have walked through that process already and survived the 10-year or the 20-year journey. That helped me a lot, because talking to someone who was with me along the same journey at the same time, it was interesting. We didn’t all have the same reaction. We couldn’t — some things we could relate to and some things we couldn’t. But when you talk to someone who has survived maybe 15 or 20 years, it gives you a different perspective. It makes you have a more positive outlook. [That person] can say, “Well, you may not want to eat those oranges that you love so much,” because I love oranges a lot. But while I was taking chemotherapy, I couldn’t eat them. Now I don’t eat oranges as much as I did. Different little things like that will help you, [so you’re] ... not as hard on yourself while you’re going through the process of the chemotherapy.

But back to the surviving-end of everything: I don’t know how much we can stress being connected to the right group of people. If you don’t have — some people don’t have good family members that they can go to, or don’t have a large family. Or maybe they don’t have a religious background, and they’re not involved in a church. Well, you can look at your local city, wherever you’re located, and look at maybe different nonprofits that are there that you can reach out to. Check with your insurance company to see if you could actually go in and speak to a social worker, or some type of therapist, so that you can stay grounded, and go through your process that way.
Journaling: it’s so therapeutic. It’s still therapeutic for me, to this day. I have enough information to write a book. It helps to go over that information, and see how you process, how you’ve grown, and how you’ve come through the whole ordeal. That alone is support — it’s support. That’s how I got through my process with cancer.

I’m still getting through it. … Just because the treatment ends, it is still not over. This is a lifelong journey that you’re on when you receive that initial diagnosis that you have breast cancer. You have to attend to yourselves every day. Make time for you to have fun, to laugh, and to live, because all we have is the moment that we have now.

That’s my little spiel on staying connected. Thank you, so much.

ELYSE SPATZ CAPLAN, MA: Sharon, thank you so much for sharing so much wisdom, and so much honesty, about your lifelong journey.

I think one of your concluding remarks is so very important, and it really … [highlights] our mission here at Living Beyond Breast Cancer. Your comment was, “When treatment ends, it’s not over.” … We definitely hear that, day in and day out, through all of the programming that we cover. I’m sure Alisha has heard that numerous times in her practice. I think it is part of our responsibility to make sure we’re educating the community, that when treatment ends and the rest of our lives begin all over again, there’s a period of recovery — as … a nonprofit … or as women affected or diagnosed with breast cancer. That’s [the] survivorship piece, [and] that can go on for a very long time. We need lots of support in different ways. I really appreciate you sharing that very important point. …

With that … I would like our operator … to let people know how they can get into the question queue by phone, and also online.

OPERATOR: Thank you. We will now conduct the question-and-answer session. If you would like to ask a question, please press “star, one” on your telephone keypad. A confirmation will indicate that your line is in the question queue. You can press “star, two” if you would like to remove your question from the queue. For participants using speaker equipment, it may be necessary to pick up your handset before pressing the star keys.

You can also submit your questions via the Web by using the ask-a-question feature on your screen. Thank you.

ELYSE SPATZ CAPLAN, MA: We’ll just take a few minutes to allow people to get their question formulated, whether by phone or online.

I think while we’re doing that, Alisha, I’m wondering if we can go back to you for a minute with some reflection on what you heard Sharon [say]. … I would imagine there may be some things that you could highlight, from the social-worker-and-provider background, that really resonate, [and] can add a bit more richness for our listeners.

ALISHA ELLIS, LMSW, MA: Absolutely. I think it was excellent that Sharon brought up the value of bringing paper and pen and another person, because absolutely the mind, once we hear something that is disturbing, sometimes we just shut down. It’s an unconscious process. All of us, at some point, have dealt with some form of trauma. In essence, when one hears, “You have breast cancer,” that is truly a traumatic experience for many people, and so having someone present [to help retain] … parts of [your] conversation with your provider [may help you when you] … write down your thoughts afterwards.

Often, in that first appointment, there’s no rush to make an immediate decision. Part of this is taking it in, going home, sitting down and literally formulating a plan. … Sharon was spot-on about bringing pen-and-paper to every appointment, finding ways to do your own research, and being your own best self-advocate. … Because if the cancer team is akin to the — we just watched the Super Bowl — if it’s akin to watching a team, [then], in essence, you are the quarterback. You have all of these individuals who are either blocking for you, or individuals who are helping to drive the ball down the field. But, truly, it starts with you navigating the process. It means proactively doing some research.
Now, I do want to caution people. Not all the information that is available online is validated. So yes, it is about going back to your providers and asking questions. But, again, central to that process is you know yourself best. And so the conversation about how to treat you should be collaborative. It’s about leveraging that person’s medical expertise along with bringing your expertise about you and the things that matter most to you. Absolutely critical.

ELYSE SPATZ CAPLAN, MA: Thank you so much, Alisha. I’m really delighted that we’re able to … go back and forth a little bit with this different format today.

I have a question that’s come in online. … I think we can start with Alisha answering this, but I’d also be curious to hear Sharon’s thoughts: … “At what point during my breast cancer treatment can I consider myself as a survivor?” Certainly we talk about this a lot at Living Beyond Breast Cancer. But I would like to hear both Alisha and Sharon’s thoughts. We’ll start with Alisha.

ALISHA ELLIS, LMSW, MA: Excellent question. The term “survivor” means different things to different people. … Some people will define themselves as “survivor” [from] the moment [of] … diagnosis. For others … survivorship is reserved for once you are done with active treatment. The notion of survivorship may extend well past the point when one is done with active treatment.

For example, there are women who, 20 years after they are in remission, still define themselves as survivors. That is completely appropriate. Again, I think the term “survivor” is both a person, and an individual title. If the term “survivorship” allows you to feel empowered at the point at which you are diagnosed, and you are prepared and want to define yourself as a survivor, I personally say, “Kudos. Take on that title.” But, again, it’s individual. It’s personal.

ELYSE SPATZ CAPLAN, MA: Sharon?

SHARON REGISTER: Yes, I absolutely agree with that. Personally, I saw myself [as] a survivor from day one. Although I was afraid, and I didn’t know exactly what to expect, I said, “You know what? If I’m going to do this, each day, each treatment that I’m still here, that means I survived. I survived the treatment. I survived the chaotic thoughts.”

It is a personal thing. You may want to say, “Well, I’ll wait until I’m done with my treatment to say that I’m a survivor,” or until you’re comfortable saying that. They give us a five-year window … then you can say you’re a survivor. I’ve met a few people who said that, “Well, you’re not really a survivor yet.” And I … [responded], “Well, I don’t agree with that.”

It’s just a personal thing. It does empower you to see yourself as a survivor. I say if you survive one day that means you’re a survivor.

ELYSE SPATZ CAPLAN, MA: I’m just going to add to your comments, ladies. Having been diagnosed with breast cancer 21 years ago myself, I asked that same question of my surgeon at the time of my surgery: … “When can I call myself a survivor?” The surgeon’s response was, “From the moment of diagnosis, because you are living.” It is defined in different ways, and I think that really respects our individual differences on how we look at our cancer experience, and what resonates for us.

Another question that’s been submitted, and while neither of our speakers are medical doctors, I wonder, Alisha, if you can share some of your thoughts on what it means to be diagnosed with triple-negative breast cancer. If that’s too medically-based for you, we can answer that differently, through the staff, after the program.

ALISHA ELLIS, LMSW, MA: I’m so [glad] that … question was raised, because the facts are the facts. We know there is a higher percentage of African-American women dealing with triple-negative breast cancer. The term itself can be very scary and confusing, the term “triple-negative.” Part of it is … not just the dealing with the ambiguity that goes with cancer, but then I think triple-negative is also unique in that you have a smaller population of people who are dealing with it, and then the term itself can also, again, be incredibly scary to deal with.

My advice in terms of a support for people with triple negative — and Sharon mentioned the need to be connected
with people who are going through a similar process — there are specific resources available for triple-negative breast cancer survivors. I do encourage anyone who is dealing with triple-negative to tap into those resources, and know that there is a Triple Negative Breast Cancer Foundation. Leverage that resource in particular.

There is a growing groundswell of information out [of] that. But, obviously, truly understanding what the term triple-negative means and talking to your medical team about that [is important]. Again, [it] is absolutely critical [to tap] ... into people who may be dealing with and going through a similar process.

ELYSE SPATZ CAPLAN, MA: Absolutely. I’ll just add that triple-negative has often been called a misnomer. It’s what the cancer is not. It is not positive for the estrogen or progestosterone receptor or the HER2 antibody. Ask your doctor those questions. But vitally, as Alisha said, gain support.

I will mention, again, that in April we will be having our annual triple-negative breast cancer webinar. It’s April 17. Also, Living Beyond Breast Cancer published a Guide to Understanding Triple-Negative Breast Cancer. ... You can download the PDF of the triple-negative breast cancer guide, [or you can] order a hard copy. Again, as medicine is becoming more tailored and personalized ... our resources also need to be more specific and personalized.

I have another question that’s come in that I’d like both of you to address. That is coming from a woman who ... finished her chemotherapy treatments just about ... two years ago. She’s wondering when she can help herself get past the thought that she caused her own breast cancer.

Alisha, I wonder if, from your background, ... [what kind of guidance do you have for] people who are carrying that worry, that ... [their own actions] may have caused their cancer.

ALISHA ELLIS, LMSW, MA: Elyse, I am thankful to the caller for bringing that up, because often that’s an underlying question people have. What did I do, or what did I not do, that might have caused this to happen? Logically, your medical team has probably said to you — and if they haven’t, then they probably have alluded to the fact — that there was nothing that you did directly to cause this, per se. Are there things that may put people at a greater risk of developing cancer? Yes. But is there one thing that an individual can point to and say, “That’s it. That’s the reason that you developed breast cancer”? No.

Part of this is acknowledging and saying that you didn’t do anything to cause this. Now, there’s a downside to that, right? If you did nothing to directly cause this to happen, how does one prevent it from ever happening again? And there lies the piece where Sharon mentioned: that it’s a lifelong process, that even once you have completely ended your active treatment, no one can completely guarantee that cancer will not resurface.

But, are there things that you can do in terms of wellness and overall good health to try to sustain yourself? Absolutely. That’s not just specific to people dealing with cancer. They are things, in terms of healthy lifestyle, a healthy balance of weight, as well as reducing alcohol intake, that allow us, in general, to live a healthier lifestyle.

With that said, I think it’s absolutely critical that if there is a part of you that’s wondering if you did something to cause this, that at this point it’s about embracing that you did nothing directly to cause this. It simply happened.

ELYSE SPATZ CAPLAN, MA: I would just say to the person who submitted this, since she informed us that her diagnosis was two years ago. ... If you’re continuing to struggle with ... any aspect of your diagnosis ...[it might help to talk to a] counselor, a social worker or some professional [who] might assist you with moving forward, and not feeling stuck — if you’re feeling stuck. Alisha, you might be able to comment, and if Sharon has anything to add, I welcome that. ...

ALISHA ELLIS, LMSW, MA: Absolutely. I would say ... this is a statement ... made by many people. Know that you are not alone in this thinking. There may be many, many people on the [webinar today], and people who are not on the call who are dealing with the exact same thoughts. How courageous of you to actually ... give voice to what many people have said or thought.
I absolutely encourage you to not only talk through the things that feel ... uncomfortable, but even the [other thoughts you have]. ... [You may think]: “I know that, logically, [so I don’t need to get help for it].” [But] emotions aren’t always logical. We need to have a forum where we can safely talk [to] ... people who will reassure us, who will educate us.

Yes, I wholeheartedly encourage everyone, and not just when things feel out of control, but even when ... life is starting to feel somewhat OK again. I still think it’s important to have a resource ... you can talk to, outside of your medical environment: ... whether [it's] a social worker, a counselor, ... your pastor or a source of spiritual support, or a combination of [spiritual and mental health support]. ... Yes, it is important to talk through those thoughts and those feelings, and not carry that.

ELYSE SPATZ CAPLAN, MA: Absolutely. Sharon, we have a question for you that I think probably is on the minds of many people. ... What ... kept you going ... as you were going through your treatment?

SHARON REGISTER: Thank you so much for that question. It’s important to the process of “getting through,” because there are days that you do [get through it. And there are days when] you just want to quit, and ... say, “Well, forget it. It takes too much energy to do this thing.” But when you have three little ones looking at you, and they ... [don’t] understand ... what's going on, that gives you the kick to say, “You know what? I’ve got to beat this. I’ve got to do this.”

My kids were my inspiration [in] ... everything I had to endure. ... My husband was wonderful as well, but when you have babies depending on you — my 10-year-old asked me one day, because I tried to explain it to him the best way I could, he just looked at me with his eyes all glossy and ... [said], “Mommy, does that mean you’re going to die?” I said, “No, son, that's not what it means. I've just got to do things to make me better, to help me. And I need you to help me.”

ELYSE SPATZ CAPLAN, MA: Absolutely. Our children can be a very good source of support, and [motivation for] keeping our eye on the ball, ... and looking ahead. That distraction, for lack of a better term —

ELYSE SPATZ CAPLAN, MA: — can be very, very useful in a very adaptive way. I definitely am resonating with what you just shared with us, Sharon. Thank you for that.

... I want to shift for the moment to caregivers, because we haven't spoken ... much yet about support for caregivers. I’m wondering, actually from both of your perspectives ... can you provide some comments [on that]? ... What advice would you give to those who might be caring for someone with breast cancer?

I’ll let you speak about that, and then perhaps Sharon can give some additional insights. I know you [mentioned], Sharon, about your husband having to ... find support in other ways, too. Let’s kick this off with Alisha speaking about support for caregivers.

ALISHA ELLIS, LMSW, MA: Sure. ... When I think about the support that caregivers offer, I think about the analogy of ... [when you] get on a plane, and ... they tell you ... to put the oxygen mask over your face first [in the event of an emergency, even] before you attempt to help others, right? Very often, caregivers struggle [with helping themselves], ... because they’re so focused on how to fix [the situation], and how to make the cancer either go away, or
how to [prevent their loved one from] … enduring additional pain. Part of this is helping your caregivers in not only caregiving for you, but caregiving for themselves.

… For those of you … [who already have a close relationship with your caregiver, which is often the case], part of it is really taking the time, and talking to your caregiver about how you can nurture them. Because, in return, they’re going to give it right back. … [It’s important to schedule that] time to have non-cancer-specific outings, whether it’s date-night or movie-night — [time together] that has absolutely nothing to do with cancer. … [That will give] your caregiver [a chance to] … recharge [his or her] batteries because, again, most often your caregivers are trying to figure out how to make things better.

The hardest part, for many of them, is realizing that sometimes it’s not in their control to make it better, [and] that they are, in essence, going along for the journey as well. It may mean that you have to make it OK for them to not fix it.

ELYSE SPATZ CAPLAN, MA: Sharon, do you have something to add from your perspective?

SHARON REGISTER: Yes, I do. Actually, that’s what I was saying earlier, about how sometimes as a cancer patient going through the process, my husband, he was such a good support. He cleaned. He cooked. He did it all. He listened to me, and he offered whatever he could offer. But I still noticed that he was … being … weighed down with the diagnosis, for one, and then he had to carry the load of everything — of all of my duties plus his.

I feel that having routine breaks away from the house is so important. Once, I noticed that he was really having a hard time, [but wasn’t] … telling me. … We made schedules for — I have a large family. I was blessed to have participation, but everybody doesn’t have that — but [try to find a] … way that you could give him a break from cooking and cleaning, with the kids. He needs an assistant, so that he can go on … a [mini] vacation [at times, during your treatment process]. …

That’s what we did, actually. I would have my aunt and a cousin come over, and they would entertain the children, do homework. Then, [sometimes] someone else would … come over and prepare dinner. [That made] it a little bit easier to do the caregiving, because it can be … [a lot to bear]. When [your caregiver] … has something that they love a lot, like sports, make sure they have time to do those things they love, away from the home, and not be so bogged down. … [That time will help them to be] recharged and ready to go again.

ELYSE SPATZ CAPLAN, MA: Absolutely. I think both of you brought up some very important points, that everybody needs a break. … For caregivers to be in that role, in addition to all the other roles they might be playing in life or in their work, [is daunting]. … We do need to take time to pause, and refresh, and recharge; … [to] step away for a little bit, and … enlist other people who can take [on the caregiver role for a while]. There’s the “care for the caregiver” aspect we always have to be thinking of, as well as the woman going through her breast cancer experience, finding support in multiple different ways.

With that, I’m wondering if we can field the very big question of managing and living with the worries and fears of breast cancer recurrence. Someone dropped a question in [online] about having finished treatment a little while ago. We know, at LBBC, that’s the number one topic we hear, over and over, that women want to learn more about: … how to cope with and … manage the worry that the cancer might come back [once] treatment is over.

Alisha, why don’t we start with you?

ALISHA ELLIS, LMSW, MA: Sure. A critical question and, again, something that often is on the minds of many people, regardless of where you are in the cancer journey: “When and how do I deal with life after my treatment has ended?” … Part of it is recognizing that it’s important — well, let me step back. …

Often when one is going through treatment, the allocation of … time is not your own. When active treatment ends,
some of that time ... can [be] reclaimed [by you]. That time that would have gone to travel ... [for] treatment can now be devoted to doing things completely unrelated to cancer. You may have to consciously make effort, even though initially there's an element of trepidation, of, “Do I really go back out and start enjoying life again? What if during my three-month, my six-month appointment with my doctor, I'm told that something is not quite right?”

Here’s the real key: I think it’s about really enjoying and taking time to celebrate, one, but then also finding ways to silence that voice that might be saying, “But what if? But what if?” Every single person, I don’t know one survivor who hasn’t had that voice say, “But what if?”

I think it’s balancing that out. The way to balance that out is ... [by] talking to people about some of those fears, giving voice to them, but then also talking about it with your providers. ... They've heard those same concerns [before]. When you are having those fears, when those thoughts begin to bubble up, I think it’s important to not just deal with that by yourself. ... Talk with others about it, so that they can help you create a greater balance, and [you can] begin to reclaim ... aspects of life that [were] altered as a result of treatment.

ELYSE SPATZ CAPLAN, MA: Thank you, Alisha. Sharon, do you have anything to add about ... how you have coped?

SHARON REGISTER: OK, so, yeah. It’s quite normal. I’ve talked to my doctors about it several times. ... It’s OK. If you think that at your next appointment you’re kind of nervous, or in six months or three months you have to go back to the doctor, I would get a little bit antsy. But the main thing that my doctor shared with me, [is that] if it's not consuming me, if it's not to the point where it’s causing me to just totally shut down and just go into total freak mode — I should say that I don't know if that’s the right word to say. But if you’re spazzing out like that, then maybe that’s an indication that you probably need to speak with a professional to get you something to try to relax.

... I just have fun each day. I live, and I celebrate “me” now more than I've ever done. I make a schedule. I have a calendar planned already for this year. I guess you can say it’s a bucket list. Not to say that I’m going to go anywhere, because I’m not, but just making sure that you’re planning fun, time to focus on things that are going to enrich your life. ... [I also plan in] ... conferences and workshops, [so that I can] be informed and educated, [and feel empowered].

What if it does come back? Well, if it does, then we’ll handle it then, and we’ll deal with it. We’ll defeat it again, and we’ll keep surviving.

It’s OK now to think, “It may come back.” That’s OK. But at the same time I have to make sure that I’m focused on living a healthier life, [and focusing on] what I can do to prevent it from coming back, instead of worrying about if it’s going to come back. ... The thoughts will come, but am I eating right? Am I still drinking three cups of coffee a day? Have I exercised? Different things. Am I surrounded with positivity? Am I stressing out about something? All those things matter. If we’re living a healthier lifestyle, chances are the thoughts may not become so intrusive that [they will] ... make you spaz out.

I think it’s totally normal to think that, after being diagnosed with cancer, when you’re going back to your next appointment, your follow-up, your CT scan.

ELYSE SPATZ CAPLAN, MA: I totally agree with everything you’ve said, both Alisha and Sharon. ... What I would like to highlight as we wrap up today is the theme of resiliency [that I think] ... has come up from your conversation with our audience today. What I am hearing you say, in different ways, Sharon, is that in the face of challenge and hardship and struggles, of going through a diagnosis and treatment and side effects and all the many things we’ve discussed today, that we have to fortify our support networks, and get what we need through different points in our journey; that overall there is this strong resiliency at some point that may emerge, that helps strengthen us and get us through the hard times.

With that, I would like to remind everyone again about our resources that you can get on our website, lbbc.org in the Library. It’s Getting Connected: African-Americans Living Beyond Breast Cancer. Again, to highlight our Triple-Negative Breast Cancer guide, but there are many
other subjects that you can benefit from, including our [Guide to Understanding Intimacy and Sexuality], [Guide to Understanding Lymphedema] and so many [other] subjects. ...

I also want to remind folks again about peer emotional support. There was a last question that came in from a woman [who] lived in a small community, and she wanted to know how she could connect and talk with others. I would encourage you and others to please call our [Survivors' Helpline] online, or by calling (888) 753-LBBC or 5222. I'll give you that number again. It's (888) 753-LBBC or 5222. We can address that question on our website at a later date, but very important, whether you live in a small town or a major city to look for different ways to gain support.

On behalf of the staff at Living Beyond Breast Cancer, I sincerely want to thank Alisha Ellis and Sharon Register for bringing their time, their expertise, their insights to our listeners today. With that, I hope all of you have a good rest of your day. ...

Thank you all, and have a good rest of your week.

SHARON REGISTER: Thank you. You do the same.

[END OF TRANSCRIPT]