



Partner Spotlight: SHARE Cancer Support

Christine Benjamin, LMSW
Breast Cancer Program Director
SHARE Cancer Support

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.

Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr. When someone is affected by advanced cancer, like breast cancer or ovarian cancer, it's a heavy, emotional load, and you certainly need support. Your family does too. Where do you get it? Well, one organization that's devoted to it is SHARE Cancer Support based in New York. And joining us now from New York is Christine Benjamin, and Christine is the breast cancer program director. Christine, thanks for being with us.

Christine Benjamin:

Thank you, Andrew. Thanks for having me.

Andrew Schorr:

So, Christine, let's start with you. I know you're a social worker, but you're also a breast cancer triple-negative survivor yourself. So you not only help lead the program that supports people, but you know what it's like very personally, don't you?

Christine Benjamin:

I do. I do, and I'm one of many women in my family before me who have had breast cancer as well.

Andrew Schorr:

Wow.

Christine Benjamin:

It's been our family makeup, part of our family history for as long as I can remember.

Andrew Schorr:

Well, all right. So that's a terrible situation, of course, but then anybody who has dealt with that says, how do we cope? And I guess the first thing is you're not alone, right, and that's what SHARE is about?

Christine Benjamin:

That's true. SHARE's services are provided by peers, women and some men who have dealt with breast and ovarian cancer, both early stage and late stage.

Andrew Schorr:

Tell us about your focus on advanced disease, what kind of programs you're doing, and what are the challenges you're trying to help patients and their families deal with.

Christine Benjamin:

So SHARE has a robust metastatic breast cancer program. We offer 13 support group sessions each month on the telephone for women living with metastatic disease. Two of those sessions are in Spanish and one of those sessions for young women. We also have two in-person support groups each month, and as well as we have a dedicated help line, so people can call in and speak to another woman who is living with metastatic breast cancer. And we also offer educational programming via webinar and in-person as well.

Andrew Schorr:

What are the challenges that you hear about all the time and you know personally as well?

Christine Benjamin:

So many challenges, and I wish we were able to address them all. One of the things we hear is that there are not a lot of support services in less populated cities and places, difficulties, fear and anxiety, not being able to connect with others living with metastatic disease, difficulty explaining the disease and its treatment to family and friends.

Andrew Schorr:

So when people participate in your programs—and tell us how it works. So how do the discussions go? Can people ask questions? Can they connect with others? How does it work?

Christine Benjamin:

Absolutely. So people are free to call in. We provide them with a toll-free number. They can call in to one of the groups. The groups are facilitated by others living with metastatic disease, and people are free to talk about whatever they need to talk about.

Often people are interested in hearing what other—what other patients and what other participants are—what their treatment is, what medication they are on. There's a lot of talk about complementary and alternative medicine. Patients are always looking for the next available treatment. They share information about what side effects they're dealing with, how to manage those side effects. They talk about dealing with friends and family and being able to explain the disease to them so that they are able to receive the support that they need.

Andrew Schorr:

Now, how would you or others who are leading these programs at SHARE, how do you make sure they stay on track? And also sometimes people get inaccurate information through other sources. How do you make sure what people are hearing and what they're sharing really is helpful and credible and valuable information?

Christine Benjamin:

So that's really the job of the facilitator. Our facilitators are trained, and they also receive continuing ongoing education that's provided by oncologists in the field. If a facilitator doesn't know something, we ask them to let people know that they don't know and then they can go find the right information to be able to give that to the participants.

Our facilitators are really incredibly knowledgeable people. They attend—they attend different conferences like ASCO or the San Antonio Breast Cancer Symposium. They participate in webinars where they receive a lot of medical information. So they're very, very well informed. And if they're not, they know not to make something up, or they're not to provide false information. They know to let someone know that if they don't have the answer, they can find out and get back to everyone.

Andrew Schorr:

Christine, from your experience as you've been doing these programs, how much of a difference does it make? What sort of change have you seen in people who come the first time to after they've been participating to just feel more in control, more confident even with these serious diagnoses?

Christine Benjamin:

Well, I mean, I can give you an example of a woman who participated in SHARE's programming sort of from the beginning of her early-stage diagnosis until literally the end of her life through a metastatic diagnosis as well. And I went back and counted how much contacts she had with SHARE staff. So I went through our logs and I counted, and she called the help line over 200 times as an early-stage patient.

And then as a metastatic patient she attended—I think I said we offer 13 support group sessions every month, two in Spanish. Because she didn't speak Spanish, she attended 11 support group sessions every month to be able to help her deal with her fear and anxiety around metastatic disease. And we were able to provide support to this woman continuously as much as she needed as often as she needed it, and the experience was invaluable to her, just incredibly useful.

Andrew Schorr:

And that use of the service, that's okay. That's what it's there for, right?

Christine Benjamin:

That's okay, yes. We usually don't have that level of usage, but if it's needed—our people have all different levels of fear and anxiety and all different levels of need, all right? And if we can help, we're here to do that.

Andrew Schorr:

So, Christine, you have your own personal story. So how does it make you feel as a breast cancer survivor, patient in the past and living with triple negative where we're still hoping that new treatments can emerge? How does it make you feel to be doing this, your own personal commitment?

Christine Benjamin:

Well, it's an incredible feeling to know that you've helped someone. And, in fact, I just hung up the phone with one of our volunteers. She was looking for information about how she can help someone, and she was talking about the feeling that you get from helping someone else. It's just—it's just an incredible feeling, right?

And because I'm a long-term survivor of triple-negative breast cancer, for newly diagnosed women with triple negative, it's a scary diagnosis, right? The first thing we do is go on Google, and we look at stats, and the prognosis is not a good one according to the statistics, and people become very fearful and anxious. And so if I can talk to someone and let them know that I've been around for 17 years after my diagnosis, that provides hope. That provides them with a sense of, you know, they can survive this as well.

Andrew Schorr:

Right. Right. And I guess I have to ask a key question. Do people pay at all for these services, or how is it supported?

Christine Benjamin:

That's a great question. Thank you for asking that. So all of our services are free to people, to participants, and our funding comes from numerous different places, from individual contributions to grants, city funding.

Andrew Schorr:

Christine Benjamin, thank you for sharing your own personal story and your personal dedication to helping others affected with advanced breast cancer and also SHARE Cancer Support and its commitment to women with ovarian cancer as well. Thanks for being with us, and we wish you the best with your own personal health.

Christine Benjamin:

Thank you, Andrew. Same to you.

Andrew Schorr:

I'm Andrew Schorr, delighted to connect you with SHARE. Remember, knowledge can be the best medicine of all.

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.