

# Metastatic Breast Cancer

## THE COST OF CARE:

# Paying for Treatment You Can't Afford

BY ERIC FITZSIMMONS

**J**acqueline Breedlove had a lot to look forward to in 2014. She had just retired from her career as a social worker and was about to move from California to North Carolina. But before she left for her new life, Jacqueline was diagnosed with metastatic breast cancer. Soon she found herself alone, in a new state, with little financial support. She's had to draw on her savings and go into debt to pay for expensive treatments that she will have to continue getting for the rest of her life.

Jacqueline is not alone. Her challenges are similar to those faced by many other people who have been diagnosed with metastatic breast cancer. **Yousuf Zafar, MD**, an associate professor of medicine at Duke University, says about 40 percent of people being treated for cancer report experiencing financial distress at some point. Around 16 percent report severe financial distress. In order to pay for treatment, people may have to go into debt, refinance their home, delay other major expenses and make major changes to their lifestyle.

"What we're seeing is a large proportion of patients are facing medical bills ... that they can't afford," Dr. Zafar explains.

Even with health insurance, people with metastatic breast cancer may pay thousands of dollars in co-pays, expenses and deductibles, a minimum cost you cover out-of-pocket before your insurance company will pay. If you have to stop working or change your work schedule, the loss of income can make it even harder for you to keep up with those costs.



Jacqueline Breedlove

## Asking for Help

It's OK to ask for help. A great first step is talking to your healthcare provider about resources.

Jacqueline is now 66 and living in Raleigh, North Carolina. Moving as she started treatment meant a new health insurance plan, a new pharmacy and a new healthcare team. And her new doctors wanted to run their own tests, the same tests she had done in California, each with a co-pay of \$3,000.

Looking for help, Jacqueline spoke to her social worker, who found a co-pay assistance program that now helps pay for treatments. She found other programs as well, but many help only with living expenses, not medical bills. The constant search for financial support can be draining.

"[There's] all that negotiating you have to do, and if you're not feeling well ... it becomes really hard sometimes," Jacqueline says.

Speaking with your healthcare team can lead you to new sources of assistance. Your providers may know of local resources, such as co-pay assistance programs from pharmaceutical companies and financial help from your cancer center or local charities. Sometimes they can also work with you on a payment plan suited to your income, Dr. Zafar says.



With you, for you.

“In many cases, patients are suffering through the financial burden of treatment by themselves and they are not letting their healthcare team know [that they are struggling financially], or at least not letting their healthcare team know in time,” Dr. Zafar says.

Studies show the stress of healthcare costs can affect your health. People paying out-of-pocket for medicine are less likely to take it as recommended than people who get assistance. And overall, more financial distress has been linked to people reporting a lower quality of life.

When people are struggling with bills, Dr. Zafar says, they may try to stretch treatments out to save money.

“They might not take their treatment as prescribed, they might take less of their treatment, all to try to make ends meet,” he says.

Not taking treatment as recommended can be dangerous and increase the risk of breast cancer growing or spreading, or the treatment not working as well as it should.

## Being Prepared

“There are some things that can be done proactively to reduce the financial burden of cancer. The number one thing someone can do is make sure they have adequate health insurance,” says **Joanna Morales, Esq.**, CEO of Triage Cancer, a national nonprofit providing education and resources for cancer survivorship.

Some people with metastatic breast cancer let their insurance lapse. You may leave work or change jobs, losing your employer-provided coverage. But it’s important to maintain coverage during this time. If your coverage does end, for any reason, you can find new coverage by signing up through COBRA if you want to continue on the plan from your employer, moving to a spouse’s plan, seeing if you are eligible for Medicaid or Medicare, or buying a private insurance plan at [Healthcare.gov](https://www.healthcare.gov).

In choosing a plan, consider what level of coverage is appropriate for your needs, Ms. Morales says. A higher monthly premium may seem like a difficult expense to pay. But as you face expensive and ongoing breast cancer treatments a plan with higher premiums and better coverage can save you thousands of dollars in out-of-pocket costs. Higher premiums often mean lower deductibles, lower co-pays and lower out-of-pocket maximums (the highest amount an insurance policy can require you to pay out of your own pocket during that year).

## Finding Assistance

**Denise Young**, 62, of Hatboro, Pennsylvania, has faced many financial challenges through 7 years with metastatic breast cancer. By asking questions and being persistent, she finds ways to pay her bills. During treatment for DCIS in 2009 and the first months after a metastatic breast cancer diagnosis in 2010, Denise kept her job and used up her sick and vacation days.

Since leaving work in 2011, she has relied on different kinds of assistance to pay for living expenses and treatments.



Co-pays for ado-trastuzumab emtansine (Kadcyla) alone cost Denise about \$1,500 every 6 weeks. She works with her healthcare team to find co-pay assistance programs. When a grant from one foundation runs out, she applies for another, then another. She visited her state representative, who helped her find government programs, including a property tax rebate and help with utilities.

“You learn to do without. [There] are a lot of extras and I don’t need the extras anymore. I’m happy with what I have. I’m just happy to be here,” Denise says.

When there isn’t money left, Denise lets her doctor’s office know and they work out a payment plan. Or, they find ways to adjust the dose or timing of her treatment to make sure she still gets the medicine she needs while she works with different assistance programs.

## Keep Asking

Jacqueline learned there are resources to help pay for treatment and living expenses, but they won’t come to you. If you are struggling to pay your bills, asking for help is an important first step.

“Because I am a former social worker, I knew to ask and look for these types of [programs], but a lot of people don’t,” Jacqueline says.

Jacqueline still struggles, especially with the debt she racked up paying for previous treatments. But she is in a better position now than she was.

Dr. Zafar says more people should have financial conversations with someone on their healthcare team. Many feel embarrassed bringing this concern to their doctor, or believe their doctor isn’t the person to approach. But with more research showing the ways stress and finances affect health, Dr. Zafar says financial distress is something your doctor should know about.

“I want to know if our patients are able to afford their treatment. If they can’t afford their treatment, they’re not going to be able to take it the way that I prescribed,” Dr. Zafar says.

When is the best time for that discussion? Dr. Zafar says, “The sooner the better.” 🍷

## WHO CAN CONNECT ME TO FINANCIAL ASSISTANCE?

- **Your healthcare providers:** Can direct you to help from your medical center or local area, or to other professionals in your treatment center who can.
- **Pharmaceutical companies:** Many have foundations to help people pay for medicines, or to assist with co-pays.
- **Elected officials:** Can direct you to government assistance programs for healthcare costs and general financial assistance.
- **American Cancer Society and other charities:** ACS has a tool to search for assistance programs in your area. Other organizations list assistance programs.
- **Healthcare.gov:** Connects you to available health insurance plans and subsidies you can apply to your monthly premium.
- **CancerFinances.org:** A website by Triage Cancer and The Samfund with information on financial topics and a tool for finding assistance.

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## COMMUNITY CONNECTOR ON A MISSION:

# A Q&A With Kathy Townsend

BY ERIN ROWLEY



Kathy Townsend

**K**athy Townsend, 48, from Helotes, Texas, was diagnosed with hormone receptor-positive, stage IV breast cancer to the bones in 2015. She has been married for more than 25 years and has three adult children and one teenager.

Kathy is a Living Beyond Breast Cancer Community Connector. The Community Connector program provides the tools and training to help volunteers use their personal breast cancer experience to make a difference in their communities.

Kathy answered questions about family life and her volunteer work from LBBC's writer and content coordinator, [Erin Rowley](#).

## Erin

You're a very family-oriented person. When you were diagnosed with breast cancer, how did it impact your family life?

## Kathy

When I was first diagnosed with metastatic breast cancer, my family immediately went into a state of shock, disbelief and confusion.

## Erin

How did being diagnosed with cancer affect your relationship with your husband?

## Kathy

I have a very supportive and loving husband. Even before I was diagnosed, he always put my needs above his own. This did not change after my diagnosis. He is even more invested in doing everything he can to ensure I am well cared for and happy.

My husband is a fixer by nature and he will stop at nothing to make sure my needs are met. Unfortunately, no matter how much he wants it, he cannot fix my cancer and he cannot change what lies ahead. That is something that weighs heavy on his mind. Learning to accept that I cannot be cured is by far the hardest thing he will ever have to face.

## Erin

Has your cancer diagnosis brought the two of you closer together, or driven you apart in any ways?

## Kathy

Cancer has in some ways made us closer. We try to take advantage of moments we have to spend quality time together. We do couples outings and trips together whenever possible. But in some ways it has also driven wedges between us, especially when it comes to intimacy. Physical intimacy has its challenges due to my hormone receptor-positive pathology and treatment. We are continuously searching for other ways to embrace intimacy.

We have good days and bad days. When times are good we try to enjoy them and not waste any opportunity for joy and happiness. When times are bad, we do our best to get through those moments by drawing strength from each other. We are learning to listen to each other, to take care of ourselves better and to take life one day at a time. I find it difficult to look too far ahead to the future. So instead, I live for today. We used to spend so much time preparing for the future, but now living in the moment has become our new normal.

## Erin

How has cancer affected your relationships with your children?

## Kathy

Teaching my children to be independent has always been important for me as a parent. When I was diagnosed, it became even more urgent to ensure that all of them were secure and able to take care of themselves. My youngest daughter, who is still in high school, has had to bear the most weight of my diagnosis. She has not had the same type of support from me that her three older siblings had. In many ways, I need to lean on her for support. I often worry that she feels burdened by my diagnosis, but she assures me that she is OK and understands my limitations.

## Erin

How has cancer affected the way you and your husband parent your kids?

## Kathy

I have a very open relationship with all of my children when it comes to my diagnosis. I think this has helped them feel more secure. Because we have always encouraged independence in our children, our parenting style really has not changed that much. I am very thankful that they feel comfortable going out into the world and finding their own paths. It brings me a sense of peace knowing they will be OK.

## Erin

Why is being an LBBC Community Connector important to you?

## Kathy

One of the things I love about being a Community Connector is being given a chance to talk to people about my diagnosis. Stage IV breast cancer can be very isolating at times, and reaching out to others and telling my story gives me a sense of empowerment that I am making a difference.

I've volunteered at health fairs, participated in advocacy events and have had opportunities to mingle with researchers, physicians and pharmaceutical representatives. I have been truly amazed at the dedication of so many to supporting our community.

LBBC was one of the first charities that helped me to find a community of support, and I love being given an opportunity to help connect others who have been affected by breast cancer to this organization. Support is very important to help cope with the many overwhelming decisions and emotions that come with the territory of a breast cancer diagnosis. 🍌