

Metastatic Breast Cancer

WHEN YOU CAN'T WORK:

Receiving Disability Benefits After a Metastatic Diagnosis

BY ROBIN WARSHAW



Francis Cao

Frances Cao, a nurse from Nashville, Tennessee, was working full-time when diagnosed with metastatic breast cancer. A few days later, she met another woman with metastatic disease who was receiving Social Security Disability Insurance (SSDI) benefit payments. The woman said Frances might want to apply for SSDI because, with a stage IV diagnosis, her chances for approval were good.

Disability insurance replaces part of income people lose due to medical conditions that prevent them from working. “I did not know anything” about navigating SSDI’s approval process, says Frances, who is 47 and lives with her husband and two teenage sons. She applied, but was denied.

She then consulted a lawyer who specializes in disability. He filed an appeal, submitting medical records to show Frances’ diagnosis met Social Security’s definition of disabled.

At her appeal hearing, Frances was bald. “I really looked sick because I was deep in my chemotherapy,” she says. She was amazed when officials asked if she could work. “I was brutally honest,” she recalls, telling them of her treatment plan and several weekly medical appointments. “I said, ‘Realistically, I have to deal with my mortality every day.’ I didn’t sugar-coat it. Then everyone got quiet because they realized how serious it was.”

Three weeks later, in October 2013, she was approved. Her first disability payment arrived in February 2014. “By that time we had already gone through our savings,” Frances says. She estimates disability provides about 40 percent of her former income.

Prepare Before Applying

Frances was lucky to learn about disability coverage so shortly after her metastatic diagnosis. Many people simply don’t know about it or don’t realize they qualify.

“When people have to stop working, whether temporarily or permanently, all of a sudden they’re faced with, ‘How do I pay my bills?’” says **Debra J. Wolf, JD**, a New York attorney with LegalHealth and expert in disability law.

Before leaving your job, get a copy of any *private disability insurance* plan your employer provides. Read what you must show to qualify. Find out if your state mandates *short-term disability* coverage, or if your private policy covers it.

Whether currently working or not, learn if you qualify for SSDI, Social Security’s *long-term disability* program. This has an expedited approval rule, called Compassionate Allowances, for metastatic breast cancer. You may also qualify for SSI, another federal program. (See sidebar on next page, on understanding disability coverage.)

To learn how much your SSDI monthly payment might be, create an account at the Social Security website, ssa.gov, if you don’t already have one. Your estimated benefit is shown there.

“How do I pay my bills?”

It’s best to apply for disability as soon as you stop working. “Make sure the doctor not only supports your disability [application], but that medical records support it,” Ms. Wolf says. When you apply, include a letter from your doctor that confirms your diagnosis, states you cannot work and has your doctor’s contact information. Include any medical records you have available.

Stephanie Fajuri, JD, a lawyer with the Cancer Legal Resource Center in Los Angeles, says problems arise if the doctor does not detail medical reasons why you can’t work. “In some circumstances, the doctor will say, ‘She’s doing great, she has less pain.’ While those are certainly positive things for the patient, in the context of a disability application, it does not look good,” says Ms. Fajuri.

Understanding Disability Insurance

Private disability insurance: May be a benefit through your job or may be purchased as an individual. Rules for collecting vary by contract.

- Many employers require that you also apply for SSDI (see below). The private plan benefit is then reduced by your SSDI amount.

Social Security Disability Insurance (SSDI):

Public, federal disability coverage provided to you if you can't work as you did before, can't adjust to new or different work due to a medical condition and have a disability expected to last at least one year or result in death. These three requirements are how the government defines "disabled."

- Qualifying depends on your age, years you've worked and what you paid in Social Security taxes. You may also apply for SSI (see below) if you don't have enough work history.
- SSDI has a 5-month waiting period. Benefit payments start in the sixth month.
- The Compassionate Allowances rule requires Social Security to **fast-track approval processing for those with metastatic, or stage IV, breast cancer** or whose disease cannot be removed with surgery. If you qualify, state in your application you request Compassionate Allowances consideration. The 5-month waiting period still applies.
- After 2 years on SSDI, you qualify for Medicare, regardless of your age.

Supplemental Security Income (SSI): Also a Social Security program, SSI pays a fixed amount to disabled adults who meet limited income or financial resource qualifications. SSI has Medicaid healthcare coverage. Visit the SSI Eligibility Requirements on ssa.gov.

Short-term disability insurance: Some employers have private short-term disability insurance plans, as do a few state governments—California, Hawaii, New Jersey, New York and Rhode Island—and Puerto Rico. These cover less than one year of disability.

Long-term disability insurance: Long-term disability insurance can be provided by an employer, purchased as a private plan or obtained as SSDI. After a waiting period, these policies generally provide benefits to those who are unable to work or, for SSDI and SSI, will be disabled for longer than one year.



Sarita Jordan

Suzin Glickman

Working After Disability

Suzin Glickman, a teacher and former lawyer from Chevy Chase, Maryland, considered applying for disability but, "I thought you had to work full-time at the time of your diagnosis in order to get benefits." That isn't true, but many people think it is.

By the time she applied, her benefits were based on a small, part-time job. Suzin now works 4 hours per week and collects SSDI. "In the 8 years since I was first diagnosed, and through my metastatic diagnosis, not one doctor, nurse or social worker said to me, 'You know, you might want to look into applying for disability.' Nobody ever brought it up," she says.

Although it's better to not be working when you apply for disability, SSDI allows a *trial work period* after payments begin. This lets you try working again before losing disability status and payments. In 2015, you lose disability if you earn \$780 or more monthly before taxes for at least 9 months over a 5-year period. Those 9 months do not have to be in a row.

"Some people don't pay attention to exactly how much they've made or over how many months. That's where it can be a little tricky," Ms. Fajuri says. Read private policies closely before deciding to work again, she advises. Some won't allow any type of working.

If you're not ready to leave your job, you may ask for work *accommodations* under the Americans with Disabilities Act (ADA). This lets you change certain job conditions, such as your schedule or duties, to manage health issues. The Family and Medical Leave Act (FMLA) provides up to 12 weeks of unpaid leave without the threat of losing your job, during a 12-month period. Not all employees are covered under these laws; it depends on the size of your employer, and sometimes other factors.

Using Legal Help

Getting and keeping disability benefits is "very complicated and a mess," **Sarita Jordan** says. At 36, in 2005, she was diagnosed with early-stage breast cancer and received a temporary disability retirement pension and health coverage from work. The pension—not available in many situations—was a regular, temporary payment by her employer, based on her being medically unable to perform her supervisory job. She also had SSDI. The pension was reviewed yearly.

In 2012, she was feeling good and involved in breast cancer advocacy. No longer considered disabled by her employer, she was given a smaller retirement amount. Her health insurance ended. She found work as a cancer patient navigator at a Philadelphia hospital, with medical insurance coverage. "It was a job in my passion, which was great," Sarita says.

Six months later, she was diagnosed with metastatic disease. She thought her long-term disability policy would help. But a medical report stated she did not have brain metastases although she had bone metastases in her skull, for which she was being treated, and mets elsewhere. The insurer and her employer understood that report to mean that Sarita was not disabled, so they denied benefits under the private policy. “I was undergoing radiation to my skull and wasn’t in a condition to argue,” she says.

She was let go from her patient navigator job in April 2014. She collects SSDI and won’t be eligible for Medicare until mid-2015. For now, the hospital treating her is covering the costs. (Some hospitals help fund treatment for those without insurance. Talk to a hospital social worker about this.)

Sarita plans to call a lawyer for advice. In general, you will have to pay a private disability attorney a fee for services, often a percentage of back payments. The National Cancer Legal Services Network includes 40 groups nationwide offering free legal help, including disability expertise.

You don’t need a lawyer to apply for disability, but Ms. Wolf thinks it’s important to talk with one beforehand. A disability lawyer can analyze your case and help strengthen it. The attorney can explain private policy details, sort out how to qualify and whether you can earn income or not.

“A lot of common mistakes I see on applications that result in denial are very avoidable,” she says.

Even if you’re still employed, take time now to understand the details of your disability coverage. That step can be a big help if your situation changes. 🍷

Four Disability Insurance Tips

1. Before applying, learn what’s required.

Federal information is online at ssa.gov/disabilityssi. If you live in California, Hawaii, New Jersey, New York, Rhode Island or Puerto Rico, check on rules to qualify for short-term state disability. If you have a private plan, get a copy of it.

2. Tell your doctor you’re applying.

Ask for a letter detailing your diagnosis and inability to work.

3. Apply as soon as you can no longer work.

Benefits are paid from when you become unable to work, not from the date of your diagnosis.

4. Find a disability lawyer, especially if you are denied.

The National Cancer Legal Services Network, nclsn.org, and Cancer Legal Resource Center, disabilityrightslegalcenter.org, can answer questions and connect you with help.

LIVING LIFE TO THE FULLEST:

A Q&A with Ayanna Kalasunas

BY JOSH FERNANDEZ



Ayanna Kalasunas

Ayanna Kalasunas was blown away by how quickly her life changed after one medical appointment. Before she was to begin chemotherapy for early-stage breast cancer in 2013, tests revealed she had metastatic breast cancer.

The 35-year-old Philadelphia resident received this news shortly after her longtime boyfriend Michael proposed to her.

After getting settled from the shock of this diagnosis, Ayanna decided she was going to live every moment of her life to the fullest. With Michael, family and friends by her side, Ayanna began treatment, planned her wedding and got married in August 2014. She bought a house and continued working.

She now tries to support and inspire others living with metastatic breast cancer in different ways, such as contributing to LBBC’s recent blog series *Hear My Voice* and speaking at the 2015 Annual Conference for Women Living with Metastatic Breast Cancer, scheduled for April 11 and 12 in Philadelphia.

Ayanna talked with Josh Fernandez, LBBC’s writer and web content coordinator, about how she copes with the diagnosis, the support she receives from her husband and more.

Josh

What helped you cope with the shock of this diagnosis?

Ayanna

I think one thing that helped me cope with the diagnosis was having a mom who also had metastatic breast cancer. I knew you could still have a good quality of life. It can be scary and confusing at times, but I've fortunately and unfortunately seen the disease in action.

This made it a little less unknown for me, which was helpful. My mom always lived with an amazing amount of positivity and grace. The things she was passionate about helped me realize I needed to stay true to myself. For that to happen I had to try to maintain my current standard of living as much as possible and be positive, which was one of the best treatments for myself.

Josh

You were diagnosed a month after you got engaged. How did you tell Michael about your diagnosis?

Ayanna

After my initial ultrasound, I called and asked him to pick me up. He was one of the first people I needed to vent to.

He's always been extremely supportive from day one. He went to almost every single doctor's appointment with me. He wanted to know what this diagnosis meant, the treatments and what they mean, symptoms and side effects and so on. It was a lot [for me] to take in, so he was there with me taking notes.

Josh

What do you think it is about your relationship that makes you and Michael so resilient?

Ayanna

We both want each other to be really happy. I knew cancer was going to affect my life in different ways, such as I knew I was going to have tons of doctor's appointments or that sometimes I would feel really sick and tired.

Doing non-cancer things was our way of maintaining control over our lives. Our thought process was that if we bought a house and planned a wedding, we're fine, because

those are the things normal people do. It was about being happy and not giving cancer the power to change our lives.

Josh

You shared your story for the launch of our *Hear My Voice* blog series and you are also speaking at our Annual Conference for Women Living with Metastatic Breast Cancer. What do you think is the impact of sharing your story of this diagnosis?

Ayanna

For me, I think it was very cathartic just to be able to write the blog entry. After posting it on social media, so many people I've been in touch with have reached out to me, whether through comment or message. It meant the world to me to know that people do want to hear my story.

The one thing about this disease is that you can feel very alone even within the breast cancer community. People with early-stage disease don't understand what it is like to live with metastatic disease.

As I talk about what it's been like, it's been very freeing to speak my truth. Even if only one person reads my story and feels hopeful, less afraid or inspired, then I feel better. It's been extremely rewarding for me to be more vocal about my disease and my experiences.

Josh

It can be challenging for those living with metastatic breast cancer to express the complex emotions they feel to loved ones. What tips or suggestions would you recommend to others?

Ayanna

You have to meet yourself where you are. You have to know you're going to have good days and bad days. You have to allow yourself to feel all those things. When you're well versed and practiced at doing that, communicating those things to other people will come naturally.

I sometimes have to remind myself to be honest with the people around me, because why shelter or hide them from what you're going through? Your friends and family don't want you to go through it alone. You have to be honest about those things. 🍌

To register for our 9th Annual Conference for Women Living With Metastatic Breast Cancer, visit lbbc.org/metsconference.

To read our blog series, *Hear My Voice*, visit lbbc.org/Audiences/Living-with-Metastatic-Breast-Cancer/Hear-My-Voice