



BLACK HEALTH MATTERS

A Black Woman's Guide To: Cervical Cancer



Welcome to Our Cervical Cancer Guide



Roslyn Young Daniels
President & Founder of
BlackHealth Matters

“ At Black Health Matters, our mission is to provide our community with education, information, and inspiration to lead healthier lives and combat the health disparities that impact us.

Black women are disproportionately affected by cervical cancer, with 30% of us more likely to be diagnosed with the disease. If you have received a cervical cancer diagnosis, this guide will provide some essential information and resources to help you navigate diagnosis, treatment, and survival. ”

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The Facts: Cervical Cancer

“We don’t know for certain why Black women have higher rates of cervical cancer; but the reason they are more likely to die of their disease is due to lower screening rates and being less likely to having access to treatment by the right type of doctor, a gynecologic oncologist.” -Carol L. Brown

1.

New Cases

About 13,960 new cases of invasive cervical cancer will be diagnosed this year.¹

2.

Mortality Rate

Black women are 30% more likely to develop and 60% more likely to die from cervical cancer than non-Hispanic white women.²

3.

Age of Diagnosis

Cervical cancer is most often diagnosed between the ages of 35 and 44. The average age of diagnosis in the United States is 50.³

4.

5 Year Survival Rate

The five-year survival rate for Black women with cervical cancer is 56%.⁴

5.

Likelihood of Diagnosis

Black women are more likely to be diagnosed with cervical cancer at a later stage and have lower five-year survival rates.⁵

6.

Rural Areas

Black women in rural areas are 50% more likely to be diagnosed with cervical cancer than white women.⁶

7.

Pre-Cancer Diagnosis

Cervical pre-cancers are diagnosed far more often than invasive cervical cancer.⁷

8.

Age 65 and Up

20% of cervical cancer is developed in women 65 and over.⁸



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Tamika Felder On **Cervical Cancer** Survivorship, Motherhood & Leaving a Legacy

“But the biggest problem I see is Black women are still falling through the cracks.” -Tamika Felder

A few years ago, we shared Tamika Felder's cervical cancer survivorship story, where she talked about her diagnosis at age 25, life afterward, and how it led to her creating Cervivor. Her non-profit patient advocacy platform provides education, support, and community for those diagnosed with the disease. We caught up with her recently to discuss how perceptions about the disease have changed, why the statistics on Black women remain so high, her legacy, and the unexpected gift of motherhood.

How do you think knowledge of cervical cancer and its treatment have changed?

Felder: We're doing better than we were but are not where we should be. Sometimes, I feel like I'm not an expert, but I am because I have experienced the disease. I have my ear to the streets talking to patients.



Women of color across the board are being overlooked, but Black women are falling through the cracks because:

1. We are diagnosed late.
2. Our follow-up isn't good, whether it is on us or our medical team.

I can speak to that firsthand. I often say the only difference between me and someone else who looks like me who has been diagnosed is I had great insurance and a primary care doctor who found my cancer and woman-handled me to make sure I followed up.

I kept saying, "I don't have cancer." My father had died from cancer, and I thought I knew what it looked like. I got all of these second opinions. One of them, an older Black female doctor at Howard University Hospital, was the catalyst that led me to schedule my hysterectomy when she told me my cervix looked like chewed-up meat. I was mad when she said that, but I scheduled the surgery.

What is different today?

Felder: We have better tools. When I was diagnosed in 2001, we only had the PAP test. The HPV test came in 2003, and the vaccine in 2006. There is still a lot of controversy surrounding the HPV vaccine, but I wholeheartedly believe in it because I see too many people of every ethnicity die of cervical cancer.

But when I see someone who looks like me and is around the same age, I have survivor's guilt because, unlike breast cancer and blood cancers, we should absolutely be winning the war. After all, we know the cause of most cervical cancers.

We have diagnostic screening tools to detect abnormal cells to ensure that if people are diagnosed, we can get them treated early, and we have a vaccine to prevent it in future generations.



What made you start Cervivor?

I was pissed off, I was sitting at my desk in the newsroom, and there was information about a breast cancer walk. I thought, where is the walk for cervical cancer? The doctors I saw for second opinions and the one who found my cancer kept saying they saw my situation all the time. How come I am not hearing about it? They told me women thought their husbands were cheating and vice versa. I saw the need for education. Patients weren't talking about cervical cancer because it's embarrassing. I saw that the disease had a marketing problem.

And I couldn't stop talking about cervical cancer. Here we are decades later and still have to talk about it. I am a Black woman from South Carolina, you don't tell all your business. But I am also a storyteller because I worked as a television producer for many years. I created a toolbox for telling your story and getting involved. I wasn't the first person to talk about cervical cancer, but I was the first black woman to be vocal about the disease.

“I am okay being the coochie cancer lady. That wasn't my dream growing up, that this would be part of the legacy that I leave, but I own it now.”

-Tamika Felder 5

I thought my legacy wouldn't be the lives I brought into the world. It was going to be the lives that I saved.



Tamika Felder and her son Chayton

But a little over a year ago, your life changed when you and your husband became parents with the help of egg donation and surrogacy. How has your son Chayton impacted your work?

This baby has become a beacon of hope for people because it is another way to share my story. A woman sent me a message that I was her surrogacy mentor. And I said, "God, you have stirred up some stuff in me." Who knew that becoming a mother would be the continuum?

One survivor said, "It's like your story has come full circle."

For me, that means my son won't have to worry about HPV. My stepdaughter won't have to worry about HPV-related cancers.

And if someone is diagnosed with an HPV-related cancer, it'll be something that they got, not something they did to themselves because it's so common.



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Why Black Women Over 65 Still Need **Cervical Cancer** Screenings

“Many women in our community don't consider the importance of gynecological screenings when they are no longer of childbearing years.”

Cervical cancer is a preventable disease, but if we stop screenings at age 65, many more Black women will die from the disease as a result. That is because we are already diagnosed at later stages and have a lower five-year survival rate overall. The American Society of Clinical Oncology says, “For Black women, the 5-year relative survival rate is 56%. Older women also have lower survival rates. Women who are 65 or older have a 46% relative survival rate.”

Several regional studies have proved that these guidelines may need further examination. At the University of California Davis Comprehensive Cancer Center, researchers found that 1 in 5 cervical cancers diagnosed from 2009-2018 were 65 and over. A large majority, 71%, of these women received a diagnosis at a late stage. The patient's 5-year survival rate for late-stage patients 65 and over was between 23.2%-36.8%. However, that percentage shrank the older the patient, with the lowest survival rate for women over 80.



According to [Human Rights Watch](#), In Georgia, data shows that from 2014 to 2018, Black women had cervical cancer mortality rates almost one and a half times as high as white women, even though overall cervical cancer rates for both groups are nearly the same. While in that state, Black women over 70 are almost three times as likely to die. Researchers believe that guidelines that end screenings at age 65 represent missed opportunities to save lives.

Racial disparities are especially glaring in rural areas where Black women face a cervical cancer incidence rate almost 50 percent higher than white women. In [Appalachian Kentucky](#), the cervical cancer rate is also twice the national average.

Last year, [The American Cancer Society](#) said that:

- About 13,960 new cases of invasive cervical cancer will be diagnosed.
- About 4,310 women will die from cervical cancer.

While most diagnoses are caught between the ages of 35-44, the average age for a cervical cancer diagnosis is 50.

In a previous study, researchers found that the incidence of cervical cancer rose steadily with age, peaking at ages 65 to 69. In fact, in this study, the incidence of cervical cancer among women ages 65 to 69 was 84 percent higher than previously reported.

For black women, the numbers are even more alarming. In this study, black women had higher cervical cancer rates than white women at nearly every age, with the most significant difference among the 65 to 69 set.

“Our corrected calculations show that women just past 65 when current guidelines state that screenings can stop for many women, have the highest rate of cervical cancer,” study lead author Anne Rositch, an assistant professor of epidemiology and public health at the University of Maryland School of Medicine, said in a release. “It will be important to consider these findings when re-evaluating risk and screening guidelines for cervical cancer in older women and the appropriate age to stop screening.”

According to Rositch, we need further studies to determine “whether the continued increase in cervical cancer rates with age and the higher rates in African-American women represent a failure in our screening programs or a failure of the women to be screened so that appropriate interventions can be applied.”



Many women in our community don't consider the importance of gynecological screenings when they are no longer of childbearing years. But, a study found that women over 65 were less likely to be screened for cervical cancer. The Centers for Disease Control says, “The only way to know it is safe to stop being tested after age 65 is if you have had several tests in a row that didn't find cancer within the previous ten years, including at least one in the previous five years.”

- You should have three normal tests in a row for the Pap test alone.
- You should have two normal tests in a row for the Pap-HPV co-test.
- Women at high risk should talk with their doctors about how often to get screened and at what age.
- The CDC says screening after age 65 may be appropriate for some women at high risk, including women with a history of cervical lesions or cancer, women whose mothers took a hormone called diethylstilbestrol (DES) while pregnant, or women who have a weakened immune system.

If you or a loved one is approaching 65 or they are all older, make sure you ask about whether continued screening for cervical cancer is appropriate.





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7 Ways to Support A Loved One With **Cervical Cancer**

“Once she has decided on a treatment plan, "don't go to Dr. Google and tell them to drink all the garlic, oregano, oil, and other stuff," Felder says.

When someone we love is diagnosed with cervical cancer, we are often not sure of the best ways to support them. Our loved ones are often so inundated with information and emotions that they're unsure what will help. Tamika Felder, cervical cancer survivor and founder of Cervivor, a non-profit patient advocacy group, offers these suggestions to support your mom, sibling, friend, or family member.

Be Present.

Don't worry about what you will say to your friend or family member. Start by showing up for them. She may or may not want to discuss their diagnosis, but follow her cues. If she wants to sit in silence, get comfortable with that. But begin by watching and listening to her.

Don't Try to Be a Medical Expert.

Once she has decided on a treatment plan, “don't go to Dr. Google and tell them to drink all the garlic, oregano, oil, and other stuff,” Felder says.



“I believe in that stuff, too. But I also believe in chemo, radiation, and all that. When an individual decides how they want to be treated, and it really is their decision, you have to support it as a loved one.”

Take Her to a Rage Room (or Set One Up Yourself).

She may be feeling angry and helpless after receiving a cancer diagnosis. Allow her to express her frustration by booking a [rage room](#). In these rooms, participants (who wear protective goggles, gloves, and a hard hat) get to express their anger by smashing, breaking, and crushing everything in the area for between 15 and 20 minutes (price varies based on the number of people). You can also set up a spot in your backyard with items she can break, protective gear, and a baseball bat. It won't solve all her woes, but it will provide a cathartic release.

Set Up a Meal Train.

Food may be the last thing she is thinking about when your friend or family is managing a cervical cancer diagnosis and treatment. But she must eat, and if she has children and a spouse/significant other, they could also benefit from a meal train. A meal train is now a technology-assisted version of what our community has been doing forever: providing food for those experiencing challenges. In this case, you can get together with her family and friends to organize meals for her during recovery and treatments. Two free sites that will help you get started are mealtrain.com and takethemameal.com.

Give Her PJs With a Purpose.

One of Felder's favorite suggestions is [KickIt](#) Pajamas. The collections designed for cancer patients' hospital stays, treatment, and recovery have functional elements like front wrap closures, snap sleeves, and interior pockets and are made from soft cotton fabric. Choose from gowns, pajamas, capes, wraps and accessories.



Don't Forget to Check On Your Strong Friend With Cancer.

Your girl, mom, or sibling may say she has everything under control but don't assume that is the case. Make a habit of checking on her. She is used to doing it all, but you can look for ways to lighten her load with cleaning or laundry services, for example.

Know That Her Journey Continues After Treatment.

Cancer is a gift wrapped in barbed wire, a therapist once told Felder. "The gift is coming out on the other side, leaving you feeling like a worn puzzle piece. After you've played with the puzzle countless times, the pieces never fit together the same way," she explains. And once your loved one is finished with treatment, don't assume everything will return to normal. "We're done with treatment, but treatment isn't done with us. It sometimes takes months to a year for the residual effects of that chemotherapy and radiation to be out of our bodies." Your loved one may have secondary concerns, including GI issues, and move slower than she used to.

Please check out [Cervivor.org](https://www.cervivor.org) for more support resources.



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You Have Been Diagnosed With Cervical Cancer, Now What?

“Treatment of cervical cancer can trigger early menopause. If you want to have children, it is important to discuss fertility preservation options with your healthcare team before embarking on your treatment.”

When a Black woman is diagnosed with cervical cancer, her mind starts racing, and her reactions may run the gamut to include anger, anxiety, fear, depression, and shame. But while you may be on an emotional rollercoaster, you also must figure out her next steps. Here is some information you don't want to miss:

Make Sure You Get a Second Opinion.

According to Dr. Carol Brown, MD, FACOG, FACS, a Gynecologic Surgeon at Memorial Sloan Kettering Cancer Center, “If you are diagnosed with cervical cancer, the most important thing is to get an opinion from a gynecologic oncologist, a specialist who has had many years of training just to be able to take care of women with cervical cancer.” To find a Gynecologic Oncologist near you, visit the Society of Gynecologic Oncology [website](#). Check with your insurance company to ensure that the second opinion is covered.



Understand Your Diagnosis.

Your doctor will categorize the type of cervical cancer according to stages. The American Society of Clinical Oncology ([ASCO](#)) says staging describes where the cancer is located, if or where it has spread, and whether it affects other body parts. Those stages will range from I to IV, with substages within each group. And they factor into your treatment recommendations.

[Cancer.net](#) suggests asking the following questions:

- What is my diagnosis, and what does it mean?
- What is the stage of the precancer or cancer? What does this mean?
- Can you explain my pathology report (laboratory test results) to me?

Treatments Plan Will Depend on the Stage of Your Cancer.

Rachel Clark Sisodia MD, Associate Professor of Harvard Medical School and a Gynecologic Oncologist and Gynecologic Surgeon at Mass General Brigham Hospital, [notes](#) that precancer dysplasia, for example, can be fixed with an in-office procedure. “With early-stage cancers, it is important to know that surgery gets pretty aggressive, pretty quickly, and that is what is required to cure your cancer,” she explains. “For more advanced cancers, those tend to be harder to cure. They are almost always treated with a combination of chemotherapy and radiation.”

Know Who May Be Part of Your Medical Team.

A gynecologic oncologist will oversee treatment, but they may work alongside a gynecologic surgeon, a medical oncologist, and a radiation oncologist, depending on your care plan.



Discuss Fertility Preservation Options If You Are Of Childbearing Years.

Treatment of cervical cancer can trigger early menopause. If you want to have children, it is important to discuss fertility preservation options with your healthcare team before embarking on your treatment. At NYU Langone Perlmutter Cancer Center, those with smaller tumors may be candidates for radical trachelectomy. In this procedure, doctors leave in place the uterus, the ovaries, which contain a woman's eggs, and the fallopian tubes, which carry the eggs to the uterus. Another option to preserve fertility is freezing your eggs before treatment.

Don't Neglect Your Mental Health.

The shame associated with having a form of cancer connected to a sexual organ comes with stigmas that make us want to hide it. Don't. Remember that cervical cancer is a result of HPV, a sexually transmitted infection that nearly all sexually active people get in their lifetime. Talk about your diagnosis with family and friends. Make sure they are being screened. Add a social worker, therapist, or counselor to your team to discuss your concerns.

Get Support For Those Who've Been in Your Shoes.

Finding virtual and in-person support can assist you further in managing your cervical cancer journey. A few organizations to explore are Cervivor, a global non-profit education community of patient advocates who can provide inspiration, empowerment, and a safe place to learn more. Founded by Tamika Felder, a Black woman who survived the disease, it serves all women impacted by the disease, but the organization also has groups like Cervivor Noir for Black women. The Resilient Sisterhood Network promotes education on women's reproductive diseases through in-person events and webinars.

Patient Screener: Cervical Cancer

Here are 12 steps you can take to feel more prepared for your Cervical Cancer journey.

- Learn as Much as Possible.
- Build a Strong Healthcare Team
- Have a Treatment Plan
- Work on Managing Your Symptoms
- Seek Emotional Support, Family, and Community
- Focus on Nutrition
- Stay Physically Active
- Prioritize Rest
- Keep a Health Journal
- Don't Ignore Financial Planning
- Always Stay Informed About New Research
- Share Your Knowledge and Experience with Others

