How a Black Woman Is Coping With an "Old White Man's Disease"

Bladder cancer patient manages the stress of a disease where recurrence is common.

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In the months leading up to November 2022, Carlette Winfrey was getting ready to celebrate the 40th anniversary of pledging her college sorority. She and her sorority sisters — many of whom she hadn't seen in years — planned to meet up at the homecoming game at Grambling State University.

"Of course, everyone was trying to lose a little weight," said Winfrey, who is 62.

Winfrey and a friend started eating healthier, exercising more and hydrating. Drinking half a gallon of water a day, Winfrey, a nurse case manager, didn't find it unusual that she started getting up more than usual at night to use the bathroom. But soon, she was making four, five, even six trips a night.

If she knew she'd be away from home or the ambulatory clinic where she works, she would limit her beverage intake so she could better manage the number of times she'd have to seek out a bathroom.

"It really started taking up a lot of brain space," said Winfrey.

Then she spotted a bit of pink blood after wiping, which she attributed to sitting down too hard on her Peloton. Not long after, she noted a nickel-sized drop of red blood, and that prompted her to contact her doctor, who recommended a CT scan. The imaging revealed a 1.4 cm (about half an inch) tumor in her bladder.

She began treatment with a urologist at a local clinic and had surgery — a transurethral resection of a bladder tumor, or TURBT — in late December and again in February. In between, she cooked Christmas dinner for eight people.

Seeking a second opinion

In early 2023, she contacted Fred Hutch Cancer Center for a second opinion. As a nurse, she understood the value of being treated at a comprehensive cancer center where the focus is exclusively on cancer.

“I need the focus to be cancer,” she said. “I needed that level of expertise. I’m a nurse and I know it’s out there so why shouldn’t I take advantage of it?”

Plus, she’d been advised elsewhere that she’d need to have her bladder removed, and she wondered if a specialist at a cancer hospital might suggest a less aggressive approach.

“I said, ‘OK, I get it, but let me see if there’s a chance I can work on this a little bit and figure out a way around this,’” she said.

In February, she saw Jonathan Wright, MD, MS, a bladder cancer specialist at Fred Hutch, and decided to transition her care. Wright took samples of Winfrey’s bladder to assess whether BCG, an immunotherapy treatment that she’d started under her previous care regimen, had been effective.

When he saw no evidence of cancer cells, Wright told Winfrey that he wouldn’t need to remove her bladder. He put her on BCG maintenance treatments, followed by periodic cystoscopies that assess the interior of the bladder to see if the treatment continues to work. Winfrey also had blue light cystoscopy in which cancer cells light up bright pink, making them easier to detect.

Bladder cancer is the sixth most commonly diagnosed cancer, although it’s four times more common in men, said Wright. As a result, women are often diagnosed at a more advanced stage of disease than men due to delay in diagnosis.

Unlike prostate cancer, which is more common and aggressive in Black men, bladder cancer is the opposite: it’s less common among Black people.

“Then you take the fact that it’s already less common in women, and it’s even more worrisome that bladder cancer may not be considered by providers as a possible diagnosis,” said Wright, who noted that Winfrey has no smoking history — the biggest risk factor for a bladder cancer diagnosis.

Primary care providers may not initially suspect bladder cancer as the cause of women’s symptoms — blood in the urine, frequency, urgency and burning. Instead, they may attribute symptoms to a urinary tract infection or dysfunctional uterine bleeding.

“Someone asked me, ‘What are you doing with an old white man’s disease?’” said Winfrey, who is Black. “My dad was a smoker and I wonder if that is related. I’ve been overweight all my life, and I wonder if that is related.”

Winfrey has non-muscle invasive bladder cancer, which accounts for most bladder cancer cases. The median age at diagnosis is 73; less than 5 percent of patients are younger than 55.

“The natural history is frequent recurrences that result in intensive surveillance — every three months for two years, then every six months for two years, then annually until year 10,” said Wright. “It’s not a surprise when we find recurrences. We expect them as more than half of patients with high-risk non-muscle invasive disease will have a new tumor develop in their bladder

over the next three to five years."

Most people with bladder cancer won't die from their disease, but it does have a major impact on their quality of life.

"It's the most expensive cancer from diagnosis to death because of the intense surveillance with procedures, CAT scans and surgeries when there is a recurrence," said Wright.

A global shortage of BCG

To reduce the risk of recurrence, the most commonly used therapy is BCG, or Bacillus Calmette-Guerin, a weakened bacterial strain that stimulates the immune system to prevent bladder cancer cells from returning or spreading. BCG is live attenuated bovine tuberculosis — cow TB, in other words — which is cultured, then chopped up into pieces so tiny that the chance of actually contracting TB from it is "exceedingly rare," according to Wright.

BCG is mixed into a solution then fed into the bladder through a catheter, where it sloshes around for an hour or two. Patients are instructed not to use the bathroom during that time.

"Your bladder says, 'I have an infection.' Then immune cells come down to fight that infection but there's no actual infection, so they find any cancer or precancerous cells and kill those instead," explained Wright, who noted that BCG — which has been used since the 1960s — is one of the first immunotherapies.

There is a global shortage of BCG, which has prompted researchers to investigate other options.

"This is a huge problem and one that Fred Hutch is actively working to solve by participating in trials," said Wright.

Fred Hutch has served as a clinical site for a research study examining an alternative to the traditional BCG strain. The data is currently under evaluation.

"You can think of it like last year's COVID strain versus this year's," said Wright. "Because these are bacteria-based drugs, we need to determine whether disease will respond to this new type of bacteria."

Another ongoing study is comparing BCG with chemotherapies.

Research studies, or clinical trials, are an integral component of cancer care at Fred Hutch. When patients volunteer to participate in clinical trials, they gain access to promising new treatments and play a role in the development of better cancer therapies. Winfrey is participating in Wright's study to determine whether a special urine test effectively assesses the risk of recurrence.

Wright noted Winfrey's can-do attitude toward a cancer that he described as incredibly burdensome.

“Carlette has an aura about her, this positivity, despite knowing she may well have recurrences,” he said. “This cancer is not just cut it out and be done. It takes an emotional toll on patients. I tell them to expect recurrence, but I also tell them we are going to continue to track and find it early. Just because you have a recurrence doesn’t mean I have to take out your bladder.”

Maintaining that perspective helps Winfrey contextualize her disease.

“I’m a ‘let go, let God’ kind of person,” she said. “I had the freedom to change doctors and facilities. I thought I needed to be in the best possible place to treat my cancer, and that’s why I got to this place.”

Being diagnosed with cancer has been less jarring than Winfrey imagined.

“I always thought if I found out I had cancer that I would fall out crying, but I have not shed a tear over this,” she said. “I’m in a bladder cancer Facebook group and there is a 30-year-old woman with eight-month-old twins. My children are 27 and 29. This is a cancer with lots of room for treatment, and all I can do is take advantage of that.”

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