



Mechele Leon wrote and performed her one-woman play *Bladder Interrupted* to convey her feelings about having bladder cancer.

THEATRE

The bladder's tale

What happens when a professor of theatre finds out she has bladder cancer? She writes a one-woman play about it, of course.

BY TAMMY WORTH

In an intimate, packed theatre at the Kansas City Fringe Festival in July 2017, Mechele Leon took her audience on a journey that began with the discovery of blood in her urine in March 2016 and ended with the removal of her bladder later that summer.

Leon, who teaches theatre at the University of Kansas, told her story in the one-woman show *Bladder Interrupted* through a series of smart, humorous skits. During the hour-long production, which she calls a self-story, she used fairy tales, puppets, comedy sketches and even a pastiche of the storytelling show *The Moth* to guide her audience through her journey of disbelief, fear, illness and recovery.

Cancer may be severe, Leon said in the opening, but that doesn't mean there's no comedy. "I called the incontinence hotline," she began, "and they asked, 'Can you hold, please?'"

The first chapter was a fairy tale, which began with plans for a nice evening walk. As Leon sat on stage, turning the pages of her oversized book, she delivered the tale in short sentences and a pleasant, sing-song voice that contrasted unnervingly with the unfolding severity of her condition. At first there was shock when she found that her toilet was full of blood. Then there was the discomfort of the intense bleeding that caused clots to form, preventing her from emptying her bladder. Leon described the worry she felt when the doctor told her that she might have bladder

cancer. But it was only when she got the results of the tumour analysis and heard words such as 'muscle-invasive' and 'chemotherapy' that she admitted to herself: "Now I'm afraid." As the lights dimmed and she put away her book, the room was still with the weight of her realization.

In a sketch set in a 'communiversity', Leon welcomed the audience as 'life-long learners' to her community-university class to learn about bladder-cancer treatment. As the teacher, Leon described the standard surgery in which the bladder (played in a cameo by Mr Potato Head) and the lymph nodes are removed, and a diversion is created to deliver urine through a new opening (a stoma) in the belly to a collecting bag. She teased her students with the names

MELANIE RODRIGUEZ

of the treatments, deliberately mispronouncing complex terms such as 'bilateral pelvic lymphadenectomy' (removal of the lymph nodes). Leon even used practical demonstrations, using sausages to illustrate how the small intestine is co-opted to shunt urine from the kidneys to the stoma and into the urostomy bag. Sticking with the earlier toy theme, she compared herself post-surgery to a Betsy Wetsy doll, which wets itself after drinking water.

Leon also drew on her blog *C67point2* (<https://c67point2.wordpress.com>), named for the code for bladder cancer that US doctors use to claim reimbursement from insurers; she wrote the blog in the months after her diagnosis and continued it right through her treatment. Leon sat in silence as the stage went dark and her blog was typed out on a large screen. She conveyed the frustration she felt when she first looked up her condition online and discovered the scant facts about bladder cancer. At the time there was little genetic research, and treatment protocols had barely changed for 30 years.

Bladder cancer, she lamented, receives only one-tenth as much US research funding as breast cancer. Although it is less common, she said, bladder cancer has a higher mortality rate than breast cancer. It seemed to her that breast cancer also elicited more sympathy. While she was having chemotherapy, volunteers passed her by to assist nearby breast-cancer patients wearing pink hats, pink t-shirts and pink ribbons. She was not part of the 'breast-cancer sisterhood', but belonged instead to the 'grandfather-has-bladder-cancer golf club'. She felt that her bladder cancer made her seem a little less worthy.

Leon's play ended on an upbeat note: a genuine voicemail from her doctor telling her that she was cancer free. The audience cheered and clapped with relief. In her final moments on stage, Leon looked back, able to contemplate her experience now she was on the other side. She realized that the mythology that attends cancer treatment — with patients valiantly 'fighting' for survival — did not apply to her. What got her through this challenge was not being a warrior, but being a story-teller. Initially the tale was dictated by the doctors and their information about her condition. But gradually, she was able to weave her own narrative as she progressed from diagnosis through treatment to recovery, which gave her the opportunity to "try on different roles with new stories to tell... and there are so many ways to do it." ■

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Q&A Mechele Leon

Take it away

Mechele Leon, an associate professor of theatre at the University of Kansas in Lawrence, was diagnosed with bladder cancer in March 2016. After treatment, Leon was left with no bladder, a urostomy bag, and a story to tell — which became a one-woman play called Bladder Interrupted.

Why did you turn your experience into a play?

Writing blogs did not reflect my story. I experienced it through the ways people behaved towards me, and the way I felt about things that happened. I always kept my sense of humour and would text people from the emergency room and joke about what I was seeing. The show was an adventure discovering what my voice might be in a situation like this.

What did you learn from the research you did after your diagnosis?

I did a lot of reading, and with each fact I was more appalled. I would have a moment where I'd learned something new — like, oh by the way, they have to take out part of the vagina when they do surgery — and I practically fell out of my chair. I learned how poorly bladder cancer is funded and researched. By the time I walked into my doctor's office, I'd had weeks to worry about it. I would have been better off just getting the story from my doctor.

You say the play helped you figure out who you are with cancer. Did you have any epiphanies?

It was like the moment in the Mel Brooks film *Young Frankenstein* where a woman takes a candle off a bookshelf, causing the bookshelf to spin around, trapping Gene Wilder on the other side, and he yells, "Put the candle back!" I wanted to scream that, but I am on the other side and you can't put the candle back. Cancer

makes it clear you're not going to live forever. Life is shorter than you think and it scares you.

What has been the response to the play?

One night my surgeon came with his family and the stoma nurses from the University of Kansas Hospital. They said that it was fantastic to hear a patient's story. My oncologist and his family also came. I think they were surprised by the creative treatment of this disease. I knew the show was funny and educational, but I didn't know how people would feel about listening to it. I have since been invited to join a patient-advocate programme from the University of Kansas Cancer Center called PIVOT (Patient and Investigator Voices Organizing Together). I will be a part of teams that inform doctors about patient experiences in a way that might help guide research priorities.

In the play, you rebel against the idea of a cancer patient being a warrior. Why?

It sets some cancer patients apart from others and gives us a misleading sense of responsibility for our recovery — that because you have a positive outlook and others don't, you will do better. I have seen the deaths of two of my best friends who were both fighters. I believe in fighting and in the desire to live, but if cancer gets you, it gets you.

Why did you decide to have your bladder removed instead of trying to save it?

Chemotherapy and radiation can sometimes save your bladder. But the fact that I had a very aggressive form of the cancer clinched it for me. The percentages didn't look good on any other procedure than the radical cystectomy. I wasn't going to gamble with my life.

The play doesn't deal much with the physical aspects of losing your bladder. Why not?

I don't have an issue with having a urostomy bag. I'm more concerned about the health repercussions. I have a direct line from my kidneys to outside my body, and if urine back-washes into the kidneys it can cause infections. It's important to keep the kidneys healthy because they're all I have now.

Why did you decide to have an 'ostomy' rather than other available options?

You've got to pick a system you can live with for the rest of your life. They can take your intestines and rebuild a urinary reservoir inside your body, but the continence isn't guaranteed and the 'neobladder' can get infected. With an -ostomy I can go hiking and swimming and don't have to worry about leaking. The big picture is: what is going to give you the most normal life? I refuse to go crazy about a dumb bag. And there are some perks. I can empty it when I'm hiking — and I don't have to squat.

INTERVIEW BY TAMMY WORTH

This interview has been edited for length and clarity.