

**Sexual Dysfunction in Oncology Patients:
Erin Sullivan's Mission to Reform Cancer Care**
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"Don't worry, honey. You're young, healthy, and sexually active. You shouldn't have any sexual health effects. They'll give you a dildo down in radiation and it'll take care of any problems you could have."

These were the words Erin Sullivan's colorectal surgeon used to reassure her when she was diagnosed with anal cancer in 2008. Sullivan wasn't sure what that meant. What kind of problems? What kind of dildo was the doctor talking about?

In the fog of post-diagnosis shock, questions about sexual side effects and dildos seemed like the least of her worries "It's almost painful, the diagnosis. It's so confusing, just the shock and awe of 'How did I end up here?'" says Sullivan.

The confusion was compounded by another offhand comment the doctor had made: "I usually only see this [HPV-related anal cancer] in gay men, now I see it in women your age."

She wondered if the doctor thought she had frequent anal sex. She and her husband had only tried it once. Was that what she was referring to with "sexual side effects?" How would she tell her mother about the diagnosis? What kind of assumptions would people make about her?

The breakdown in communication around sex didn't stop after that first visit. A few weeks into radiation treatment, Sullivan mentioned the dildo comment made by her surgeon. The radiation oncology staff were baffled. They had never heard of such a thing. Maybe she meant a vaginal dilator? It turned out a dilator was, in fact, what the surgeon was referring to. Despite this conversation, Sullivan was never provided one. The radiation oncologists didn't think she needed it.

Six weeks after her last treatment, Erin Sullivan was pronounced cured and told to resume sexual activity. The only guidance given was to "go slow and use vegetable oil."

Her first attempt at sex with her husband proved to be incredibly painful. "I thought he was hitting a wall that he was trying to split open," she says. "There was blood. It was bad."

When she followed up with medical oncology, the resident could only provide platitudes: “It sounds like you’re dealing with this really well.”

“Do you mean because I can talk about it?” responded Sullivan. “I’m not, or I wouldn’t be talking about it.”

The attending physician wasn’t much help either. He admitted they didn’t see many anal cancer patients, and maybe she just needed more time to heal. Sullivan and her husband tried a few more times before the doctors sent her back to radiation oncology. The doctor there didn’t seem to think the treatment should have caused any problems and referred her to a gynecologist.

It was five months after treatment that Sullivan was finally able to see a gynecologist. That’s when she learned there was a thick web of scar tissue throughout her vagina, a complication that could have been prevented had she used vaginal dilators in the weeks following treatment.

Radiation-induced vaginal stenosis (VS) is a common side effect experienced by up to 80% of females with anorectal cancer. It’s more common in patients receiving brachytherapy (BT) in combination with external beam radiation therapy (EBRT), though it can still occur in patients who receive EBRT only. Because Sullivan did not require BT and her physicians did not have a lot of experience with anorectal cancer in females, they may have been more inclined to dismiss her complaints.

At the same time she was dealing with all this, Sullivan began to life coach fellow cancer patients through their own journeys. She soon learned that almost everyone she was helping— people with a wide range of cancer diagnoses— were experiencing sexual side effects. In fact, some studies suggest the percentage of all cancer patients who experience sexual dysfunction is higher than 60%. But nobody was talking about it.

Over the next year and a half, Sullivan was subjected to treatment after treatment in an attempt to regain her sexual function. Despite surgery, dilators, pelvic floor therapy, creams, pain relievers, and muscle relaxers, she continued to struggle. At one point, the gynecologist said to her, “I’m sorry, this isn’t going to work. We can’t reverse this damage. You waited too long to get treated.”

But Sullivan hadn’t waited at all. “As soon as I knew I had problems, I went to the next appointment to complain about it. They should have known I was

going to have problems and given me dilator tools in radiation like the surgeon said. She was right, as quirky as she was. But they didn't even know what that meant because sexual health side effects in patients hadn't been normalized. Patients weren't sharing their struggles with clinicians because clinicians weren't asking."

"When the doctor said that I had waited too long, I was so emotional. I said, 'I didn't wait. You did.'" And that's when I felt the strongest that this shouldn't happen to people. Shame on oncology professionals who choose not to set patient expectations regarding sexual health. They should know this."

She tried offering in-person patient resource groups on sexual health and cancer, but realized the real change needed to happen within the healthcare system. Her sister had put her in touch with a gynecologist who was also passionate about sexual health and cancer, and soon Sullivan was speaking to groups of cancer clinicians about her experiences.

That led to a meeting with the Iowa Cancer Consortium, and a suggestion that she apply for funding to educate more clinicians. In 2017, Sullivan's project, All of Me, received its first grant. The first thing she did was run focus groups with patients and clinicians to identify the barriers to care.

"There were a couple of things patients said that I hadn't realized. Often during this time in their life, patients— depending on the treatment, depending on their relationship, if they have small kids at home— may not be sexually active. They don't even know that there are changes happening. Which is all the more reason why your provider who does know should tell you about it."

"Patients also think their oncologists are God-like. Because if I'm going to be okay, it's going to be because he or she saved my life. If they don't normalize it for you, if they don't tell you it's an important thing to think about, you don't think about it."

Later, Sullivan says, when patients do experience sexual problems that they haven't been primed to expect, they think "Well, they tell me I shouldn't have any issues so there's something wrong with me." And, she adds, many patients feel so grateful to have survived cancer, that it feels greedy to ask a doctor to fix their sex life.

Clinicians had their own barriers. Many felt they didn't have the expertise to help patients with sexual problems that might be far beyond their own scope of

practice— for instance, body image, difficulty reaching orgasm, or poor communication with a partner. They often felt they didn't have enough time, that patient loads were already too high, and bringing the issue up might extend a 15-minute check-up into an hour-long consultation.

Sullivan's solution was to help them realize that they didn't need to become sex therapists. While providers did need to understand the sexual health effects of the cancers they treat, they didn't need to have all the answers. They just needed to normalize the problem, encourage people to anticipate and ask for help as soon as possible, and refer them to those who *could* help.

She developed a tool to help clinicians write their own 30-second script that would address six key points from the very first visit: sexual side effects of cancer treatment are common and expected; sexual health is an important quality of life issue; treatment-related sexual problems are a healthcare issue; support and resources are available; it may not seem like an issue now, but could later on; and addressing sexual problems sooner is better than later.

All of Me ran workshops to help patient care team members develop and role-play their 30-second scripts, and provided table signage and brochures for waiting rooms to reinforce the messaging. The workshops were a hit.

"Workshop attendees were so receptive," says Sullivan. "It was great to see people appreciative of the education and telling stories of what their patients would say to them, how [the patients] appreciated it so much."

Over the next several years, Sullivan continued to expand the work, piloting training programs within Iowa and developing materials that would allow organizations to run their own education and training.

In 2023, the All of Me project has become a brand new nonprofit, After Cancer, and Sullivan has her sights set beyond Iowa. In five years, she hopes to see sexual health implemented as a standard goal of care for cancer patients nationwide. She acknowledges that while the in-person training, where clinicians are asked to develop and role-play their 30-second scripts, has been the most impactful, it will be difficult to scale without more resources.

She'd also like to provide more e-learning courses and decision-making resources, including an app, for clinicians; a directory of providers trained in sexual health for cancer patients; and one day, perhaps an app to support patients.

According to Sullivan, many clinicians don't know that widespread sexual health problems in cancer patients exist, or how critical it is to address the issue soon after diagnosis. "They don't know that it's a thing, because it hasn't been normalized at their facility," she says. "Patients are going to start pushing back on that."

Erin Sullivan is making sure healthcare providers are up to the challenge: "They want to be champions for their patients. They want to help them. They just need the education to do it."

If you're interested in becoming a Sexual Health Champion, learn more about After Cancer's services for individuals and organizations [here](#).