**Overcoming Stigma: What Patients Wish Their Care Team Knew About Openly Discussing Sexual Health and Cancer**

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After being diagnosed with cancer, navigating treatment, side effects, and the pain of uncertainty can be grueling to endure. One common side effect of cancer is sexual dysfunction, resulting either from treatment or the cancer itself. Many patients do not receive enough education and resources regarding sexual health from their care team, and most find it difficult and embarrassing to initiate these conversations. In these honest, in-depth interviews, Erin and Alique share about their experiences with sexual health and cancer, what went wrong, and how things could be better.

**Erin’s Story**

Erin Sullivan Wagner is the Executive Director of [After Cancer](https://www.aftercancer.co/), a nonprofit that aims to address sexual dysfunction by providing coaching, education, and workshops for both providers and patients with cancer.

In 2008, Erin was diagnosed with anal cancer and received five weeks of radiation and two weeks of chemotherapy at the beginning and end of radiation. “I went into treatment excited that I had a very survivable cancer. And I’d been told three times [by three different providers] I wasn’t going to have sexual health issues. So I believed them and didn’t think anything more about it.”

In a meeting with the colorectal surgeon who was one of her providers determining the diagnosis, Erin did not feel comfortable delving into her sexual health concerns. “I didn’t have a voice, and she didn’t leave space for me to have a voice. I was intimidated by her… I didn’t know how to start even with the questions. I felt stupid. I felt vulnerable and fragile.”

During her follow-up appointment six weeks after completing treatment, Erin received a clean bill of health and was told she could resume sexual activities.

“We tried and it was so immediate and severe, the pain involved with attempting intercourse.” Erin knew something was wrong, so she brought up the concern to her medical oncologist at her first follow up appointment. She was referred to the radiation oncology area. At that appointment they were unsure how to help her, so they referred her to her gynecologist. She was referred to her gynecologist, who then referred her to the vulvar disease clinic and prescribed her dilators and estrogen cream. Because of the delay with referrals, Erin lost almost four months in getting treatment for her sexual health concerns.

To Erin’s dismay, nothing was working to alleviate her pain during intercourse. “I got to the point where I had to try to not show the pain. And it was the most impossible thing I’ve ever tried to do.”

Over the course of eight years, Erin underwent a painstaking process of searching and failing to find any relief from the sexual dysfunction that began to chip away at her marriage. “We didn’t have counseling. We didn’t talk about it. I continued to work on finding new treatments.”

Erin worked relentlessly to find a solution to her problem, unwilling to accept defeat. But the stress and lack of answers took a toll on her relationship with her spouse. “We gradually grew apart.”

The final blow came during Erin’s last appointment with the Menopause and Sexual Health Clinic, when she learned that her sexual dysfunction was not only irreversible – but that it could have been prevented. “It had been determined, finally, that the scar tissue was around the hymenal ring at the opening of the vagina. I was never going to get that resolved because it had built up too thick in the months after treatment when I wasn’t being treated. I should have been given dilators to open the vagina and estrogen cream to keep the tissue healthy, and I didn’t know.”

Erin believes that had her care team set expectations about what sexual health issues her cancer treatment could cause, she would have been able to advocate for herself and get the treatment she needed, in time, to not have her issues become permanent. “At that last appointment my doctor said, ‘I’m sorry, but you waited too long to get treated.’

“And I said, ‘Just for the record, I didn’t wait. You did.’”

**Erin’s Advice for Providers**

Reflecting on her experience, Erin Wagner Sullivan states, “When it comes to sexual health and cancer care, I think the healthcare system fails patients all the time, which is why I started [After Cancer](https://www.aftercancer.co). They just don’t know how to talk to patients about these topics. They don’t give it the importance it should have when it comes to someone’s quality of life.”

Erin remains adamant that the responsibility of initiating conversations about sexual health should lie on the members of the patient’s care team. “I think it’s unfair that we don’t explain more to patients about something that they don’t have a voice to ask about. It feels cruel to me.”

Once Erin began coaching patients with cancer, she began to realize just how prevalent sexual dysfunction was. Many of her clients, like herself, did not receive the resources or referrals they needed from their care teams. “We were struggling for so long. Why was I not referred to couples counseling or sex therapy?”

“Every single care team member that addresses side effects with their patients (nurses, advanced practice providers, social workers, radiation therapists, pelvic floor therapists, or anybody that might be in a position to talk to patients about side effects) should be talking about sexual health.” Erin teaches providers that actions as simple as giving their patients a 30-second message about the relationship between sexual health and cancer, along with a brochure on sexual health, can impact how patients preserve their sexual health and quality of life.

**Erin’s Advice for Patients**

In her work of advocating for patients with cancer, Erin Wagner Sullivan advises patients to “speak as plainly as possible” and to ask straightforward questions like “Will I ever be able to have penetrative sex again? What can I do now that maybe would lessen the severity of symptoms I might have? Is there anything I should read? Is there anyone I can talk to?”

Erin emphasizes the importance of knowing that “all questions are appropriate to ask. If sexual dysfunction is listed anywhere in the literature you are given, that is something you need to know more about.”

Erin wants patients to know that sexual health is a vital part of their quality of life, and they should not be ashamed to advocate for themselves. “I think patients feel greedy when they survive the cancer, have sexual health issues, and have no guidance on how to find resolution. As patients we bargain with God and the universe to spare our lives, and any request beyond that feels greedy.”

**Alique’s Story**

Alique Topalian, PhD, MPH, is a Research Scientist working in Survivorship and Supportive Services. Alique was diagnosed with Acute Myeloid Leukemia (AML) in 1998, when she was four years old. She recovered, only to become the first person known to relapse after 22 years.

In her late 20’s, Alique started to notice symptoms of sexual dysfunction including lack of libido, abnormal uterine bleeding, and pain during sex, so she went to see her gynecologist. Her gynecologist ordered a series of diagnostic tests, and she was diagnosed with cancer the next day.

Alique describes her care team as “receptive and helpful” during the process of fertility preservation. However, her other sexual health concerns were not met with the same attentiveness. “The reproductive endocrinologist was the one who put in a referral for a sex therapist and had a real conversation with me about things, and I felt like for the first time in so many years somebody was finally taking me seriously. Before that, I got pelvic floor physical therapy, but I had to fight for that for two years before I even got that referral.”

Like Erin, Alique also experienced the negative impact of sexual dysfunction on her relationship. Frustrated that her care team was not taking her concerns seriously, she was forced to resort to crying and begging for help. In tears, she explained to her provider, “I’ve been in a long-term relationship, and I think this is the person I’m going to marry, and I’m scared this is going to ruin it. I’ve been coming here for years telling you that something happened to my libido. Can somebody please help me?”

**Alique’s Advice for Providers**

Dr. Alique Topalian emphasizes the importance of making appropriate and timely referrals for patients dealing with sexual dysfunction. She states that after bringing up her sexual health concerns to her doctor, “it took four years to even get a referral to a sex therapist.”

Alique notes that she had to endure multiple changes in providers over several years before being recommended alternative solutions such as changing birth control methods to treat her symptoms.

She urges providers to listen to their patients’ concerns. “Don’t minimize symptoms when people are coming and saying this is a serious problem multiple times. Don’t make it get to the point where your patient has to break down in your office before you try to help them.”

Alique also wishes that care team members put more emphasis on helping patients with their relationships that may be impacted by sexual dysfunction. “Cancer already puts enough of a strain on your relationship by changing your roles, from partners to caregiver and patient in a way. Having sexual health issues on top of that changing of roles can be really difficult to face.”

**Alique’s Advice For Patients**

Dr. Alique Topalian encourages patients to engage in candid conversations with members of their care team, while acknowledging the hesitation that may arise. “It’s not a conversation you want to have. It’s awkward! I hate having this conversation.”

When discussing a topic as taboo as sexual health, Alique advises patients to rip the band-aid off: “I know you don’t want to talk about it with your doctor, but I would just take a deep breath and then just spit it out.” She implores patients to let their care team know when symptoms are affecting their quality of life.

Alique strongly recommends that people experiencing sexual dysfunction reach out to their cancer community. After attending the [Escape to Thrive](https://escape4advocates.org/) conference, Alique realized that she was not alone in her struggle. “It was the first time that I’ve ever talked about my sexual health issues with anyone besides one of my doctors. And almost everybody in the room had experienced the same things… It empowered me to start talking about this issue.”

“Talking to other patients and having that community gave me hope for the first time in years, and I felt like there may have been hope for me for a change instead of just going to these doctors who made it seem like it was just never that big of a deal.”

Alique works closely with the adolescent and young adult cancer community. In addition to local support groups, she recommends adolescent patients look into [Elephants and Tea](https://elephantsandtea.com/), [Stupid Cancer](https://stupidcancer.org/), [GRYT Health](https://grythealth.com/), and [Cactus Cancer](https://cactuscancer.org/). “Those are some of my favorites that are tailored to the adolescent and young adult community.”

**Don’t Go It Alone**

Are you a patient, a partner, or a provider looking for more resources on how to have honest conversations about sexual health? Check out the [After Cancer](https://www.aftercancer.co) website for a variety of tools and workshops addressing sexual health and cancer.

Your experience is unique, but you are not the only one struggling with sexual health concerns and cancer. There are people who are ready to listen to your concerns and help you find solutions. Don’t go it alone.