

## Under Toad Days: Surviving the Uncertainty of Cancer Recurrence

**A**fter my very last radiation treatment for breast cancer, I lay on a cold steel table hairless, half-dressed, and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead, I was sobbing. At the time, I wasn't sure what emotions I was feeling. Looking back, I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy, and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned, and terrified. This was the rocky beginning of cancer survivorship for me.

Now that my cancer treatment is done and my disease is no longer visible to my physicians and their diagnostic tests, I have begun to deal with the weight of its uncertain return. For me, this uncertainty is evil and murky like the "Under Toad" in John Irving's novel *The World According to Garp*. In the beginning of the novel, the protagonist watches his young son playing near the water and yells warnings to him of the strong undertow. The boy mistakenly hears "Under Toad" and spends the remainder of his time looking for the toad monster lurking underwater, just out of sight. Irving continues to rely on the Under Toad as a symbol of evil throughout the book. After my own experience, I can no longer think of the Under Toad as just a compelling image in a book. Instead, the image has become a bit too real, for what is the uncertainty of recurrence if not an Under Toad?

I have now finished surgery, chemotherapy, radiation, and reconstruction; I'm done, according to the medical profession. But I don't really *feel* done. I think we survivors are never truly done. We just move from the quantifiable, treatable disease to the immeasurable uncertainty of survivorship. Believe me, the former is easier to deal with sometimes. Being in the midst of active treatment means being seen regularly by a nurse or a physician—being *cared* for. As I got up off that radiation table for the last time and walked away, I found myself alone with a cancer ghost who would not let me forget where I had been or allow me to freely choose where I might be going. Call it what you will, it is the Under Toad to me.

Now I have what I call Under Toad days. On these days, I am suddenly overwhelmed with fear and sadness,

and I find myself frozen to my keyboard until these feelings wash over me and I can surface again. Will I see my 5-year-old go to kindergarten? Will I see my son get married? Will the kids remember me? Will they find ways to cope with my death? Will my husband be okay? Will I have terrible pain? I have to fight my way back into control, and I often find myself sweaty, exhausted, and hours behind on my work. These Under Toad days have become less frequent as I live further into survivorship, but they don't go away. Instead, I brood a lot now. Before cancer, I was not terribly introspective, but cancer seems to have left me with an empty space that allows my thoughts ample room to sit and stew awhile.

But my life is not all Under Toad days. I have moments of surprising clarity, too. Ever since my chemotherapy ended, I have awakened each morning with a flash of happiness. I'm alive! I'm so lucky! Well, with all the chaos in the mornings at our house, this moment of joy wears off rapidly, but I still appreciate its lovely tingle. Before I found that lump in my breast, my life seemed relatively calm. I did not recognize that I was just barely in control. My husband and I had two kids in full-time day care and new, busy clinical practices, and we were running flat-out all the time. With my diagnosis, all semblance of stability vanished, and our lives fell apart. Three years later, I have my hair and my bearings back, and I can see how thinly veiled our stability was and how askew my priorities were. While many people will look back over their lives and wish they had changed some of their priorities, I have had the unusual opportunity to reassess my priorities at age 37 and to act on them. I've dropped a day of work to spend time in the kids' schools. I spend more time touching and playing with my kids (and I listen to them breathe at night). I've found an ice-hockey team that keeps me skating and laughing until late at night, and I have gained a deep trust in and respect for this body that has endured so much and been so resilient. Best of all, I have an incredibly supportive husband, who loves me no matter what this disease has done to my body and soul. But no matter how I try, I cannot outrun this Under Toad.

We cancer survivors are millions strong, and our ranks will continue to grow as improved cancer treatments extend lives. But because the struggle with uncertainty after treatment is completed is usually a silent battle waged out-

side of the physician's office, most physicians don't think or talk about it. In my life as a primary care physician before cancer, I certainly did not. Now I believe that we physicians need to talk to our cancer survivors about the unique struggles of survivorship. Oncologists need to focus on preparing breast cancer patients for survivorship. That is, they must address the loss experienced by survivors when active treatment is over and they are sent away from a very intense environment. They must help survivors understand the impact of fear and uncertainty on their lives and what might help reduce these stressors.

The primary care physician will be seeing an increasing number of survivors and must focus on how their survivors are faring, both emotionally and physically. Are their patients struggling with uncertainty? Do they have a support group to talk about such issues in a safe environment? Do they have late medical complications of past treatments? Are they depressed? What is the quality of their lives? These are questions that need careful thought and research.

With the creation of the Office of Cancer Survivorship (OCS) at the National Cancer Institute, we have been given a strong signal that the health and well-being of cancer survivors is an important issue and one that deserves research funding. While still a fledgling organization, the OCS has supported much research already. The present focus of the OCS is on the long-term survivor, a relatively new entity. Research funded through the OCS may help us clarify exactly what physicians should be asking about when we see the long-term survivor in our clinics, and how we will measure the quality of their lives and the late effects of their treatments.

Uncertainty is a slippery foe, but it is one worth rec-

ognizing in our patients. To start with, simply talking to survivors about their fears and the changes cancer has brought to their lives will let them know that their physicians are aware of the millions of silent struggles going on everyday. I think all of us survivors have our good days and our Under Toad days. I look forward to learning to minimize the bad days and to build on the good days. Some of the tools that have helped me to minimize the bad days and build on the good ones have also helped many cancer patients before me. Probably the most important tool for me has been a support group of extraordinary women with whom I can share all my fears and successes. I also saw a psychologist during my treatment, who made me realize that this experience is traumatic for everyone and that I was not abnormal for finding the whole experience so trying and for feeling so vulnerable. And finally, writing about what I was feeling throughout my cancer process has allowed me the freedom to express myself and a safe place to kick and scream and call it all unfair. I feel lucky to be a breast cancer researcher as well as a survivor, and I look forward to exploring how uncertainty affects survivors' quality of life and perhaps finding ways of minimizing Under Toad days for others. In the meantime, I'll keep away from the water.

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