A Caregiver's Perspective: Honoring Your Hopes and Fears

Know you are not alone. Many others have had your experience, including me.

May 7, 2018 By Gina Paglucia

As humans, we seek validation. To have a shared experience, to know that someone else has been there, who has felt what we felt and thought what we thought. Sometimes, it is hard to find the validation we seek — or we can't bring ourselves to seek the validation in the first place.

I was a caregiver for my husband who succumbed to cancer in 2012 at the age of 51, nine months after his diagnosis. Initially, I didn't seek validation or support. I was focused on keeping my family going and relying on my own inner strength. I only sought validation much later, in the months and years after my husband died, when I had the space and energy to open up to others.

It was good, and confirming, and comforting. I wished I had been able to do this sooner.

In December 2011, after a month of tests, scans, and biopsies, my husband was diagnosed with stage IV cholangiocarcinoma, also known as bile duct cancer. My husband, the scientist, took the news stoically and methodically went about telling friends, family, and his colleagues of his illness and the proposed treatment, assuring them of his hopefulness. He continued to work while receiving two aggressive lines of chemotherapy and a series of radiation treatments, and he stayed hopeful even when he no longer qualified for clinical trials.

While I had a much different reaction, there are no right or wrong reactions. Every caregiver will have a unique reaction to a cancer diagnosis, as well as a different experience during or after the cancer treatment.

First, I was in denial (hoping this was a mistaken diagnosis), then I lived in fear, and then I tried to avoid others. I learned from research that the disease was deadly and little good news was available. In the initial weeks after the diagnosis, I told myself that sharing the news meant it might be real, and I didn't want it to be real.

As the weeks went by, I found myself vacillating daily between fear, doubt, and hope. I wasn't sure how to handle these conflicting emotions; I worried about being too negative, and I felt guilty at times for not always being the cheerleader — the strong, hopeful one.

Many days, I lived in sheer, pure panic. “What if he doesn’t respond to the treatments and what if the metastasized sites increase?” I thought. Other days, I focused on the positives — my husband was getting the best treatment at Dana-Farber, he had a large support network, and he had always been healthy.

I found it really hard to share this mix of feelings. A few friends understood and listened, hearing and validating both my fears and hopes. But others only wanted to share my husband’s hope and allowed no room for my fears. As time went on, I steered clear of these folks.

I share this story now because you may be a caregiver experiencing these polar thoughts and feelings, and you aren’t sure how or what to think about them. Or you feel as though you are supposed to always be supportive and positive. Or perhaps you don’t have a place or someone to validate your positive and negative experiences.

Know you are not alone. Many others have had your experience, including me. Seeking validation and honoring all your feelings and thoughts — both negative and positive — is a good thing to do. Giving these thoughts and feelings a space to co-exist and sharing your fears and concerns may actually make you feel less anxious.

If you find it helpful, share these thoughts with others — either those who have gone through a similar experience, or friends and family who will openly listen. Search out other blogs, articles, or podcasts, or learn more about the supportive resources at your hospital or cancer center.

Being a caregiver can be challenging in so many ways — physically, emotionally, psychologically. If you can give yourself the space and time to find that common bond, your own crisis may be that much easier to bear.

Gina Paglucia is a former caregiver and current co-chair of Dana-Farber’s Adult Patient and Family Advisory Council.

This article was originally published on April 11, 2018, by Dana-Farber Cancer Institute. It is republished with permission.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.cancerhealth.com/article/caregivers-perspective-honoring-hopes-fears