

Survivorship Story: Brian Hill

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Topics Discussed

Body Image

Your body image is what you believe about your own appearance, even though other people might see you differently.

Finding Meaning

Some survivors think that finding meaning is one way to better understand their cancer experience. When you try to find meaning in your cancer experience, it means you are trying to understand the greater purpose or reason behind your illness.

Healthy Behaviors

Many people benefit from living a healthy lifestyle, especially cancer survivors. Good nutrition, exercise and other healthy behaviors may help your body heal from the physical harm cancer and its treatment may have caused.

Lymphedema

Lymphedema is a condition that affects your lymphatic system, which is made up of tissues and organs in your body. Lymphedema is swelling of arms, legs or trunk that occurs from the build-up of lymph fluid.

Physical Rehabilitation

Physical rehabilitation is the process of physically recovering from your cancer and adjusting to any physical changes you may experience.

Sadness and Depression

There is often confusion about the difference between sadness, "mild depressed mood" (sometimes called mild depression) and the medical condition known as "clinical depression."

Brian is an oral cancer survivor.

I became a cancer survivor in 1997 when I was diagnosed with a squamous cell carcinoma, which began on my right tonsil, and by the time they found it, had bilaterally metastasized to both sides of my neck and my lymph nodes.

Oral cancers are extremely survivable if they're caught early. If you're caught as a stage 1 or 2, you have an 80 or 90 percent chance of surviving and going on with the rest of your life. Unfortunately, that doesn't happen often enough. In the early stages of oral cancer you may not know that you have it. It can be very asymptomatic. You can have a little white spot or red spot in your mouth and not think much about it because it doesn't bleed or doesn't have pain associated with it.

All cancer treatments are difficult. I mean, those of us that have been through them refer to them as the slash, burn, and poison technologies, because you either go through surgery or chemotherapy or radiation, all of which, are fairly devastating. I mean, radiation treatments, while you're there, don't seem to be very much, but the radiation sickness that develops and goes on for months and months after the end of treatment is quite debilitating. I'm just now starting to have loss of function in parts of my face and in parts of my right shoulder as a result of nerve damage from the radiation.

Brian Hill (continued)

There are long-term effects of radiation. That's a cumulative during your lifetime. About my third year out when I really felt that I was almost normal—as normal as cancer survivors feel, I developed the inability to control the corner of my mouth and I thought, "Wow, that's really strange. What's happening here?" At first I was thinking I had a little stroke or something because the side of my face started drooping a little bit. Then I started having what they call fasciculations—my trapezoid just started going into contractions, I mean violently. My wife said on Star Trek there's a species of aliens called the Cardassians, and they have these necks that look like lizards that kind of taper out with great big muscles, and my neck would just jump out, like a whole inch, and I had absolutely no control over it at all. When I went back to my doctors to ask about it, they said that about three to five percent of the people get nerve damage as a result of the radiation itself, and it takes a while to manifest itself. It may get worse; but it won't get any better.

As a by-product of having a radical neck vasection, all the lymph nodes on the right side of my neck, plus the fatty tissues that were here were removed. And, of course, this is a part of one of your body's systems that is there to filter out things and it has a whole—I mean it's connected throughout your whole body—to your upper chest, to your armpits, to your groin, and it's a very sophisticated system. When you just take a chunk of it out at one time, all the fluids that are associated with that system that normally would come to that area still come, and as a result of that you develop edema in that area, a collection of fluids, in the area where those tissues were.

It's one of those body processes that just takes time for your body to work its way through. It does find new pathways and it does find ways around it, but during the period of time when you have it, it's quite disconcerting to have, you know, a huge bulge in your body, for me, which was kind of funny looking, because I had a huge deficit on the other side. But it did pass and if it doesn't drain properly the doctors will intervene, because drainage of these fluids is essential for this area to heal properly.

So here's the thing that saved your life causes a whole new thing down the road, which gets into this thing about survivorship, you're always waiting for the other shoe to drop. Some things they can predict, because they know the effects of the treatment, and they know that there will be some long-term effects that will increase as time goes by. Other parts of it, you just hope that the thing itself doesn't come back. But, you know, look at me. I'm one of the lucky ones.

Related Stories



Ann Fonfa is a breast cancer survivor.

Ann talks about how she dealt with physical changes in her body after cancer, how cancer affected her sexuality, and how her husband's support has helped her during her survivorship.

Ann Fonfa's story is available online at: www.LiveStrong.org > Survivorship Stories > Ann Fonfa



Neil Moore is a melanoma survivor.

Neil talks about how his treatment for cancer caused side effects, like lymphedema and neuropathy, later in life. He also discusses how he handles living with uncertainty.

Neil Moore's story is available online at: www.LiveStrong.org > Survivorship Stories > Neil Moore

Brian Hill (continued)

I don't think that people should be embarrassed by any question that they have, because as you go through this process you really have to be your own advocate, and you have to know as much as possible. You know, chance does favor the prepared mind, and the more you know about it the more you will be able to understand what's going to happen to you. I don't think anybody should leave the doctor's office after an examination or after an interview with the doctor with questions still on their mind.

I found that by having my wife go to my meetings with my doctors with me, it was important because she heard things that I didn't hear. They're going on and on, and I'm missing part of that, and she's up there scribbling notes. So that when we got home, we actually were able to revisit everything that was said, what was discussed, and then go back with intelligent questions the next time around.

When I came out of treatment, I was significantly depressed, enough where it's not just being sad. Clinical depression requires sometimes medical intervention to help you through it. I went on some anti-depressants to help me get through some of the thoughts that I had that were interfering with my emotional healing. In my parents' generation, the idea of going and seeing a psychiatrist, was something that was kind of verboten. You didn't do that. That was admitting that you were unable to cope or unable to function in your daily life. I found it to be one of the most satisfying and rewarding things that I've ever done. I learned so much about myself by talking to someone that understood what I was going through. But I also found that I did need medication to get through it. It was important for me to talk to some person who was remote from my immediate family and remote from my doctors, to help me work through these issues. And I don't think that without that professional assistance that I would have had as rapid a return to a normal perspective on life as I had.

I'm completely different now than I was before. That's so hard to describe to people, because my life up until cancer was pretty much about me. You know, I wanted to get ahead in business, I wanted to make money, I wanted to do things Brian wanted to do. Once I was given another chance to do something else, my whole priorities changed. I wasn't worried about how I would be when I

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Brian Hill (continued)

got through it, I just wanted to get through it and get on with this new opportunity that I had.

I don't think that any day goes by when I can clearly say I haven't thought about cancer today. I mean, I have great days. Don't get me wrong; I'm loving my life now, but it's still there. I mean, in Vietnam you could wear your helmet and your flap jacket and stay close to the ground, everything that you did, and you could still be the one that the golden bullet found. And cancer is the same thing. It can happen to you at the drop of a hat.

I think that you are emotionally changed by any of these kinds of experiences as a human being and in your daily life. Talking about emotions is a difficult thing for guys. It's really hard to express your emotions and still be the stoic guy that everybody wants you to be. But it does change you emotionally, and it makes you vulnerable. It's different in the fact that we're used to internalizing those things, because we're the tough guys. We're the strong ones. But it can really take the wind out of your sails, and once that happens, a variety of insecurities crop up because guys deal with emotions differently. And that may be chauvinistic to say that guys deal with this differently than women, but to a certain extent I believe that we are so conditioned as men to just tough it out, just suck it up and get through it, that when you have signs of weakness and all that, it creates another thing inside you of saying, "Am I now less of a guy than I was before?" which really isn't the case. I'm stronger than I ever was. But it doesn't mean that the little insecurities and little voices aren't there.

Survivorship means having a second chance. The more you realize how lucky you are, I think that you develop a passion for not wasting your time. I spent most of my life wasting my time doing frivolous things, from chasing women to driving fast cars, doing all the things that in life that are essentially unimportant. This snaps you right back into reality, and you start making value judgments of how do you want to spend your day. What am I going to do today that is going to be the optimum thing I can do today? How am I going to spend my time? What am I going to think about? I looked inside myself and found that I really didn't like myself that much before now that I had this new chance.

I'm Brian Hill, and I'm a five-year oral cancer survivor.