We've Almost Cured Childhood Cancer — Now What?

by Sheri Sobrato Brisson  |  Updated 26 Sep 2017 at 2:19 PM

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It’s heartbreaking that the average age of children diagnosed with cancer is just six years old. But fortunately, due to breakthroughs in medical research and treatment, today nearly 90 percent of these children will survive.

However, the devastating fact is that 60 percent of these young survivors will go on to suffer “late effects” from their earlier treatments even decades later, such as infertility, heart failure, or secondary cancers. Added to these physical challenges of surviving cancer are significant but equally important emotional issues that arise from living through the trauma of a cancer experience.

I should know. I’ve been there. As a 30-year brain cancer survivor, I know that we must do a better job helping survivors and their families live with and beyond their cancer. Let’s admit it — cancer changes us. After cancer, I struggled to “get back to normal.” Yet having cancer, especially at a young age, is far from normal.

My cancer made me different from everyone I knew; there was no way I could go back to my life as if nothing had happened. I feared that if I truly embraced life once more, would it all be
taken away again? At the time, I didn’t even know that this is what I thought, let alone did I allow myself to express this fear. Instead I was stuck. My life was on hold.

My cancer interrupted my life as I knew it. It took away my carefree young adult years and gave me a level of maturity I did not want. It seemed I couldn’t relate to anyone anymore, and only in allowing myself to really acknowledge that did the tears come. I needed to feel the sadness for everything I had lost — my innocence, my youth, my fertility — before I could move on.

Perhaps I had never let myself feel this pain because I was one of the lucky ones. I had survived something that no one on record had survived. I felt I had no right to feel sad — but in fact, I did. I had been through way too much for my age.

I didn’t have roles models for what it meant to be a survivor. Instead, I made it up as I went. I learned that being a survivor means much more than living beyond one’s prognosis. It means confronting healing at an emotional level too. While I recognize we have a long way to go before every young person survives cancer, it is truly amazing that we’ve come as far as we have. But, in my opinion, there’s an even farther way to go to help children and teens live with being a cancer survivor.

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Here are a couple of things I’ve learned that I hope we can use to help young people not just to survive, but to thrive:

**Encourage them express their full range of emotions.** There is no such thing as “negative emotions.” Support young
patients to feel what they are feeling at the time, or whenever that emotion is triggered. It may be quite uncomfortable to sit with difficult emotions, yet it allows the opportunity to both process these feelings and helps the child feel heard and understood. Sometimes discovering one’s true strength comes only from the opportunity to confront the pain head on.

**Acknowledge that cancer will always be part of their identity.** One’s cancer may no longer be up front and center, but cancer does change us — perhaps for the better. Cancer becomes an integral part of us — so it’s important to acknowledge that cancer can become an asset, not a liability.

Who will those young people you love or work with become years after treatment?

**Let them tell their story.** The meaning we give to the challenges we face in life — how we tell our personal story — is part of what helps us heal. By acknowledging our story and sharing it with others, we incorporate our trauma into who we are, little by little. Journaling, creative writing, and expressive art are all tools that help young survivors define and embrace the meaning of their experience. Help these young survivors "own" and be proud of their personal stories.

**Help them build resilience.** They can take an active role in learning to support their own emotional health. Encourage them to connect to others in an authentic and empathetic way. Help them discover their strengths born out of challenge by working with them to identify and label them. Finally, support them in keeping perspective and accepting the changes, both in themselves and their life situation, one step at a time.

I’m not the person I was before cancer. But I hope in some
ways I’ve used my survivorship to become more than I was before. Who will those young people you love or work with become years after treatment? By supporting their experience as survivors as much as we supported their experience as patients, we can help young people learn to thrive during potentially decades of life after their treatment is over.

**Sheri Brisson has dedicated her life to working directly with children and teens with health challenges. She is releasing the first-ever mobile game to build resilience in teens facing health challenge, **Shadow’s Edge**, available for free from Oct. 21st on Apple and Google.**

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