

Limbo - What Cancer Patients Do After Treatment?

This sounds like fun doesn't it? Standing on a golden beach, the sun beating down, crowds cheering, as you waddle your way under a flexing pole. I bet you're thinking that's the celebration of finishing cancer treatment. Unfortunately, you'd be wrong. Limbo is not so much what you do, as where you go.

For months you've been coddled and cooed over by doctors and nurses, attentively listening to your every ache and pain, on standby 24 hours a day in case of that dreaded 101.5-deg F fever. They've prodded you, pricked you, sent you for blood tests and CAT scans, shot you with radiation beams, or dripped in some mysterious fluid that goes around your body like a Pac Man seeking out and destroying cancer cells.

Then, if you're lucky, comes: "You don't need anymore treatment. You're in remission!" Yes! I made it. I want to jump for joy. I want to climb every mountain and sing "Edelweiss." I want to gyrate my body under a pole on a sunset beach! But I can't. Why? Because what I actually feel is a total anti-climax. I should feel really happy, but I don't. WHAT'S WRONG WITH ME!!!

You are, my fellow cancer thriver, in LIMBO. You finally realize it when the next thing the doctor says is: "Come back and see me in 3 months time." What! But I've practically been seeing you every week for the last 6 months. Don't you love me anymore? Am I not your favorite patient anymore? What happened? Fact is he or she doesn't need to see you anymore. Your cancer has gone. But what do I do? No chemo goals to reach. No tumor blood markers to pore over. No nurse to call when I feel terrible. Help!

I've been through it twice, and both times I've likened it to being pushed out to sea on a boat, all alone. No crew, no fellow passengers, just you, the wind and the horizon. And I can tell you it's very, very scary. Thoughts start to twirl in your head. Why don't I feel "normal"? Will I ever feel "normal" again? What does the future hold? Will my cancer come back? Oh no, I'm already starting to worry about those 3 month check ups! It's a grieving process: loneliness, disbelief, anger over loss, depression. Then, hopefully, you find some kind of balance, a new "normal." How long does it take? Maybe a couple of months, maybe a year, maybe longer. But most of us, at some point, find our new normal in limbo.

As local writer Glenna Halverson-Boyd says in her wonderful book "Dancing in Limbo", "Surviving cancer is like learning a new dance, we struggle at first but ultimately we master the steps and more importantly it can be fun". We look normal, we sound normal but underneath we're not. And that's what everyone who hasn't had cancer needs to know. Limbo is very painful, especially when those around you have no idea what you're going through. But persevere. Ask for professional help, talk to other cancer survivors. You are not alone. Life will go on, you WILL dance in limbo. It won't be the life you had pre-cancer but you sure as heck can enjoy it!

Kay Kerbyson is Secretary of the Los Alamos Council on Cancer. Help for cancer patients in Los Alamos can be found at www.losalamoscounciloncancer.org.