

## CONTENTS

# Back to 'Normal'

BY CHARLOTTE HUFF

*Strategies help patients adjust to life after treatment.*

For months after her diagnosis of non-Hodgkin's lymphoma, Jen Singer operated on full-throttle fight mode. The 40-year-old mother of two had been diagnosed with a 15-centimeter stage 3 mass in her left lung; the malignancy wrapped around her heart. Singer endured several weeks of aggressive chemotherapy in the hospital, followed by four rounds of outpatient chemotherapy and, soon after, five weeks of radiation, totaling 25 rounds.

To outsiders, it seemed like Singer handled it all. She negotiated an extension on her looming book deadline, writing the final chapters—in bits and pieces—from her hospital bed. She refused to halt her New Jersey home's extensive renovation, which included a kitchen demolition, an addition, and a new roof, among other construction headaches. She strived to retain a sense of normalcy for her sons, ages 10 and 8.

Amid it all, the humor writer approached her diagnosis with, not surprisingly, a steady patter of jokes. She joked about her "G.I. Jane" hairdo after ditching her head scarf. She pointed out the wisdom of gutting her kitchen, given that everyone was delivering meals to her doorstep anyway. She wisecracked that the mass, when she first spotted it on a PET scan, looked like "I'd inhaled Connecticut."

It wasn't until December 2007, weeks after treatment ended and six months after her June diagnosis, that Singer realized it was OK to wallow a bit—to be angry or morose or edgy about the future. In subsequent weeks, she cycled through the various stages of grief, even after the cancer went into remission. "I still have a one in four chance of it returning this year; it's still touch and go," Singer says. "And it's OK to be upset about that."

During those months of fighting cancer, that final day of treatment can beckon as an enticing respite, a punctuation mark and, above all, a stair step back toward one's pre-cancer life. Increasingly, though, clinicians are realizing that the reality can be far more complex logistically and emotionally, a transition—dubbed the re-entry phase—that can require months or years to navigate.

That final walk out of the doctor's office or clinic, with just checkups slated for one's future, can be both thrilling and terrifying, says Susan Leigh, RN, a Tucson-based cancer survivorship consultant and cancer survivor herself. "It's one of the scariest times for most survivors, and no one prepares you for that," she says. "I think we have to do a lot more work helping people [prepare] for life

after treatment.”



Jen Singer continues to fine-tune her life after treatment for lymphoma. Photo by Ryan Ashby

## Navigating Re-Entry

Re-entry stress can figure in a number of ways, says Julia Rowland, PhD, director of the Office of Cancer Survivorship at the National Cancer Institute. Newly minted survivors worry about cancer’s recurrence, and at the same time they’re often coping with the evaporation of their safety net—from those weekly phone calls and casseroles to the encouraging smiles of clinicians in the chemotherapy room. And, it can take months to physically feel like oneself again, or a reasonable facsimile, Rowland says.

At the same time, family roles and emotions, including those of the patient, may shift. Everyone, Rowland says, has to adjust to the “new normal.”

Issues involving re-entry tend to be most acute during the first six months after treatment, but can extend considerably longer, Rowland says. As a rule of thumb, the longer the cancer experience—from the first suspicious symptom to the final treatment appointment—the longer the time needed to recover from the physical and emotional ripple effects, she says.

Plus, the post-treatment picture can vary substantially depending upon the type of cancer and its long-term prognosis, clinicians point out. Someone recovering from initial breast cancer treatment may still require ongoing hormonal treatment or follow-up surgery, such as reconstruction. Other survivors may enter a gray zone for other reasons, such as when it’s more uncertain whether the malignancy has been eradicated.

Even those former patients with substantial reason for optimism may wrestle with frustrating logistics and limitations, particularly in the initial post-treatment months, says Priscilla Furth, MD, who works with cancer survivors at Georgetown University’s Lombardi Comprehensive Cancer Center. Family members and spouses may long to flip a switch to their pre-cancer existence, Furth says. They may have grown weary of stomaching the food dropped off by friends.

“They want the food you cook,” she says. “There can be a push within the family to restore the normal family structure—to get the strangers out of the house.”

In other situations, patterns and habits may become difficult to break, she says. The father, for example, may have grown accustomed to taking the lead where discipline is concerned while the mother is undergoing treatment.

Meanwhile, former patients may only have just begun sorting through their own emotions surrounding their cancer experience. They second-guess their aches and pains. They can exist in perpetual limbo, waiting for that next scan or blood test. D.J. Pappas, a licensed professional counselor at Duke University, says her patients frequently comment that they are struggling more now that they’ve completed cancer treatment.

Singer seconds that sentiment. “I was in fight mode,” she says. “Now I’m in I-hope-it-doesn’t-come-back mode. I’m a doer. It’s easier for me to fight than it is for me to hold my breath.”

☒ It's one of the scariest times for most survivors, and no one prepares you for that. I think we have to do a lot more work helping people [prepare] for life after treatment. ☒

—Susan Leigh, RN

## Completing the Transition

One of the biggest mistakes someone can make during the re-entry phase is to isolate oneself, says Debra Thaler-DeMers, RN, an oncology nurse at the Stanford Cancer Center in California. Share the experience and your ongoing frustrations, whether that’s to a support group, a counselor, or a trusted loved one, she says.

“The more you are alone, the more you are going to think about every ache and pain,” says Thaler-DeMers, who has fought several bouts with cancer, including Hodgkin’s disease, skin cancer, and, most recently, breast cancer.

Thaler-DeMers says don’t be shy about asking loved ones for continued assistance, both with daily logistics and emotionally. If a loved one responds oddly, gently call them on it. Use “I feel” statements, she suggests, such as: “I feel you are uncomfortable when I talk to you about cancer.”

Thaler-DeMers, who was diagnosed with Hodgkin’s disease nearly 30 years ago, says today’s survivors can benefit from numerous support groups, exercise classes, and other forums—in person and virtually—that didn’t exist decades ago. In recent years, the oncology community also has moved more aggressively to address the post-treatment gap. In the wake of the 2005 Institute of Medicine report on cancer survivorship, treatment summaries and survivorship plans are being offered more frequently to assist patients with that transition.

Beyond coping with emotional stresses, recently treated survivors also will need to rebuild themselves physically, getting better sleep, focusing on good nutrition, and regaining physical strength, Furth says. It’s a lot to juggle, along with the expectations of loved ones. Take time to transition back to previous life, she says. Warn loved ones that recovery can be erratic, with good days and bad.

“That’s very hard for friends and family to understand,” she says. “They will see you behaving normally and then they will see you exhausted again.”

Neither should survivors feel pressured to succumb to the tyranny of positive thinking, Thaler-DeMers says. To some extent, Lance Armstrong’s picture-perfect ending proved to be a disservice to cancer survivors, she says. “If they don’t feel like they can win the Tour de France after their treatment, they don’t want to share that with other people.”

Sometimes, that transition to a “new normal” can allow survivors to re-examine their life choices. Marsha Bell, who wrapped up radiation for her ductal carcinoma in situ breast cancer in February, rebooted her self-described Type A workaholic tendencies. During her radiation treatments, she took a leave of absence. Then, on the advice of Duke counselor Pappas, she worked part-time for the first several weeks after returning to her senior-level human resources job.

Now back at work full-time, Bell is determined not to clock late hours more than one night a week. The 54-year-old also has beefed up her exercise regimen and has teamed up with her husband to shed some extra pounds. “What I’ve learned is I need to slow down and start really focusing on my own health and taking better care of myself,” says Bell, who is embracing a renewed physical and emotional resiliency. “Once you go through this (cancer), you are either going to cave into it or feel stronger.”

Singer, who also sees a counselor, typically follows up her sessions with a vigorous workout. But she also recognizes that she doesn’t have to rewind the clock completely. Her husband continues to make the boys’ lunches and lay out their clothes on school nights. “Why do I have to do all of that when he seems perfectly capable?” she quips. “Why take it all back?”