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Surviving "Survivor" Stereotypes

BY CURTIS PESMEN

Patients face how cancer will define them once treatment ends.

At first glance, the lean, sweaty guy doing barbell curls in the far corner of the gym under the watchful eye of his trainer doesn't look like someone who spent 45 days in a surgery-induced coma. Then again, eight-year stage 4 colon cancer survivor Jon Henderson, 48, of Boulder, Colorado, delights in pumping up and knocking down stereotypes about what middle-aged survivors are supposed to look like and how they're supposed to feel.

At second glance, up close, face-to-face with Henderson in the gym, you can't help but notice the portable oxygen tank at his side, with nostril tubes clipped into place. That's not from the cancer—well, not exactly. It's from surgery on metastatic tumors in his lungs that led them to shut down, a condition known as adult respiratory distress syndrome that put him into prolonged unconsciousness. If he didn't push himself like this in the gym, chances are he wouldn't need the oxygen feed, says trainer Kevin Schoeninger, who's recording every set. This is when you realize Henderson, a former TV producer and rock musician, has his own particular idea of how a cancer (and coma) survivor should act—no matter how frightening his prognosis may have been.

"Once people know you have it—cancer—they look at you a whole different way," Henderson says. "It's the dead-man-walking look. But once you get out there, you can educate friends and family. In my case, we've been looking at this as treating a chronic [as opposed to fatal] disease for almost eight years. That makes it a little more acceptable, and people feel better about it when they're around you."



Jon Herderson's post-treatment identity includes member of the rock band, Spyz. Photo by Sammy Dallal

After drug therapy and multiple surgeries, Henderson and members of his long-time rock band, Spyz, made a documentary film and soundtrack called *Big C* about survivors and newly diagnosed cancer patients. “We decided to be upfront about it. We tried not to get into a situation where you’d hear: ‘Oh, poor Jon! Look at him. He’s got cancer.’” In total, Henderson sought to become a survivor voice (with an athletic build) versus becoming a quiet victim with a lingering lung impairment.

It used to be that cancer patients and survivors were afraid to admit they had the disease, much less showcase it. In fact, colon and prostate cancer patients kept even quieter about their conditions than did their breast cancer cohorts through the 1980s and '90s.

Cancer times have surely changed. Witness the multi-hued ribbon awareness campaigns, the LIVESTRONG yellow bracelets, the myriad support group websites, the hot-selling books like *Why I Wore Lipstick to My Mastectomy* by Gerylun Lucas, *Saving Graces* by Elizabeth Edwards, and even *Cancer Schmancer* by Fran Drescher.

Taboos have lifted, but not completely. Stereotypes linger. In truth, the community of 10 million-plus survivors in the United States has been pushed—too hard at times—toward “tough survivor” as the ideal notion. Patients have felt forced, time and again, into “be strong” postures by those close to them who are trying to help. Yet not everyone fits this ideal; or if they do aspire to it, they may need some time to adapt.

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Making Your Own Path

Survivors who don't fit the cancer warrior stereotype may wonder if they're

somehow not doing enough for their future health—for their cause. Despite many well-intentioned public-awareness advances, private hurt too often goes unnoticed.

When Emily Myers, of Jackson, Mississippi, was diagnosed with breast cancer at age 29, she didn't want to be known as "the cancer girl." She simply wouldn't forfeit her identity to a disease, especially before she had a chance to define herself as a professional woman.

"The way women around here would describe me is, 'She has long, thick hair and is blessed on top. And has a big personality.' That package was who I was." But five years after her diagnosis (post-mastectomy and reconstruction), and beyond her role as director of marketing and public relations at River Oaks Hospital in Jackson, Myers now regularly reaches out to women in her community about breast self-exams and mammograms.

"When survivors lose their pride, they also lose part of their identity," says Jean Schleski, LCSW, a therapist and women's cancer support group leader at Rocky Mountain Cancer Centers in Denver. That loss too often enables others' views of what a survivor should be to take root.

"The other night," Schleski says, "one of our women said, 'I feel like a man. I've lost my hair. I've lost my breasts. I've gotten fat because of the chemo.' Plus, she is postmenopausal, also due to the chemo. We talked a lot about what it means to feel you've lost your femininity, and what it means to be a woman." Often, the younger the woman, the more emotional (and powerless) she may feel about having "lost" part of her femininity.

Stereotypes of Cause - and Effect

On the afternoon of January 16, 1997, author Peggy Orenstein, then 35, took a call from her breast surgeon, who told Orenstein her biopsy had come back positive for cancer.

"It can't be true," Orenstein thought. "I'm only 35. I don't have a family history of cancer." She burst into tears, feeling, in part, that it must have been something she'd done. "But I eat organic broccoli," she said the day she was diagnosed.

Now 10 years later, she appears to have shrunk the impact of her breast cancer greatly, however brutal it was at the time. "I know people who went through cancer in a totally crappy way, and they lived well into their 70s. I think we have overblown the role of attitude," as in: You gotta be tough if you're gonna beat this! But Orenstein also says she felt the need to speak out in some way—to tell her story during a very vulnerable time, which she did in *The New York Times Magazine*. This wasn't, she says, to show she was "strong," but to make her own way into what therapists call "the new normal."

"I think you should be allowed to be a person, to be human during all this," says Orenstein, who lives in Berkeley, California. "I mean, you wish if it happens to you, you'd be brave and strong. And I'm not saying I wasn't brave and strong, but I found it liberating to write about it. When I wrote about it, I could cope. With a breast cancer diagnosis [at that stage of my life], I just needed to write every

morning so my head wouldn't explode. I did it to survive." In other words, there are different ways to be strong.

Karen Syrjala, PhD, a biobehavioral scientist at Fred Hutchinson Cancer Center in Seattle, says survivors should, for the most part, resent the feeling that they must be—and stay—positive. “People are entitled to their feelings,” she says. And they're entitled to them at every stage of treatment and survivorship. “We know from the science of emotion that the most harmful way, the most damaging way, to manage emotions is to dictate them.”

The Anger License

When I decided to publish excerpts from my “private” cancer journal in *Esquire* in 2001 and 2003, I did so with trepidation. Could a scared colon cancer patient be as out front as the countless breast cancer survivors that had gone public before? Would I be viewed as weak if I wrote about my—or my wife's—crying jags? Would others think I wasn't fighting hard enough to defeat my cancer with everything I had?

“There certainly is a mind-body link, but I don't think the mind causes cancer and I don't think the mind can cure it,” says Barrie Cassileth, PhD, chief of Memorial Sloan-Kettering Cancer Center's integrative medicine service in New York. Sometimes, truth be told, I believed those around me were being weak. I clearly recall friends and colleagues who read parts of my story and later asked, tentatively, “How's your health situation?”

“How the hell can you take the sucker on if you can't call it by its name?” I shot back, but not to their faces. The first way to tackle stereotypes is to confront them, I thought, not hide behind safe language. “It's stage 3 colorectal cancer, and I'm hooked up to a port-a-cath stashed in a fanny pack that's pre-treating my tumor while I get daily blasts of radiation. I'm a 24-7-6 (six months total treatment) anti-cancer assault unit.” That's how my health situation was, even if I didn't quite say it aloud.

“You have a license to be angry,” Daphne Haas-Kogan, MD, my radiation oncologist at University of California-San Francisco, counseled me one morning early on. She wasn't telling me I should always be mad. Instead she intimated, I was “allowed” to be angry once in a while during some nasty treatment.

Releasing anger, writing, or even rock music can help in healing to build a new survivor mindset. Even if you're not quite a Lance Armstrong cycling champ, the new and humbling survivor, it turns out, may be able to mine past strengths to mesh the rocky present with renewed hope that's both sunny yet grounded in reality.

As Miles Little, PhD, and colleagues at the University of Sydney, Australia, wrote of survivorship identity in the journal *Psycho-Oncology*: “People manage discontinuity by [referring] to stable ‘anchor points’ in their beliefs and values; by reconstructing versions of their pre-[cancer] identities, drawing on memory and finding ways to preserve a continuity between past memory ... present experience and constructions of the future”

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In the case of Ellis Corets, 75, of Bellevue, Washington, a long-distance cyclist diagnosed with prostate cancer at age 62 and who had radical prostatectomy surgery, sitting on a bike seat for hours soon after surgery wouldn't seem a likely way to promote healing.

Yet for Corets, a self-proclaimed bike-hound, he badgered his surgeon about how soon he could return to the road. "I had done the Seattle-to-Portland ride every year since 1989, about 200 miles," he says. "I saw no reason not to do it that year, either. And I rode it 11 consecutive years after my surgery."

But Corets isn't all bluster. "One of the women riders in our group that year came up, put her arm around me before the race, and said, 'You've already won. Just by being here.' All sorts of people were cheering me on." Corets did what he thought he should do, not what the average patient was "supposed" to do only a few months post-op. He rode. And rode.

"As I've said to my own faculty, I wouldn't aspire to be Lance Armstrong—even not having had cancer. I mean, I can't be Lance Armstrong," says Dr. Syrjala. "It just isn't realistic. But what he tells us is that strength and physical capacity can be regained. And that's not specific to him."

There are all kinds of body-mind strength. Just ask Orenstein who decided with one ovary, three miscarriages and breast cancer behind her that it was time to try to conceive and give birth to a baby. Her daughter, Daisy, is now 3 years old. These examples of strength, different and unexpected, stretch beyond the so-called survivor stereotypes. Far beyond.