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The New Survivors

Jasan Zimmerman was 6 months old when he was diagnosed with neuroblastoma of the left neck in 1976. First the cancer was surgically removed, then he was treated with radiation. Perhaps it was exposure to all that radiation that caused the thyroid cancer when he was 15. More surgery, more radiation. But this time, old enough to grasp the situation, he was terrified. "I didn't want to die," recalls Zimmerman, who grit his teeth through the grueling treatment. Almost as difficult was the aftermath:

Traumatized by the experience, he spent his teen years sullen and depressed, without quite knowing why.

He tried to put it all out of his mind—until cancer appeared for a third time in 1997. He was 21 and had just graduated from college. Again Zimmerman was successfully treated. He pursued life goals, including a master's degree in microbiology, but his inner turmoil remained.

For 11 more years, he went for checkups, always fearing a return of the dread disease. "I'd get road rage on the way to the doctor. Even the smell of clinical antiseptic could piss me off," he reports. Despite some scares, the cancer never came back, but living with his history itself became a burden. How soon into a new relationship would he need to confess his medical past? Would he ever be free of the threat? By 2003, he was so angry that he punched a wall and broke his hand.

Today, Zimmerman is able to turn his back on the ordeal. He's done it only by embracing his role as a survivor and speaking out to many of the 1.4 million Americans diagnosed with the disease each year. His message is about the ability to overcome, and he openly describes his own experience. "Each time I share my story people feel hopeful," he says. And he does, too. "I was living under a thundercloud. It's taken me decades to grow from the experience, but the ability to inspire people has turned a negative into a positive and opened me up."

In the past, the very word cancer summoned images of hopelessness, pain, and death; little thought was given to life after cancer because it was considered brief. The cancer "victim" was seen as the passive recipient of ill fate and terrible luck. No more.

Survivorship is increasingly common; some 11.4 million Americans are alive today after treatment and are ever more vocal about their experiences. Emboldened by effective diagnosis and treatment strategies, celebrities such as Melissa Etheridge and Fran Drescher have made public disclosure of the disease increasingly routine and the fight definitely important and profound. Tour de France champion Lance Armstrong, determined to train for the world-class athletic event on the heels of treatment for advanced testicular cancer, turned his achievement into advocacy through his LiveStrong movement.

Many cancer survivors are travelers to a highly intense edge world where they battle

death and return transformed. They leave as ordinary and burdened mortals and come back empowered and invigorated. In coming closer to fear, risk, and death than most of us, they wind up marshaling qualities not even they knew they had.

As more patients have lived longer, a body of research on their experiences has developed. It demonstrates that many cancer patients muster enormous grit for highly aggressive treatments and endure considerable pain to accrue small gains in the fight for survival. Despite therapies that weaken them physically, they can be especially psychologically hardy, harnessing and growing from their stress. Even the most narrow-minded or inflexible people may come to love art, beauty, and philosophical truth as a way of getting through the ordeal. Those who survive often come out of the experience with bravery, curiosity, fairness, forgiveness, gratitude, humor, kindness, and an enhanced sense of meaning.

Is there something about cancer itself that is transformative and growth-inspiring? Do we literally need to face death to go beyond the often petty limits of our workaday lives? William Breitbart, chief of the psychiatry service at Memorial Sloan-Kettering Cancer Center in New York City and an international leader in psycho-oncology, says we just might.

"It is in our nature to transcend our limitations, but too often we get distracted by everyday life. If life is always smooth, we're never challenged," he says. "Suffering is probably necessary to make us grow." The ultimate tool may be a brush with death. "The need to find meaning is a primary force," adds Breitbart, himself a cancer survivor, "but we may need to be confronted with our own mortality for that to occur." In the school of hard knocks, cancer amounts to earning a Ph.D.

Learning to Hope

Carol Farran, an eldercare expert from Rush University Medical Center in Chicago, sought to understand why some nursing home residents thrived despite adversity and isolation while others just withered away. The difference between the two groups, she found, was hope—not the blind or rigid optimism that usually passes for hope, but an open sense of possibility, acceptance of risk, and a willingness to work things out. Hopeful people face reality in a clear-eyed fashion, doing the best they can. One woman too sick to go outdoors, for instance, maintained an upbeat attitude by remembering the emotional riches of her past. "The hopeful person looked at reality and then arrived at solutions. If a hoped-for outcome became impossible, the hopeful person would find something else to hope for," Farran found.

The role of hope in cancer has also come under scrutiny. Psychologists at the Royal Marsden Hospital in London and Sutton studied women with early-stage breast cancer and found that risk of recurrence or death increased significantly among those who lacked hope. There was nothing mysterious or mystical about it: Hopeful patients managed their illness themselves instead of letting outsiders pull the strings. They often chose the most aggressive treatments. And envisioning the light at the end of the tunnel helped provide the strength they needed to get through each difficult day.

Yet hope was not a given for them; it was an attitude they wrested from despair. Despite being an expert on hope, Farran could not muster any when she herself was diagnosed with breast cancer. She met the news with anger, grief, and fear of death. Panic propelled her through treatment, in a total daze. Only when she went in for breast

reconstruction was a wise nurse able to penetrate her panic: "A year from now you'll be where you want to be, but there is no way to get there except by going through this experience, now."

As despair loosened its hold on Farran, she tried to embrace the flexibility she had studied in others. "I told myself to get a grip," she says. Finally she thought of her love of playing piano and decided to buy a metronome, a symbol of what she called "slow time." It was a palpable reminder to calm down, confront her fear of death, and think things through. "You can start in despair but arrive at hope," says Farran, 18 years later. Hope can be learned.

True Grit

Once empowered by hope, cancer patients have been known to search out cures in the face of daunting odds. Jerome Groopman, a Harvard cancer specialist and author of *Anatomy of Hope*, tells the story of a patient, a pathologist with advanced metastatic stomach cancer that was considered fatal. Soon word spread around the hospital that the pathologist intended to do something "mad." Without any evidence that his cancer was survivable, he insisted on doses of chemotherapy and radiation so toxic they were, by themselves, probably lethal. To Groopman and other cancer doctors on staff at the time, the effort seemed "like a desperate, wrong-headed, ultimately futile effort to resist the inevitable." Surely the treatment would deprive the pathologist of a peaceful end at home. Indeed, Groopman, stopping by the man's bedside, found him bleeding as tissues were literally burned away by the strong treatment he had engineered.

Twenty-five years later, while researching his book on hope, Groopman found that the pathologist was still going strong. "If I'd been treating him, I wouldn't have authorized the therapy and he would have died."

Similar tenacity gripped Sean Patrick, a business strategist and extreme sports enthusiast from Aspen, Colorado, whose rare form of ovarian cancer was diagnosed in 1998. Instead of simply agreeing to follow her doctor's treatment advice, she hired a research firm to comb the scientific literature and come up with a list of experts studying her specific disease. She quickly learned that her doctor had recommended the wrong treatment and if she followed through she might not survive the year.

So she fired her oncologist and hired a medical team known for experimental use of drugs. The side effects of her radical treatment were devastating. "Flu symptoms magnified a thousand times," Patrick said. There was nausea, vomiting, disabling body aches, extreme weakness, chills, and diarrhea. "I would shake so hard my teeth would knock and then have a fever so high I would sweat through my clothes." She nicknamed the side effects "shake and bake." Still, she persisted, at one point even electing a surgery so risky she was not expected to wake up. "If I hadn't taken the risk, I wouldn't be here today," she said in 2006. Her grit gave her a full decade more than anyone expected; she died just before this article went to press, in 2009.

Most people don't have the financial resources to seek such customized or experimental options, but even patients dependent on treatment approvals by an insurance company can choose the most aggressive courses that might confer even a slight survival edge. That explains why so many women with stage-one breast cancer opt for removal of both breasts instead of the watch-and-wait approach. It also explains why ovarian cancer patients subject themselves to multiple rounds of chemotherapy, often rejecting studies

contending the treatment will fail.

"Even if it is a long shot, someone is going to fall at the end of the bell curve," notes Groopman.

Soldiering On

Research shows that, even while dealing with the disease, large numbers of cancer patients deploy their tenacity in other realms of life, as well. Take Elizabeth Cowie, 44, a career sergeant in the Army who was headed to Iraq with her troops. There was only one problem: Months before deployment, in a routine Army physical, Cowie was diagnosed with early-stage breast cancer. Instead of going home to attend to treatment, Cowie poured her energy into finding a way to get to Iraq along with the soldiers she'd trained. She forsook the more extreme course of mastectomy for circumscribed lumpectomy, dramatically shortening surgical recovery, and decided against weeks of radiation therapy in favor of a new technique she learned of, called Mammastite, which delivers radiation directly to the tumor over the course of days. She underwent the procedures quietly, without telling the soldiers reporting to her until she was declared cancer-free, and went on with her deployment, gritting her teeth only when her vest chafed the still-healing surgical wound. Cowie endured the heat of Iraq while still recovering, all the while watching over and counseling the soldiers she'd become so close to.

"There were days I was so sore and the heat was so oppressive and it was so exhausting," Cowie recalls. "But I had a commitment to the people I was with. The soldiers counted on me being there. Just knowing that made me stronger, and I couldn't let them down. I put one foot in front of the other; that is how I saw my mission through."

Cowie's can-do attitude is a trait common among the new survivors. According to University of Utah psychologist Lisa Aspinwall, a sense of purpose and positivity is adaptive in cancer's midst. In reviewing the literature on survivorship, Aspinwall found that 30 to 90 percent of patients reported benefits, from increased optimism to better relationships, after diagnosis was made. At first it seemed counterintuitive. But the positive, active mind-set "is likely to help patients manage what they need to do next," she explains. "Those in treatment must make dozens of decisions. To hold things together, you need to pay attention to options. Just think about it—negative emotions orient us to threats, but they also narrow our attention. That's not the best state for navigating a complex and changing situation, just what cancer is."

Post-Traumatic Growth

The benefits seen during the trauma, however, may pale against those reaped later, after survivors have had the chance to reflect. "It's hard to grow much when you are in the middle of a war," says psychologist Lari Wenzel of the University of California at Irvine, who works with women surviving gynecologic cancer at least five years. "Instead, strength and meaning unfold for survivors as they retell their stories, again and again."

University of Connecticut psychologist Keith Bellizzi says the life event is so intense that some people use it to reconstruct their lives; they don't return to the same level of functioning but to a greater level. "Post-traumatic growth is above and beyond resilience," he says. "Life after cancer means finding a new normal, but for many the new normal is better than the old normal."

Bellizzi, 39, speaks from direct experience. He was a well-paid marketing professional when, at age 25, he was diagnosed with stage-three testicular cancer so advanced it had spread to his lymph nodes and lungs. A few months later, a CAT scan revealed a golf-ball-size mass in his kidney. Almost as upsetting as the cancer was the news that he might never have biological children of his own. "It was an opportunity to reflect on my life and face my mortality," says Bellizzi.

Following several surgeries, including removal of a kidney, along with aggressive chemotherapy, he made a vow: "If I survived, I would dedicate my life to the fight against cancer." Bellizzi kept his vow. He quit his lucrative job and went back to school, earning masters degrees in public health and in psychology and a Ph.D. in human development and family studies. In 2005, he was one of 24 cyclists chosen to ride with Lance Armstrong on the Bristol-Myers Squibb Tour of Hope to heighten awareness of cancer research. He also has three daughters—and is a leading researcher in the field of post-traumatic growth.

Bellizzi's sense of purpose is just one type of growth that survivors report. Julia Rowland, head of the Office of Cancer Survivorship at the National Cancer Institute, points to enhanced and altered relationships. "You learn who's going to be there for you and who is not—you learn who your friends are," she says. Some friends, upset by the prospect of loss, may detach temporarily or even permanently. As some friendships fade, others may be forged, especially within the community of survivors. "You also learn to empathize," says Rowland, explaining how survivors acquire new depths of feeling.

Pleasures become more meaningful, too. As a team at the University of Pennsylvania found, those suffering chronic illness end up more immersed in art, music, and books. "Appreciation is often enhanced," points out Bellizzi. Many survivors literally stop to smell the roses even if they didn't before.

The sense of self is often enhanced too. "Some survivors discover an inner strength they didn't realize they had," says Bellizzi. "A situation that might have seemed daunting before cancer may, after cancer, seem like something easily handled."

In one important study, Bellizzi looked at generativity—concerns, often arising at midlife, about the legacy one is likely to leave behind. Generativity can be expressed in many ways—making the planet a better place, giving children the love they need, being creative in work or intimate with family and friends. Midlifers surveying the past may vow to do more with the time they have left. But no matter an individual's age, Bellizzi found, cancer was a catalyst for generativity.

While cancer generally sparked more generativity in women than in men, all the survivors Bellizzi studied were more likely than those without cancer to forge a new life path reflecting their core values. Those reporting the most altered perspective "expressed an increased awareness of the fragility of life and the value of loved ones," he reports. "They also said they had learned not to worry about little annoyances." A patient with colorectal cancer said her disease had convinced her to put an end to meaningless pursuits; she resigned from her management position and spent time with her friends.

A Spiritual Dimension

Cancer can also promote a sense of inner meaning and add a spiritual dimension to life. Lisa Benaron, an internist and pediatrician from Chico, California, learned she had cancer

in the midst of other traumas. Her sister-in-law, a dear friend, had just died of breast cancer. And her marriage was falling apart. Six months after her sister in law died, Benaron, too, was diagnosed with breast cancer. Although in stage one, her cancer was a particularly aggressive kind; further, she had the gene that signals ongoing risk.

Energized by her situation, Benaron focused on researching the best treatment options and chose the most aggressive course, to gain a few points of survival advantage. The chemo was debilitating, but she still recalls fondly the days after those sessions. They were, she insists, "great times. I didn't usually get enough time off to garden, or do yoga." She did then.

She made an effort to pursue the things she loved: kayaking, walks in nature, spending time with her daughter, Molly, then 7. "I took

Molly to the Galapagos Islands on Easter break in 2004," Benaron recalls. "You could sit on the beach and the seals and iguanas would be right there within arms reach. Having cancer made me aware of how fortunate I was and how much beauty was in the world."

Her own journey wasn't complete, though, until a friend she met in the local cancer community, Theresa Marcis, sought her help to travel to Abadiania, Brazil, to see a healer named John of God. "When she was first diagnosed, Theresa had a large mass and stage-three cancer; the prognosis wasn't good," says Benaron. "But she was full of hope. She wrote the word HEAL in big burgundy letters on her kitchen walls."

Under ordinary circumstances, the logical, driven doctor would have had little in common with the free-spirited Marcis, a college English teacher. But under the influence of cancer, they became a team. Benaron helped Marcis navigate the mainstream medical minefield, and Marcis exposed Benaron to acupuncture, sound therapy, and other alternative techniques. "They were enjoyable and peaceful," Benaron recalls.

In 2008, doctors found that Marcis's cancer had spread to every bone in her body. Instead of conceding defeat, she journeyed with a colleague to Brazil to see John of God. Though her condition later worsened, she spoke of going back. When she was too sick to travel, Benaron went in her stead, "to give Theresa peace."

Still very much the logical physician, Benaron doesn't believe that John's interventions can cure. But she loved taking the trip as proxy for her gentle friend, who died hoping that John's powers would stretch from central Brazil to her home in California. "I came to realize through her that every person has their own path through life; she tapped into every good feeling within herself and threw herself into being spiritual. It helped me to see the importance of love and openness to others," Benaron says.

The California physician remembers meditating in Abadiania with a huge thunderstorm whipping up around her. "It was this gorgeous experience," she reports. "But I realized I didn't have to go across the world or down a dirt road to find it. You can be in the moment wherever you are."

Tyranny vs. Transformation

The idea that cancer can be uplifting or transformative has become controversial in the cancer community itself. Post-traumatic growth, while common, does not define all survivors. Young people, whose disease may be more challenging, often grow more

emotionally from the experience than older people. "It's very disruptive to have cancer while raising your family and climbing in your career," explains Bellizzi, "and it's the intensity of the experience and the realization that life is finite that forges change."

Not everyone diagnosed with cancer transcends the past, finds a new sense of purpose, or becomes more spiritual. And in the midst of a deadly disease, the pressure to remake oneself can feel harsh. "It's wrong to pressure people to be optimistic or change their lives," says Utah's Lisa Aspinwall.

"Some will not be able to take advantage of having had cancer," says Breitbart of Memorial Sloan-Kettering. "Some people with poor prognoses just want to hasten death. Some have a glimpse of the possibilities but do not change. Cancer is just wasted on some people."

Still, cancer patients have undeniably entered a new era in which long lives are very much a reality, and they are changed by having looked death in the eye and beaten it back. The experience has made them stronger and forced them to reevaluate the very foundations of their lives. "The bottom line for me is I finally realized that I want to turn the negative experiences of having cancer into a positive," says Jason Zimmerman, "and the more I do, the more I want to do. I don't want to miss out on anything."

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For over 11 million Americans, cancer is no longer a definite death sentence. The dreaded disease has instead become a crucible, often remaking personality and endowing survivors with qualities not even they knew they had.

Psych Basic Suggestion:

Not in queue

Resilience anger apples to apples business situations coincidence desire
disappointment giving feedback lunch negative connotations negative criticism
negative feedback negative feelings odds patience pronoun specifics
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