

KNOWLEDGE

The Survivor Has Arrived

BY KAREN PATTERSON AND ELIZABETH WHITTINGTON

Why now, more than ever before, life after cancer is part of the public discourse.

From the moment history first recorded cancer, there was also, in some small way, cancer survivorship. But that was only the beginning of the story. Like a mighty river, time and circumstance have helped what was once a trickle swell into a flowing force—one able to reshape the landscape around it.

While survivors are on the march for cancer's cures, many are also navigating more personal, and sometimes private, territory: the realization that the disease can change a person fundamentally, body and soul. It can disfigure, and it can heal.

"The Humpty Dumpty idea of 'as good as new'—a powerfully appealing notion for cancer patients—simply does not pertain," physician and cancer survivor Fitzhugh Mullan, MD, wrote in a landmark medical journal piece in 1985. "For better and for worse, physically and emotionally, the experience leaves an impression. No matter how long we live, cancer patients are survivors—at once wary and relieved, bashful and proud."

A half-century ago, the concerns of survivorship were barely a whisper. Today, they are beginning to thunder. Events have conspired to make cancer survivors a constituency that just in the U.S. is some 10.5 million people strong. Constant improvements in the means of preventing, detecting and treating tumors, and heightened awareness of cancer, are largely responsible for that number.

Yet survivorship reaches beyond the influence of those several million people. In recent decades, sea changes in society's discourse, values, and how it conducts its business have contributed to the growing muscle survivors can flex. More than 50 million people can attach meaning to a simple yellow wristband. And pink isn't just for baby girls anymore.

Here, *Heal* magazine takes a look at just some of the circumstances that have made today a powerful and pivotal moment for the future of cancer survivors.

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The survivorship movement began in part out of public dismay that cancer advocacy paid little attention to what happened after treatment. But early last century, cancer advocates had a more pressing message to impart: that treatment had to happen as soon as possible.

Survivorship simply wasn't on the map; it was hard enough to get people into care. "People were often going to the physician really when the pain set in or when the growth became so large that it was impossible to ignore anymore," says David Cantor, PhD, historian for the History of Medicine Division of the National Library of Medicine. "By that stage it was often impossible to do anything."

At that time, organizations focused on breast malignancies, he says, along with other so-called external cancers such as skin cancer. Other, "internal" cancers were naturally of interest, but they were much harder to find and treat early.

Attitudes toward the disease were marked by stigma and silence. Many patients were not even told they had cancer. "One of the prime efforts of the various cancer organizations in the early part of the century was to get people to talk about the disease itself and for it to be reported in the newspapers, as a way to educate people," says Cantor, who recently edited a collection of essays on the history of cancer published in the *Bulletin of the History of Medicine*.

As the public grew more aware and sought treatment earlier, survival (at least for a while after surgery) became more possible.

One early survivor organization, founded in 1938, was the Cured Cancer Club, led by a Massachusetts woman and breast cancer survivor named Anna Mary Chipman Palmer. The club's goal: to fight fear of cancer and show that people could survive.

At the same time, because cancer organizations didn't want to scare off an already-hesitant public, patient literature from around the 1920s to the '50s downplayed postoperative consequences. "The main concern was not to do anything that will undermine confidence in medicine," Cantor says. He cites a 1940s educational film called *Choose to Live*, in which a woman is found to have breast cancer, undergoes surgery, and "two minutes later she seems to be out of the hospital and back with her family."

By the next decade, understanding they were ignoring a vital concern for women, cancer organizations began addressing the disease's aftermath. "It's quite a dramatic shift in the '50s," Cantor says.

Around that time, he says, a New York woman named Therese Lasser was feeling achingly isolated and anxious after her own breast cancer battle. To help others after treatment, she launched the Reach to Recovery program, an outreach aimed at others in similar straits. By the end of the decade, the first movie had been made for women who'd had a mastectomy, exploring issues arising from the severity and trauma of the form of surgery that was done at that time.

The Cured Cancer Club and Reach to Recovery represent a momentous shift in thought about cancer, notes Cantor.

"It's really with movements like that that you begin to see the first glimmerings of what would become the wider survivorship movement."

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As in obituaries, the term "survivor" in cancer once meant a loved one of a person who had died. It was an era when people with cancer were called victims.

“In the public eye if you were diagnosed with cancer you became a cancer victim,” says survivor advocate Barbara Hoffman, JD, legal research and writing faculty at Rutgers School of Law-Newark. “We didn’t have that concept that you can live with a diagnosis of cancer, that you can live beyond a diagnosis of cancer.”

Before 1970, no one marched around saying ‘I had cancer’ even if they survived, says Barron Lerner, MD, PhD, associate professor of medicine and public health at Columbia University Medical Center. “It was in hushed tones; if you lived with it, it was almost like a jinx to speak about it—to tempt fate.”

In his landmark 1985 piece, Mullan coined the phrase “survivor” for one who has been diagnosed with cancer, regardless of stage, treatment duration, or recurrence status. His “Seasons of Survival: Reflections of a Physician with Cancer” essay, appearing in *The New England Journal of Medicine*, described his battle with cancer and the survivorship issues that followed, short- and long-term, physical and emotional. He urged physicians to act to meet these needs.

“If you were lucky enough to finish treatment successfully,” Hoffman says, “you were just sort of cast out, with no follow-up on other issues about how cancer might affect your life.”

In 1986, the National Coalition for Cancer Survivorship—for which Hoffman is founding chair and Mullan the first president of the board of directors—was formed. One key goal was to be an informational hub for people once they completed cancer treatment, Hoffman says. Another objective, she says, was to change the “victim” lexicon of cancer.

“Some would say that the most important contribution NCCS has made to survivorship was in changing the words ‘cancer patient’ and ‘cancer victim’ to ‘cancer survivor,’ and to include in that definition all those involved in that person’s care,” says Ellen Stovall, president and CEO, who along with Hoffman and Mullan is a long-term cancer survivor.

It wasn’t until a decade later that NCCS was joined in survivor advocacy by the National Cancer Institute and then the Lance Armstrong Foundation, both of which began to make significant investments in the study of survivorship issues. Notably, nearly 10 years of NCCS advocacy resulted in the establishment of the Office of Cancer Survivorship at the NCI in 1996. By 2004, the NCI’s budget request recognized survivorship as an area of public health concern.

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The number of survivors in the United States has skyrocketed in the past 35 years. Advancements in the science of cancer have nearly tripled the number of U.S. survivors in the past three decades—a jump from 3 million in 1971 to almost 10 million in 2001, federal statistics show. Today, at an estimated 10.5 million, there are more cancer survivors than there are people who live in Los Angeles, Chicago, Houston, and Philadelphia combined.

Currently, better than two-thirds of patients diagnosed with cancer can expect to live at least five years. In addition, roughly 14 percent of the nation’s cancer survivors were diagnosed more than 20 years ago.

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More survivors have meant more people willing and able to rally against cancer and its fallout. A recent check of nonprofit organizations listed by the Internal Revenue Service shows more than 1,700 just with the word “cancer” in their name—that’s not counting groups named with terms such as “lymphoma,” “leukemia,” or “tumor.”

Many of the earlier organizations—such as National Breast Cancer Coalition, NCCS, and Susan G. Komen Breast Cancer Foundation’s national Race for the Cure—were given unrestricted grants from oncology pharmaceutical companies, says Susan Braun, executive director of the ASCO Foundation, who early in her career held various positions in the oncology/immunology division at Bristol-Myers Squibb.

“At BMS, we understood what was going on in the world of cancer medicine, but we were less well attuned to the world of the patient and the needs of the patient, and wanted to help the patients themselves have a voice and seat at the table,” says Braun, who later went on to become president and CEO of Komen. The early grants helped survivors find more avenues to be heard publicly.

“Survivors were beginning to be a part of designing research protocol, sitting on research review committees, government committees, and activities dealing with cancer, becoming members of Congress, and being active in the media,” she says.

NCCS was one organization determined to have a seat at the table. It moved from New Mexico to Washington, D.C., in 1992, says Hoffman, because “it’s hard to be a familiar face in Congress if you’re in Albuquerque.”

A surge in public events—such as The Leukemia & Lymphoma Society’s Light the Night Walk, the American Cancer Society’s Relay for Life, and Komen’s Race for the Cure—allowed survivors to connect for the cause of fund-raising.

The rapidly growing pool of money and interest also fostered more specialized groups, from those focused on HER2-positive breast cancer, for instance, to those for pregnant cancer patients. “Today, no one has to have cancer in isolation, alone or without some kind of support, as it is available in so many ways,” Stovall says.

The Lance Armstrong Foundation started out in 1997 as one of the more specialized groups—devoted to testicular cancer. But in 2000, its board decided to focus on survivorship for people with all cancers as Armstrong learned firsthand the physical, emotional, and practical issues that cancer brings. “That really became something that we quickly recognized as being underserved for the cancer community,” says Andy Miller, LAF’s director of survivorship.

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People feel connected to one another for a variety of other reasons. Cancer survivorship is one of those reasons—a theoretically powerful one. “We aren’t

just isolated individuals wandering through the world,” says Jake Harwood, PhD, a professor of communication at the University of Arizona in Tucson. “We’re connected to all different kinds of groups, and those groups matter to us.”

The study of such groups is known as social identity theory, which examines such factors as group composition and dynamics, and why people identify with one group at one point and another at another time.

Social identities arise not just from circumstances of birth, but from events throughout life—such as enduring the cancer experience. As an achievement-based identity, cancer survivorship can be particularly appealing.

“An identity based around an experience of winning is more personally rewarding, in a sense,” says Harwood.

A sense of achievement, however, isn’t the only thing that lends power to the survivor movement. Social identity theory recognizes several factors that predict a group will be able to exert social power.

The first is sheer strength in numbers. Group members ask, “How many of us are there? Are there enough of us that we could have an impact?” Harwood says—or, at least, is there a perception of strength?

Another factor is a group’s status. “Even if there’s only a few of us but some of us are very influential or visible in the media, then we have more vitality as a group,” Harwood says.

A third source of empowerment is the notion that change is possible, with the civil rights and suffrage movements as cases in point. Progress may be incremental at first, Harwood says, but as gains are made and awareness is raised, momentum grows.

Beyond all that, the cancer survivorship movement has another interesting strength—that people are involved not just personally, but by association, because of loved ones who have experienced the disease.

“So those 10.5 million survivors ... have an awful lot of tendrils beyond them as individuals,” Harwood says.

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Social movements including consumerism in medicine and the women’s movement dovetailed with—and helped advance—the survivor movement. Three decades ago, says Lerner, as feminists in the United States gained a foothold in challenging a patriarchal society, they also began challenging

paternalism in medicine—the idea that only doctors knew what was best for their patients.

“The initial thrust of feminism in breast cancer ... had to do with informed consent,” he says. “It was all about getting your doctors to level with you and talk about treatment options.”

From there, cancer survivorship issues began to take off. Lerner credits breast cancer survivor and TV newswoman Betty Rollin, author of the 1976 book *First You Cry*, who he says dared to talk not just about living after cancer, but quality of life. Rollin highlighted the importance of appearance after her ordeal, especially given her career.

“That was like heresy. A lot of the medical profession said she was completely out of line: ‘You’re dealing with a deadly disease and you care what you look like, lady?’ ” Lerner says. “But she was right. She was years ahead of everybody.”

The wake-up call to the medical community was starting to become clear, Lerner says. “We need to pay attention to what it’s like to have lost a breast, to what it’s like to have a swollen arm every morning, to what it’s like to have lost your hair. These were crucial issues ... and gradually that wins.”

By the late 1970s, another trend furthers the shift to a more active role for the patient, Lerner says, with emphasis on things like the importance of getting second opinions. “With the rise of patient activism ... [and] what we call consumerism in medicine—the notion that you need to take charge of your medical case—the whole term ‘survivor’ became more acceptable,” he says.

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As individuals reject the identity of cancer “victim” and embrace that of “survivor,” a collective consciousness is emerging. Little more than a decade ago, the modern language of cancer survivorship was foreign to most lay people, says Gary Deimling, PhD, a professor of sociology at Case Western Reserve University in Cleveland.

According to research he and colleagues did in the early 1990s among people who’d had cancer, about 30 percent cast themselves as victims, he says. In recent research, that has dropped to 13 percent. “The language has really changed,” he says.

A cancer survivor himself, Deimling—who had non-Hodgkin’s lymphoma 23 years ago—notes that many people once considered cancer stigmatizing. But not anymore.

“We’re now seeing over 40 percent tell friends they’re a cancer survivor,” Deimling says. “Less than 10 percent say they feel less than a whole person because of cancer, even when treatments were radical surgeries.”

His research has also found many people embracing the survivor identity, agreeing with the statement that “being a cancer survivor is a very important part of who I am.”

“It’s one thing to say you’ve survived cancer, but another to say it’s a big part of who you are,” he notes.

Individuals vary widely in regard to exactly when they consider themselves a survivor. Most adopt a survivor identity by their five-year cancer anniversary, Deimling says. Some take on the identity from the day of diagnosis. Others don't feel that way until a decade later. "After that, if people hadn't identified as a survivor, they tended not to," he says.

People with cancer also take important cues from others, Deimling has learned. In his own case, a doctor told him he'd be around to watch his grandkids. While that may have been irresponsible, Deimling reflects, he latched onto that, finding the survivor identity to be a means of coping.

"Hope," he says, "is an important piece of what the survivorship movement has to say."

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Hope also arises from the example of others—especially, in today's America, from celebrities who have survived cancer. Long before *American Idol* there was *Arthur Godfrey's Talent Scouts*, a radio, then television, showcase of amateur talent during the 1940s and 1950s.

Arthur Godfrey, who died in 1983, survived lung cancer in 1959 and was very forthcoming about what had happened. "There's a great scene where he's being wheeled out of the hospital when he's finally discharged. His people are sort of whisking him out and the press is there and he stops and tells the press the story," says Lerner, author of *The Breast Cancer Wars* and *When Illness Goes Public: Celebrity Patients and How We Look at Medicine*.

Over the course of the 20th century, as celebrities gradually grew willing to go public for altruistic reasons, or because the press "outed" them, their diseases became fodder for the news and entertainment media. Revelations in the 1970s by former child actress Shirley Temple, and by first lady Betty Ford, about their breast cancers broke new ground, Lerner says.

In recent years, the likes of golfing legend Arnold Palmer and former Gen. Norman Schwarzkopf have made their bouts with prostate cancer public. Cycling great Armstrong has taken his cancer cause—survivorship—to new mountaintops.

"The public appeal of Lance Armstrong and his campaign ... was a phenomenon that had far-reaching and positive consequences for all of us who had been working hard to raise those issues for many years, but without the ability to attract the attention that Lance was able to do," Stovall says.

In his research, Lerner hasn't found any real explanation why Americans love celebrities, or celebrity survivors. They just do.

"So instead of looking to the wisest doctors or the best researchers or the surgeon general or whoever else you might see as the spokesperson for major medical issues, we look willingly at [Parkinson's disease advocate] Michael J. Fox or Lance Armstrong because they have the credibility as celebrities, they have the fame and a lot of them have the knowledge, too."

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The voice of the survivor movement resonates because the U.S. population — no matter how you slice it—worries about cancer. A lot. A series of surveys for the Robert Wood Johnson Foundation finds cancer is consistently a top concern among the U.S. public, even though by comparison America’s leading killer, heart disease, claims around 100,000 more lives each year.

In a 2001 survey, without a list of options to guide them, almost half of some 1,000 respondents named cancer as the most important health problem. (Heart disease was No. 2 at 30 percent, followed by HIV/AIDS at 18 percent.) The research was published that year in the journal *Health Affairs*.

Across the series of studies, cancer was always first or second on the list of worries, says Robert Blendon, PhD, a professor of health policy and political analysis at the Harvard School of Public Health, which conducted the research.

In a 2000-2001 survey, this time where respondents chose from a list of 79 conditions, a whopping 87 percent picked cancer as a “very serious” health problem. Breast cancer ranked second, with 84 percent.

Among men, cancer topped the list at 82 percent. And women, 92 percent.

Among blacks, 96 percent. And whites, 87 percent.

Such public sentiment is fertile ground for cancer activism, and, as Blendon notes, “It is very much driven by families and survivors. ... They’re the ones that energize other groups.”

As survival rates have improved, the balance of activist family members versus survivors has shifted. The increased presence and involvement of survivors, Blendon says, “changes the movement from one based on family members who have lost someone, to people who have actually lived through this and bring that experience to debates and discussion.”

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—Barbara Hoffman, JD

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A public worried about cancer has new, visible, and convenient ways to affiliate with the cause of fighting—and surviving—the disease. Just to fight breast cancer, social-minded consumers can Lace Up for the Cure (New Balance shoes), Crunch for the Cure (SunChips), Save Lids to Save Lives (Yoplait yogurt), Clean for the Cure (Oreck vacuums), Cook for the Cure (KitchenAid appliances), and, at the end of a long day, fall asleep Counting Sheep for the Cure (Serta mattresses). In all, Komen lists more than 80 corporate partners.

In 2004, LAF, partnering with Nike, tapped this populist vein of support for

cancer and survivorship with its yellow LIVESTRONG wristbands, an easy way to make a social statement. The wristband campaign, says LAF President Doug Ulman, was one of the first times people could take part in a cancer cause on a huge scale for only \$1. “It was a low barrier to entry, and the average person could participate,” he says.

The LIVESTRONG wristband has raised \$55 million and garnered mass public attention. “One of the things we saw was the wristband started a dialogue. People started talking about cancer again,” Ulman says. “For us and for the whole cancer community and for the whole survivorship movement, that’s what needed to happen.”

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Dialogue about cancer flourished with the 1990s rise of the Internet. The Web’s sprawl of connections provided a new avenue for advocating, fund-raising, and educating. Just one group, an 11-year-old clearinghouse for cancer listservs—the Association of Cancer Online Resources—now manages and archives over 200 lists, sending out more than 1.5 million e-mail messages a week.

The Internet has become a vital tool for advocacy. “It’s probably the biggest single advantage,” says Hoffman. “When we started NCCS, I remember typing letters to Congress, and I would have carbons of the letters. ... It’s hard to communicate that way. Now you can respond immediately by e-mail to congressional staff.”

Four years after LAF launched, its Web presence blossomed and became a national resource for survivors. “For a nonprofit, it’s cost-efficient to use the Internet, to reach as many people as possible,” Ulman says.

Also, at the beginning of this year, Armstrong began his blog, one of the many thousands online by survivors to journal their experiences for friends and family and for millions of strangers around the world. By 2005, more than 30 million Americans reportedly were blog readers. Among their many reading sites: cancer blogs hosted by the American Cancer Society and National Public Radio, and websites such as www.redtoenail.org, designed for blogging cancer survivors.

Information and inspiration now flows not just from the experts down, but from the grass roots up, giving each individual survivor a far-reaching voice. Acknowledging this social revolution, last year *Time* magazine named “You” its Person of the Year.

Last fall, for the 20th anniversary of the NCCS, Hoffman searched “cancer survivor” on Google and found 9 million hits. It felt really good, she says, to know that no matter what your diagnosis, age, sex, or other circumstance, you can find information about providers, support, insurance and employment rights, and caring for yourself and family.

“All those things that people thought about before 1986 but had to figure out how to get the answer—now you can sit in front of a computer and get the answer. That’s something we only dreamed of.”

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Still advocates are rolling up their sleeves, preparing for even greater growth

in the number of survivors. For 2007 the estimated number of cancer diagnoses is 1.4 million. In 2020, that number is projected to increase by over a third to more than 2 million.

The rising number of cancer survivors offers hope, Braun says, but the jump in diagnoses will be an enormous concern for health and survivorship advocates over the next decade. “The issues are more urgent now than they ever were.”