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## HEALTH

# Cancer Fight Shifts to Survivors

## As More Patients Outlast Disease, CDC And Hospitals Alter Treatment Strategies

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For decades, doctors, scientists and researchers have been trying to prevent and cure cancer. Now a new area of effort in this fight is emerging: how to treat cancer survivors.


The National Cancer Institute estimates that there are now over 9.6 million cancer survivors in the U.S., a number that is expected to rise as the population ages. Close to two-thirds of people diagnosed with cancer now live at least five years. That's up from a five-year survival rate of 58.8% in the late 1980s and early 1990s.

This growing pool of survivors has led to calls that more money needs to be spent studying the long-term health effects of treatments used for cancer, ways to prevent second cancers from arising years after treatment is finished, and programs that address the psychological burdens of returning to work and regular life.

In one of the most important signs of change, the Centers for Disease Control and Prevention, along with the Lance Armstrong Foundation, will release next month a plan setting out for the first time national public-health strategies for cancer survivors. The plan calls for the development of databases that track the long-term health of survivors, which may lead to better ways to identify who is most at risk of future health problems and how to prevent them.

The report reflects a significant shift in thinking by the agency. The CDC has previously published similar guidelines on arthritis, heart disease and stroke, but when it comes to cancer, the agency has

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### BEYOND TREATMENT

Cancer survivors deal with a host of health issues, including:

- Increased risk of second cancer
- Sexual dysfunction or fertility problems
- Long-term mental distress
- Late-appearing side effects stemming from treatment
- Chronic fatigue and cognitive problems

Below are some Web sites for groups focusing on issues concerning cancer survivors.

#### American Cancer Society

[www.cancer.org](http://www.cancer.org)<sup>3</sup>

ACS also has an online Cancer Survivors Network, reachable at: [www.acscsn.org/index.html?](http://www.acscsn.org/index.html?popup=1)

[popup=1](#)<sup>4</sup>

#### CancerCare

typically focused on prevention and early detection.

Long-term survival rates still remain dire for many kinds of cancer, such as pancreatic cancer. And even after someone is declared cancer-free, the chance of recurrence years later remains. But the growing interest in what is called "cancer survivorship" arises from the fact that more people will be living with cancer as a chronic health condition.

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- [Debate Heats Up on Defining a Cancer Survivor](#)<sup>1</sup>

Many cancer survivors experience sexual dysfunction issues, fertility problems and long-

term mental distress, and require continued monitoring for signs the cancer has returned. The majority of cancer survivors today are over the age of 65, when people are also more likely to have other pre-existing chronic conditions such as heart problems, diabetes and arthritis, making it more difficult to assess the financial costs of living longer after diagnosis.

Major cancer centers best known for treating patients are increasing their focus on survivors. At the Dana-Farber Cancer Institute in Boston, doctors are laying the groundwork for a new clinic to open this year to be called the Perini Family Survivors' Center. The clinic will conduct research on the psychosocial needs and long-term health effects on adults who have had breast cancer, genitourinary cancers such as prostate cancer, and Hodgkin's disease.

The President's Cancer Panel this year will publish the results of its investigation into the challenges experienced by survivors and their families, and the National Academy of Science's Institute of Medicine is issuing a report on the policy implications of adult cancer survivorship this year as well.

A new magazine devoted exclusively to cancer survivors and their families, called Heal, will start publishing this summer. The magazine, which is free and expected to have a circulation of 100,000, will focus on articles dealing with survivors' posttreatment issues, from dealing with insurance, emerging side effects of drugs, fear of recurrence, fatigue, even where to go on vacation.

#### No Consensus

There is no consensus yet on what kind of follow-up care and continued surveillance individuals with a history of cancer need. While doctors increasingly recognize that many survivors face health complications that may arise years, even decades, after their cancer treatment ends, there is a lack of evidence on the best interventions to prevent or ameliorate these conditions or which patients may be most at risk for developing further health problems. In a paper published last year co-written by Julia H. Rowland, director of NCI's Office of Cancer Survivorship, and Noreen M. Aziz, they concluded that

[www.cancercare.org](http://www.cancercare.org)<sup>5</sup>

Free teleconference on survivorship issues

#### Heal

[www.healtoday.com](http://www.healtoday.com)<sup>6</sup>

Free subscriptions to new magazine focused on cancer-survivor community.

#### Lance Armstrong Foundation

[www.laf.org](http://www.laf.org)<sup>7</sup>

Support services for survivors, research grants

#### National Coalition for Cancer Survivorship

[www.canceradvocacy.org](http://www.canceradvocacy.org)<sup>8</sup>

Survivor-led advocacy organization

#### Office of Cancer Survivorship, National Cancer Institute

<http://survivorship.cancer.gov><sup>9</sup>

Research, information on survivor issues

"long-term adverse outcomes are more prevalent, serious, and persistent than expected in survivors of both pediatric and adult cancer." And there is virtually nothing known about the impact of cancer on the health -- physical and mental -- of family members and caretakers of people with cancer.

Estimating the costs of treating and monitoring this growing population is also difficult. NCI estimates that in 2003, \$64.2 billion was spent in direct medical costs for cancer treatment and an additional \$16.3 billion was the cost of lost productivity due to illness, but these figures don't reflect the other burdens of cancer on survivors or family members who may leave the work force to care for them.

The financial data that are available suggest that the economic costs of survivorship are potentially huge. Martin Brown, chief of the health services and economics branch in the division of cancer control and population sciences at NCI, says his unit's examination of breast-cancer patients in the Medicare system reveals that one-third of the medical expenditures, close to \$1.5 billion, occur after the initial treatment ends.

The national action plan on cancer survivorship acknowledges these existing gaps, and argues that cancer survivorship needs to be treated as a pressing public-health issue. In the past, the CDC has focused on the prevention and early detection of cancer rather than cancer survivorship issues, says James Marks, director of the National Center for Chronic Disease Prevention and Health Promotion, which is part of the CDC. "But it is increasingly clear to us that the life-long consequences of diseases like cancer are the principal sources of disease burden," Dr. Marks says.

## **A National Database**

The plan calls for establishing a national database to follow cancer survivors from the day of diagnosis through the end of life -- whether that is months or decades -- and for establishing consensus on what data need to be collected so that further surveillance and prevention strategies can be developed. The Lance Armstrong Foundation says it plans to lobby Congress to increase funding for the issues raised by the action plan. CDC currently spends \$12 million on state cancer control programs. The foundation wants this budget to be increased to \$25 million so that more resources can be devoted to cancer survivorship issues.

The cancer advocacy community in particular has been pushing for more resources to be spent studying the long-term health consequences caused by the disease and its treatment. "We have been preoccupied, and rightfully so, with detecting cancer early and saving people's lives with quality treatment," says Doug Ulman, 26 years old, a survivor of bone cancer and melanoma and now the director of survivorship at the Lance Armstrong Foundation. "But once that occurs and the survivor is released back into his or her life, equal attention has not been paid to quality of life issues that can be significant."

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