

DIVISION OF CANCER CONTROL & POPULATION SCIENCES
OFFICE OF CANCER SURVIVORSHIP

CHAMPIONING SURVIVORSHIP SCIENCE AND CARE

SINCE 1996

U.S. Department of Health & Human Services | National Institutes of Health

IMPROVING THE LIVES OF CANCER SURVIVORS

In 1996, an estimated 8.4 million cancer survivors lived in the United States. The field of cancer survivorship was in its relative infancy. But as more people began to live longer after their diagnosis and were experiencing side effects of cancer and its treatment, it became increasingly clear that cancer care must evolve to meet the emerging needs of this growing population.

The cancer survivorship community, led by Ellen Stovall of the National Coalition for Cancer Survivorship, worked with researchers, health care providers, policy makers, and other advocates to highlight the needs of cancer survivors. As a result of their work, the director of the National Cancer Institute (NCI) established the Office of Cancer Survivorship (OCS) in 1996 to provide a scientific home for the support and direction of research designed to improve the length and quality of life of individuals treated for cancer. Dr. Anna Meadows was appointed OCS acting director, and Dr. Julia Rowland was recruited as full-time director of the office in 1999.

A PERSON IS CONSIDERED A CANCER SURVIVOR FROM THE TIME OF DIAGNOSIS THROUGH THE BALANCE OF HIS OR HER LIFE. FAMILY MEMBERS. FRIENDS. AND CAREGIVERS ARE ALSO AFFECTED BY THE SURVIVORSHIP EXPERIENCE.

BUILDING A Survivorship Community

The passionate cancer survivorship community that helped launch OCS has continued to inspire hundreds of others to work in the field. Today, NCI alone has more than 60 experts in areas of cancer survivorship research.

NCI regularly brings together other experts in a wide range of disciplines to address opportunities and challenges in the cancer survivorship field and to advance the science. Recent meetings focused on the economic impact of cancer, on cancer rehabilitation, and on informal cancer caregiving. NCI also cosponsors the Biennial Cancer Survivorship Research Conference in partnership with the American Cancer Society, the LIVE STRONG Foundation, and the Centers for Disease Control and Prevention. More than 500 researchers, health care providers, public health specialists, and advocates convene to review the latest cancer survivorship research and collaborate toward the common goal of enhancing cancer survivors' lives. The most recent biennial conference took place in Washington, D.C., in 2016.



the importance of understanding the survivorship experience and the many lasting effects a cancer diagnosis and treatment can have. The growing number of survivors also makes clear the vital need to address physical and financial issues, psychosocial concerns of survivors and caregivers, risks of persistent and late-occurring effects, and the value of integrated care.

68% 5+ YEARS

LIFE AFTER CANCER DIAGNOSIS (2016 STATISTICS)

> **47%** 10+ years

20% 20+ YEARS



THE NUMBER OF CANCER SURVIVORS OVER TIME BY AGE

3.6м 1975

Source: Bluethmann S, et al. Cancer Epidemiology Biomarkers & Prevention, 2016

RESEARCH IMPROVES QUALITY OF LIFE

President Clinton formally announced the launch of OCS on October 27, 1996. He was joined by then-NIH Director Dr. Harold Varmus (rear left), next to then-NCI Director Dr. Richard Klausner, and Ellen Stovall (front right) and other OCS supporters.

As medical advancements have helped make many types of cancer less deadly, health care providers, advocates, and researchers have turned more attention to quality of life for survivors. NCI is supporting research on minimizing the risk of cardiovascular side effects during and after cancer treatment, the efficacy and impact of survivorship care plans, physical activity and weight control interventions among cancer survivors, addressing cancer-related anxiety and depression in survivors and their loved ones, and other topics related to quality of life.

Recent studies show how broad the field is—and how many variables affect cancer survivorship. Results from an NCI-sponsored clinical trial indicate that suppressing certain hormones during chemotherapy could help improve fertility after treatment for some women with breast cancer. Another study suggests that the social and emotional support of marriage may improve cancer patient survival. And there is increasing evidence that the financial difficulties that often result from dealing with cancer can lead to additional health problems, such as when survivors do not pursue recommended follow-up care or experience added stress.

TREATING THE PERSON

After decades of research, medicine is entering a new era of cancer prevention and treatment that takes into account a person's genes, environment, and lifestyle to provide the right therapy to the right person at the right time. That personalized approach is also changing cancer survivorship, particularly as the U.S. population ages and caregivers are more regularly included in care delivery and research.

Looking to the future, researchers and health care providers will systematically apply interactive measures to identify who is most at risk for the physical, psychological, or financial effects of cancer and its treatment, from cardiotoxicity to depression. New approaches will pave the way to effective interventions to prevent and minimize those effects.

The medical community now recognizes that "to cure is not enough." As cancer survivorship research continues to mature, those working in the field will be able to rapidly learn how to help survivors live longer and better. As in the past, heeding the voice of survivors will be key to advancing survivorship science and care.





