

## Living Beyond Cancer: Finding a New Balance

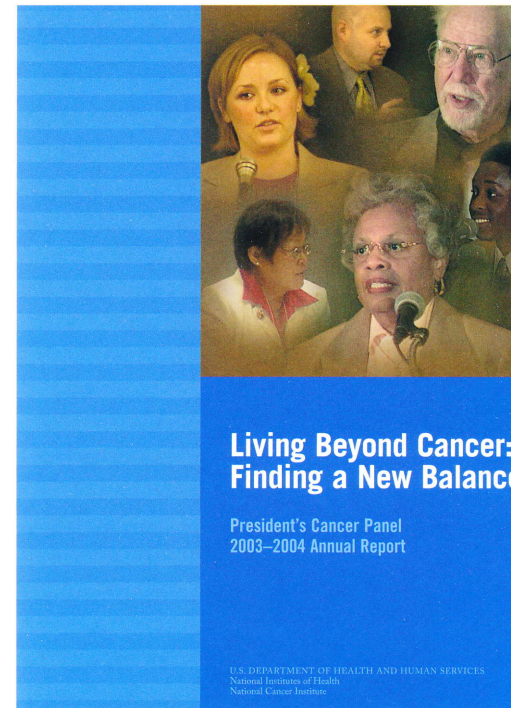
With their treatment behind them and their bodies cancer-free, the nearly 10 million survivors of cancer in America today still face many physical, psychological, and social challenges. The President's Cancer Panel spells out recommended action steps to address the challenges of cancer survivorship in its report on *Living Beyond Cancer: Finding a New Balance*. The report was presented on June 2, 2004 to the National Cancer Advisory Board, which advises and makes recommendations to the U.S. Secretary of Health and Human Services and the NCI Director on activities carried out by NCI.

“For so long, we thought if there was no longer any evidence of cancer, then everything was all right,” says LaSalle D. Leffall, Jr., M.D., chair of the panel that issued the report and professor of surgery at the Howard University College of Medicine. “The truth is that the end of treatment does not represent the end of the problems that people face.”

The President's panel held five hearings between May 2003 and January 2004, during which survivors, caregivers, community advocates, health professionals, researchers, and others shared compelling stories about post-cancer physical problems such as infertility and second cancers. They also testified about the psychological and social problems they face, including depression, fear of relapse, and difficulties qualifying for life insurance and other types of financial protection.

In response, the President's Cancer Panel issued several key recommendations:

- > Upon discharge from cancer treatment, every patient should be given a record of care already received and important disease characteristics, along with a follow-up care plan.
- > Procedures should be established to inform patients and caregivers of their rights to legal and regulatory protections.
- > Efforts should be enhanced to educate patients, survivors, families, and health care providers about cancer treatment and survivorship issues.
- > Survivors and caregivers should be counseled about common cancer-related psychosocial effects and available support services.
- > Attention should be paid to correcting inadequacies in insurance coverage for people with a cancer history.



The President’s panel also recommended specific proposals focused on survivors who are diagnosed at various stages of life. For former childhood cancer patients, the panel report addressed issues such as school re-entry and the transition to adult medical care status.

“When cancer organizations, policy makers, and others look at this report to the President, we hope they will say to themselves, ‘We must be there to support cancer survivors for the rest of their lives—not just until their body is free of the disease,’” Leffall notes.

NCI’s Office of Cancer Survivorship (OCS) cooperated with the President’s Cancer Panel to release *Living Beyond Cancer: Finding a New Balance* and has led the Institute’s efforts in addressing the report’s recommendations. OCS supports and promotes research that addresses the long- and short-term effects of cancer and its treatment. Survivorship research focuses on the physical, emotional, social, and financial outcomes that occur after cancer survivors have completed their treatment. OCS’s goal is to optimize the health and well-being of all persons living with a history of cancer.

“Having survivorship acknowledged as an important issue within the nation’s premiere cancer research institute has created a place for larger discussion of and scientific attention to the potential human costs of cure,” says Julia H. Rowland, Ph.D., director of OCS.

Findings from one OCS-funded project showed that a small group of women diagnosed with breast cancer who were given a behavioral-stress management intervention were more likely than women not given the intervention to see some positive aspects to being diagnosed with breast cancer (such as closer relationships with family members) and experienced a slight increase in immune function, leading to a lower risk of infection. Another study found that survivors of head and neck cancers are likely to have life-long difficulty communicating because treatments have compromised their speech, which causes a significant loss of quality of life because survivors tend to become isolated and remove themselves from public activities.

In addition to the President’s Cancer Panel, OCS works with other organizations to raise awareness of survivorship research. OCS participated in an American Society of Clinical Oncology media event about survivorship and worked with the Centers for Disease Control

and Prevention and the Lance Armstrong Foundation to champion the importance of cancer survivorship as a public health issue.

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<http://deainfo.nci.nih.gov/ADVISORY/pcp/pcp03-04rpt/Survivorship.pdf>

McGregor B, Antoni M, Boyers A, Alferi S, Blomberg B, Carver C. Cognitive-behavioral stress management increases benefit finding and immune function among women with early-stage breast cancer. *Journal of Psychosomatic Research*, January 2004; 56(1):1-8.

Meyer T, Kuhn J, Campbell B, Marbella A, Myers K, Layde P. Speech intelligibility and quality of life in head and neck cancer survivors. *Laryngoscope*, November 2004; 114(11):1977-1981.