

Lombardi Comprehensive Cancer Center publishes manual for childhood cancer survivors

April 3 2008

With more than 270,000 childhood cancer survivors living in the United States, researchers have turned their attention to the effects of cancer treatment that can occur years after therapy, called late effects. At the Lombardi Comprehensive Cancer Center and Georgetown University Hospital, a team of oncologists, nurses, social workers and an art therapist have created the first survivorship manual, tailored for each child treated for cancer. *The Next Step... Crossing the Bridge to Survivorship* is an educational guide designed to provide specific information related to long-term follow-up and survivorship.

“The end of cancer treatment is a time of strong emotions for patients and families,” says Aziza T. Shad, M.D., chief of the division of pediatric hematology oncology at Lombardi and the Hospital, and author of the manual. “Celebration is often mixed with anxiety and loss of security. Most families feel overwhelmed and have many questions about the future.” Shad, an internationally known pediatric oncologist, is the Amey Distinguished Professor of Neuro-oncology and Childhood Cancer at Georgetown University Medical Center.

Many of those questions center on the future health of the child. Chemotherapy, radiation therapy, and surgery may all have late effects involving any organs or body systems. Some complications can be identified early during treatment and follow-up. The majority of late effects, however, become apparent many years after treatment is

finished. Some late effects are easily treated, while others may become chronic.

“Late effects are caused by injury to healthy cells as a result of cancer treatment. Just like every person reacts differently to treatment, late effects also vary from person to person and cancer to cancer,” Shad’s manual explains. “A lot depends on the types of therapy and the doses used. Chemotherapy and radiation therapy cause most of the late effects.”

Some examples of late effects from treatment include heart disease after treatment with anthracycline chemotherapy or high-dose chest radiation, learning disabilities in survivors treated with radiation and/or chemotherapy to the brain, breast cancer at an early age in female survivors of Hodgkin's disease who received chest and neck radiation in their teens, second cancers from chemotherapy drugs or radiation used to treat the original cancer, symptoms of post-traumatic stress syndrome in survivors and their parents, and chronic pain and fatigue.

“Thirty years ago, few children with cancer survived, but now almost 80 percent of all children and adolescents diagnosed with cancer are surviving more than 5 years and the majority of them are cured,” explains Shad. “There is much to celebrate in the field of childhood cancer. We hope this manual will help ease the transition for patients and families from active treatment to follow-up care.”

The manual is customized for each patient to include information about their cancer diagnosis and specific treatment. It combines the personal health record with an educational guide about long-term effects. Also, the manual promotes a “shared care” model, incorporating primary care providers as an integral part of a survivor’s care.

“Primary care physicians and nurses can play a pivotal role in the

monitoring of potential late effects and survivorship issues,” says Shad.

According to the American Cancer Society, approximately 10,730 children will be diagnosed with cancer this year and 1,490 are expected to die from the disease. At Lombardi, patients who are two years out from treatment are automatically enrolled in the Childhood Cancer Survivorship Program directed by Shad. The program, established in 2003, is also open to all childhood cancer survivors, regardless of where they received treatment. It focuses on the unique health-care needs of survivors by:

- Monitoring and managing late effects of therapy
- Addressing psychosocial needs
- Educating survivors about their disease and the treatment received
- Promoting wellness through education on healthy living
- Encouraging participation in survivorship research
- Empowering survivors to advocate for their own healthcare needs

Source: Georgetown University

Citation: Lombardi Comprehensive Cancer Center publishes manual for childhood cancer survivors (2008, April 3) retrieved 4 May 2024 from <https://medicalxpress.com/news/2008-04-lombardi-comprehensive-cancer-center-publishes.html>

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