



WELCOME SURVIVORS

Kara, age 15,
5-year Medulloblastoma
survivor

*From the time of discovery
and for the balance of life,
an individual diagnosed with
cancer is a survivor.*

NATIONAL COALITION FOR CANCER SURVIVORSHIP

WELCOME

Cancer Survivors and Families!

THE END OF CANCER TREATMENT IS A TIME OF strong emotions for patients and families. Celebration is often mixed with anxiety and loss of security. Most families feel overwhelmed and have many questions about the future. In order to help ease the transition for patients and families from active treatment to follow-up care, the Childhood Cancer Survivorship Program at the Lombardi Comprehensive Cancer Center, Georgetown University Hospital, has put together 'The Next Step.....Crossing the Bridge to Survivorship.' This educational guide is designed to provide specific information addressing issues related to long-term follow-up and survivorship.

For patients treated at the Lombardi Cancer Center, this guide will be "customized" to include the information that is particularly relevant to the treatment they received. When treatment is complete, each patient will receive an 'off-therapy summary'. A copy of this summary along with an end of treatment letter will be sent to the primary care provider (PCP) in order to facilitate a partnership between the PCP and the pediatric oncology team at Lombardi in the ongoing care of the patient. Wallet cards containing a brief medical history and the type of cancer treatment received will also be filled out for each patient. Other features of the guide include information about different types of tumors, potential late effects specific for particular therapies, and recommended long-term follow-up. The guide also contains sections on health maintenance recommendations, cancer survivorship issues across the young adult life span, advocacy issues, and resources for childhood cancer survivors.

It is our hope that this educational guide will be a valuable tool in helping patients and families understand the paramount importance of life-long follow-up care. It is also our desire that patients and their families continue to feel supported and understand that they are not alone in adjusting to life after cancer.

Your Cancer Survivorship Team

What are Late Effects?

There is much to celebrate in the field of childhood cancer.

- Thirty years ago, few children with cancer survived, but now almost 80% of all children and adolescents diagnosed with cancer are surviving more than 5 years and the majority are cured
- Currently, there are more than 270,000 childhood cancer survivors in the USA
- 1:1000 adults younger than the age of 45 years and 1:570 adults between the ages of 20–34 years is a cancer survivor
- There are almost 100,000 childhood cancer survivors in college today
- Survivorship is expected to increase to 1:250 persons by the year 2010

With survivors living longer, oncologists now know that the cancer treatment their patients received may affect their physical and emotional health many years later. These are called “late effects”. Chemotherapy, radiation therapy, and surgery may all cause 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. A lot depends on the types of therapy and the doses used. Chemotherapy and radiation therapy cause most of the late effects.

Examples of some late effects that can occur in childhood cancer survivors:

- 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 mantle radiation (chest and neck) 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.
- Chronic pain and fatigue.

Childhood Cancer Survivorship Program

**Lombardi Comprehensive Cancer Center
Georgetown University Hospital
3800 Reservoir Road NW ■ Washington DC 20007-2197
Telephone: 202-444-7599**

THE CHILDHOOD CANCER SURVIVORSHIP Program was established in 2003 to provide comprehensive, on-going follow-up care for children treated in the Division of Pediatric Hematology Oncology, Blood and Marrow Transplantation, Georgetown University Hospital. All children two or more years off treatment were automatically enrolled. The clinic started with just one pediatric oncologist and over the years has grown to include a pediatric oncology nurse practitioner specializing in late effects, a social worker, an art therapist, a neuropsychologist, and a psychologist. In addition, the program has access to pediatric and adult multi-disciplinary sub-specialists. Since 2003, the program has received philanthropic support enabling it to expand significantly. We now provide services for children, teens, and adults, locally and internationally, with the bulk of the patients coming from the Greater Washington area, Maryland, and Virginia.

The program focuses exclusively 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

In order to meet these goals, all cancer survivors are advised to have a regular, annual late effects visit. Our clinic sees patients every Friday morning, and appointments can be made by calling (202) 444-7599.

“The Bridges to Art Therapy” is an art therapy assessment research project being conducted with patients in the Childhood Cancer Survivorship Program at Georgetown University Hospital, Lombardi Comprehensive Cancer Center. Participants in the study create three drawings, using specific materials and directives, and fill out self-report questionnaires. The study is designed to measure the effectiveness of the art therapy assessments, and to provide an opportunity for survivors to reflect on their cancer experiences in a multidimensional way—in both art and words.

As our program grows and develops with new information and resources regarding survivorship, we continue to remain focused on the essential goal of helping our survivors enjoy a fulfilling life after cancer.

Purpose of Personal Health Care Record

WELCOME TO THE CHILDHOOD CANCER Survivorship Program at the Lombardi Comprehensive Cancer Center, Georgetown University Hospital. This is a real milestone in your life! You have much to be proud of and much to look forward to in the future.

It will always be important for you to take good care of yourself and live a healthy lifestyle. We recommend that you re-connect with or identify a primary care doctor whom you like and feel comfortable talking to, and that you visit your doctor for routine check-ups. We also recommend that you have yearly evaluations at the Childhood Cancer Survivorship Program to specifically address any health problems that might be related to your cancer and its treatment.

In order to help other clinicians give you the best medical care, we have organized this Personal Health Record/Educational Guide, which includes information about your cancer diagnosis, treatment, and significant medical events, as well as recommendations for specific follow-up care after completion of your treatment. Use this resource to learn about late effects and to communicate with your oncology team about any questions or concerns that you may have.

Please also share this material with your primary doctor and any medical specialists who will care for you in the future. If any of your clinicians need further information related to the treatment you received, please have them contact the Childhood Cancer Survivorship Program at Lombardi Comprehensive Cancer Center, Georgetown University Hospital, at (202) 444-7599 during clinic hours on Monday-Friday from 9:00 am to 5:00 pm. If there is any urgent need after clinic hours or on a weekend, contact the pediatric oncologist on call at (202) 444 -PAGE (7243).

CANCER HISTORY

Wallet Cards

Family Physician: _____

Primary Oncologist: _____

Follow-up Visits

Recommendations

Risks

Childhood Cancer Survivorship Program

Lombardi Comprehensive Cancer Center

Telephone: 202.444.7599

Name: _____ Date of Birth: _____

Diagnosis: _____ Date of Diagnosis: _____

Treatment Center: _____

Primary Oncologist: _____

Family Physician: _____

Emergency Contact #: _____

Family Physician: _____

Primary Oncologist: _____

Follow-up Visits

Recommendations

Risks

Childhood Cancer Survivorship Program

Lombardi Comprehensive Cancer Center

Telephone: 202.444.7599

Name: _____ Date of Birth: _____

Diagnosis: _____ Date of Diagnosis: _____

Treatment Center: _____

Primary Oncologist: _____

Family Physician: _____

Emergency Contact #: _____

Tear out these cards and fill them out with your cancer information.
Give one to your parent and carry one with you at all times.

Treatment

Chemotherapy (drug/total dose): _____

Radiation therapy (site/dose): _____

Surgery (site): _____

BMT/SCT: _____

Major complications related to treatment:

Immunizations up-to-date: Yes No

Allergies: Yes No _____

Other Significant Medical History:

Current Medications

Drug Dose Purpose

_____	_____	_____
_____	_____	_____
_____	_____	_____

Treatment

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BMT/SCT: _____

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Drug Dose Purpose

_____	_____	_____
_____	_____	_____
_____	_____	_____



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DATE _____

DEAR DR. _____

YOUR PATIENT _____ HAS JUST COMPLETED THERAPY FOR

AT _____ ON _____.

Completion of cancer treatment is a time of celebration for patients and their families. However, it can also be a time of mixed emotions and anxiety. Patients look forward to returning to a normal life, but a degree of uncertainty remains about what the next steps should be, compounded by the fear of relapse.

Within the field of pediatric oncology, great progress has been made in cure rates for the various malignancies afflicting children. Today, almost 80% of all children and adolescents diagnosed with cancer are surviving more than 5 years; the majority are considered cured. This success has largely been due to the use of more intensive therapy using a combination of different chemotherapeutic agents, surgery, and radiation.

However, no treatment is without cost! As childhood cancer survivors become adolescents and young adults, some of them are at risk for developing complications related to the particular therapy they received. Some complications can be identified early during treatment and follow-up, and are taken care of by the primary oncologist. However, the majority of late effects become apparent many years after treatment is finished and encompass a wide variety of physical and emotional manifestations that require time and medical attention, necessitating 'long term follow up'.

Most pediatric oncologists agree that childhood cancer survivors should be followed for the rest of their lives; however, they may not be the most suitable health care providers as these survivors enter late adulthood. To provide the care and follow-up these survivors need, we believe in the 'shared care' model, where by the primary oncologist and family physician participate jointly in providing care.

The Division of Pediatric Hematology/Oncology, Blood and Marrow Transplantation Program at Lombardi Comprehensive Cancer Center, Georgetown University Hospital has established a Childhood Cancer Survivorship Program. Our team, composed of a pediatric oncologist, nurse practitioner, social worker and art therapist, follows childhood cancer survivors who have been off therapy for two or more years. Our program is exclusively focused on late effects of childhood cancer and survivorship issues. In addition, we also help our patients transition out of their "cancer world" and establish a new sense of normalcy by re-connecting them with their primary

care provider. It is important that survivors incorporate well visit check-ups into their routine care and build a relationship with their primary caregiver.

Believing in the 'shared care' model, we feel strongly that primary care providers are an integral part of a survivor's care and can play a pivotal role in the monitoring of potential late effects and survivorship issues. Enclosed for your records is an off-therapy record which summarizes your patient's cancer treatment plan, follow-up schedule for scans and lab work, appointments, re-immunization schedule, and contact names and numbers. Your patient has also been given a Cancer Survivorship Guide which gives further detail of his/her specific disease, potential late effects related to specific therapy received, information on other survivorship issues, and resources related to late effects.

All of us at the Cancer Survivorship Program look forward to working with you closely in order to provide the highest quality of care for our survivors and ensure that they are not lost to follow-up. Please do not hesitate to contact us should any questions or issues arise. We appreciate any feedback you would like to provide.

Thank you for your time and effort.

Sincerely,

The Childhood Cancer Survivorship Team