

## **Survivorship 101: Care after Cancer**

*Brooke Cherven, RN, MPH, CPON & Lillian Meacham, MD*

Childhood cancer treatment is tough. Oncologists use a combination of chemotherapy, radiation, surgery and hematopoietic stem cell transplant all with one primary goal: cure. Fortunately research in pediatric oncology treatment over the past few decades has been incredibly successful. The overall cure rate for pediatric cancer is currently close to eighty percent (80%). Most children diagnosed with cancer today will become long-term survivors. As healthcare providers we realize our commitment to the health of these patients doesn't end at cure.

Maybe you've heard the word 'late effect' or read information about health problems after cancer treatment. The treatments used to defeat childhood cancers can damage normal tissues and cause health problems after therapy; these are called 'late effects'. Research in the field of survivorship has shown that many survivors develop a health problem after cancer treatment. In an article published in the New England Journal of Medicine, looking at health conditions in a study of 14,000 adult survivors of childhood cancer, Oeffinger et al. found that 66% of the adult survivors had at least one chronic health condition, many of which were late effects of cancer therapy. Fortunately most of these conditions are not severe. Childhood cancer survivors are at risk for medical, psychological, and social problems after completing treatment (you can see a list of late effects in Table 1). Risk for these problems is influenced by many factors, most importantly: diagnosis, cancer therapy regimens and age at treatment.

As survivors move farther away from treatment, the risk of cancer recurrence decreases, but the risk for late effects is still present and in some cases increases with time, which is why life-long monitoring is crucial for survivors. Some late effects like thyroid disease, cardiac disease or infertility are not diagnosed until a decade off therapy. As patients and families transition back to a life without cancer treatment, it can be worrisome to think about potential health problems that may occur as a result of their cancer therapy. The impact of late effects on a survivor's quality of life can be minimized through early detection and intervention. Early detection can be achieved through regular screening using evidence-based monitoring guidelines. The best way for patients to maintain health is to have regular survivor focused healthcare check-ups. Survivors should be seen regularly in a Survivor Clinic or Long-Term Follow-Up clinic.

### **Survivor Healthcare Plan (SHP): A Different Kind of Roadmap**

Risk for late effects is dependent on the survivor's cancer treatment so an accurate summary of treatment is necessary to determine an individual's risk for late effects. During a childhood cancer survivor clinic visit, survivors (and their families) are educated about the specific late effects for which they are at risk, and how to screen for these health problems. The survivor team will create a Survivor Healthcare Plan, or SHP, that will include 3 things: 1) a summary of the patient's cancer diagnosis and treatment, 2) an individualized risk profile and 3) a surveillance plan listing which tests should be done to diagnose the specific late effects for which the patient is at risk. This surveillance plan becomes the "roadmap to survivor care".

**Survivor Healthcare Plan (SHP)**

**1. Treatment Summary including information on:**

- Cancer Diagnosis
- Chemotherapy – Agents and Doses
- Radiation Therapy– Body Sites and Doses
- Surgery
- Bone Marrow Transplant

**2. Individualized Late Effect Risk Profile**

**3. Individualized Surveillance Plan for Late Effects**

The *Long-term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* ([www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)), created and maintained by the Children’s Oncology Group, are used to develop the risk profile and appropriate surveillance plan for the patient.

<b>Late Effects of Childhood Cancer by Body System</b>	
<b>Learning/Psychological</b> Problems in School Anxiety and Depression Fatigue	<b>Head/Ears/Eyes/Nose</b> Hearing Loss Cataracts Cavities
<b>Endocrine</b> Problems with Growth Problems with Puberty Infertility Thyroid Problems Obesity Low Bone Mineral Density (Osteoporosis)	<b>Cardiac</b> Heart Disease Heart Attack Damage to the Heart Muscle Irregular Heart Rhythm (Arrhythmia) Stroke High Blood Pressure
<b>Lung</b> Chronic Breathing Problems Scarring of the Lungs Swelling of Lung Tissue	<b>Gastrointestinal/Hepatic</b> Liver Problems Chronic GI Problems Bowel Obstruction
<b>Kidney/Bladder</b> Problems with Kidney Function High Blood Pressure Problems with Bladder Function	<b>Musculoskeletal</b> Limb Loss Scoliosis Fractures
<b>Skin</b> Hair loss Skin Changes	<b>Secondary Cancers</b> Leukemia Solid Tumor

With the advances in pediatric cancer treatment leading to high survival rates, it is crucial to provide survivors with the specialized healthcare they need to lead long, successful and productive lives. The Aflac Cancer Survivor Program is committed to keeping survivors healthy, learning more about late effects of childhood cancer through survivor focused research and partnering with other healthcare providers to provide optimal care to survivors. In Georgia there is a network of healthcare providers who are working together to ensure that every childhood cancer survivor in the state of Georgia has access to the appropriate long-term follow-up care and CURE is a part of this effort.

To find a cancer survivor clinic contact the hospital where you received cancer treatment. If they do not have a specialized cancer survivor clinic you can receive a referral to another survivor clinic within the state of Georgia.

To learn more about childhood cancer survivorship visit the following websites:

Patient and Family Education Materials

[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

Healthcare Provider Education Materials

[www.cancersurvivorlink.org](http://www.cancersurvivorlink.org)

#### References:

1. Ries LAG, Eisner MP, Kosary CL, et al. *SEER Cancer Statistics Review, 1973–1998*. Bethesda, MD: National Cancer Institute; 2001
2. Jemal A, Siegel R, Ward E, Murray T, Xu J, Thun MJ. Cancer Statistics, 2007. *CA Cancer J Clin*. 2007; 57(1):43–66
3. Oeffinger, K., Mertens, A., Sklar, C., et al *Chronic health conditions in adult survivors of childhood cancer*. *New England Journal of Medicine* 2006. 355: 1572-1582
4. Children’s Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers Version 3.0 (2008). [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)