



Who is a cancer survivor?

In today's society, the word survivor has many connotations. The word survivor has been attached to the names of TV shows to the names of celebrities. Survivor has its own unique meaning for everyone. For the purpose of this newsletter, we will use The National Coalition for Cancer Survivorship (NCCS) definition of a cancer survivor as from the time of diagnosis and for the balance of life. This definition includes family, friends and caregivers who are affected by the diagnosis in any way.

At the Comprehensive Cancer Center at Wake Forest Baptist Medical Center, experts in specific types of cancer work together to analyze a patient's diagnosis and develop the best possible treatment. Our pediatric oncology program at Brenner Children's Hospital provides comprehensive treatment programs for most childhood malignancies.

The fall edition of Synergy will highlight the unique experiences of childhood cancer survivors. We want to share this information with all survivors and those of us who, no matter how far extended, have been touched by the long term impact of children with cancer.

Marcy Poletti, Program Administrator, Oncology Services



Childhood Cancer Survivors by Sharon M Castellino, MD, MSc, Director, AWAKE

Although childhood cancer is much less common than adult cancer, the years of life saved after successful treatment of childhood cancer are enormous. With dramatic improvements in cancer treatment there is a growing population of childhood cancer survivors in the US.

Now estimated at more than 300,000, the number of childhood cancer survivors in the US increases every vear.

Current estimates are that:

1 in 640 U.S. adults age 20-39 yrs. has a history of childhood cancer

As many as two-thirds of survivors experience at least one late effect from therapy

While most late effects are not life threatening, 25% of survivors have significant late effects

Cancer, and its treatment in the growing child or adolescent, can predispose the survivor to chronic or late occurring health problems. Late effects may be silent for several years after therapy, therefore regular and lifelong follow-up and screening are very important. Survivors can experience a range of chronic diseases at a young age, including: diabetes, heart disease, stroke, high blood pressure, and second cancers. Unhealthy lifestyles may further increase the risk of these health problems in the survivor.

The AWAKE Clinic - A Long term Follow-up Program for Childhood Cancer

Ann Ballenger Schweppe, PA and Sharon M Castellino, MD, MSc, Director, AWAKE

Current recommendations for following children, teenagers and young adults include a risk-based health strategy. The "risk" is based on the chance of a late effect related to the type of cancer chemotherapy or radiation received. This involves the survivor having a copy of his/her cancer diagnosis, treatment history, and a personalized plan for health surveillance for potential cancer-related health risks in partnership with the cancer treatment team and his/her primary care provider.

The AWAKE clinic is a long-term follow-up program at Brenner Children's Hospital, specifically for survivors of cancer treated during childhood/adolescence.



Goals of AWAKE clinic:

- -Educate pediatric cancer survivors and their families about the risk of late effects and healthy living in context of their cancer treatment
- -Ensure every cancer survivor has a treatment summary and plan of care for long term health maintenance
- -Raise awareness among primary care providers and other subspecialists who care for childhood cancer survivors

The AWAKE clinic aims for a seamless transition from regular follow-up appointments to screening and management of potential treatment-related issues. As the risk of relapse decreases, surveillance for relapse of cancer is less of a focus. The goal becomes promotion of healthy living and prevention or intervention to alleviate late effects. We aim to prevent health issues later in life that may or may not be related to cancer treatment. We discuss issues such as healthy weight, cardiovascular health, sexual health, fertility and academic or vocational maintenance. Patients may undergo tests such as an echocardiogram to monitor heart or pulmonary function tests (PFTs) to monitor lung function. Blood tests are often done to monitor liver, kidney or hormone functions which may have been affected by treatment. Screening tests are planned based on the type of chemotherapy, radiation or surgery received for the cancer. If a patient is in need of specialized services, we will facilitate this referral whether it is for mental health, physical therapy, nutrition, school counseling, or another medical subspecialty. We have a counselor and a psychologist on staff for same-day evaluation if needed. A social worker is available to assist with issues that may impact medical access, such as insurance.

The visit begins with a review of the Cancer Treatment Summary, so that parents and ultimately the survivor will have a detailed treatment record. The Cancer Treatment Summary includes a review of the patient's diagnosis, therapy received (surgery, chemotherapy, radiation therapy) and known treatment related issues. It should be shared with current and future medical providers. The patient also receives a notebook that has been tailored to their treatment and possible late effects. The book is comprised of "Health Links," which are handouts from the Children's Oncology Group that review signs, symptoms and screening options for potential long-term problems. There are also written guidelines for good life-long health maintenance (exercise, nutrition and preventing second cancers). Ultimately, our goal is not only to manage and prevent long-term effects of cancer therapy, but to empower the patient with the knowledge of their history and risks so they can be their own advocate moving forward in life.

A story of Hope...

While most 13 year old girls were having sleepovers, giggling with friends and painting their nails, Natalie was embarking on a battle for her life. Natalie Smith was diagnosed with Acute Lymphoblastic Leukemia (ALL) at the age of thirteen. She recalls, "..unfortunately, the diagnosis came in the same week as the birth of my half sister, and it was an emotional roller coaster for us all."

Following 3 weeks of fever and bone pain, the diagnosis of leukemia was made at Brenner Children's hospital, by the Pediatric Oncology team. She received six months of chemotherapy at Brenner. Her rare subtype of ALL required a stem cell transplant, which she had at Duke in July 2000. Natalie was part of the early medical experience in cord blood transplant. She recalls, "my donor was actually umbilical stem cells from the cord blood bank, as my full sister and my mother did not match me." In addition to chemotherapy, her treatment included total body radiation and many immunosuppressive medicines over the initial years from transplant. Her initial long term side effects included high blood pressure, neuropathy, and ovarian failure.

On her return to Wake Forest Baptist Medical Center for her continued care, Natalie was evaluated and prepared for one of the more distressing long term side effects of transplant in young people - infertility. In fact as more childhood survivors emerge into adulthood doctors are still learning about the effects of curative cancer therapy on the growing child. Natalie states "I went into menopause following my transplant ten years ago." Her blood levels of hormones showed what appeared to be early menopause. However, much to her and her doctor's surprise, Natalie welcomed twin sons into the world in July 2010. They were premature at 27 weeks, but are doing well now. Natalie says, "now I spend my days taking care of Luc and Sam." Fortunately her heart and blood pressure were monitored and stayed healthy during her pregnancy.

This heartwarming survivorship story is not without the costs and hardship in her young life. Natalie explains, "experience has changed the pathway of my life, in that I abandoned my goal of going to the NC School of the Arts and pursued a degree in forensic sciences at Guilford College instead. I continue to run into obstacles where my survivorship is concerned. I have my bad days and there are fewer resources for covering medical expenses." In fact one of the many challenges was that in her early 20s, Natalie was unable to get health insurance as a young person with a cancer history, despite the fact that she was not taking any medications, and had a job in a local store to support herself.



However, under the recent government bill to cover young adults, Natalie, now 24, is able to be covered under her parents' insurance policy, allowing her to complete her college education. She reminds us: "survivors have to use the same will to live that was acquired to meet the challenge of reintegrating into society head on."

Dr. Castellino's response to Natalie's story: As a pediatric oncologist, and survivorship researcher, Natalie's story is a heartwarming reminder of how far the story of childhood cancer success has come, yet how much there is to learn. With the growing population of survivors in the US, we as doctors, are learning the medical and psychosocial needs of this resilient group of young people every day. Natalie's story reminds us that fertility, health access and insurance, and fulfilling school and employment goals are just some of the issues that survivors must keep track of at a young age. Her experience is a reminder that there is hope for decades of life after a childhood cancer, and that with regular medical care and health surveillance we hope to help these young people maintain decades of health and productive life.

Is Follow-up Care Important?

Yes, follow-up care is important because it helps to identify changes in health. The purpose of follow-up care is to check for recurrence (the return of cancer in the primary site) or metastasis (the spread of cancer to another part of the body). Follow-up care visits are also important to help in the prevention or early detection of other types of cancer, address ongoing problems due to cancer or its treatment, and check for physical and psychosocial effects that may develop months to years after treatment ends. All cancer survivors should have follow-up care.

Can I Trust This Website?

Questions You Should Ask

What is the purpose of the website—educational or commercial? For example, a website sponsored by a pharmaceutical company isn't likely to give you unbiased information about a competing drug. But because that site must meet the standards of the U.S. Food and Drug Administration, it will be an excellent source on a particular product.

What is the source of the information? Generally nationally known cancer centers, medical schools, large nonprofit organizations, and government agencies provide the highest quality information.

Are you able to find contact information for the people behind the website? If you can't communicate with them, find another source.

Are the links relevant and appropriate for the site? Websites that refer you to unreliable or frankly commercial sources of information should be rejected.

Remember: The Internet is not a substitute for individualized medical care and discussion with a health care provider.

Chemobrain submitted by Lyn Wooten, RN, MSN

Patients describe it as "mental fogginess" that they notice before, during and after chemotherapy. Typical complaints include trouble concentrating, forgetting things they usually have no problem remembering, taking longer to finish tasks, trouble remembering common words and problems with details like names, dates and events. Most patients report the brain recovers, but time varies from months to years. The important thing to remember is that you are not alone, about 50% of patients report brain symptoms, and this is just another "side effect" of treatment that you will learn to manage.

There have been some studies conducted on patients with "chemobrain" that have identified some factors that seem to cause or worsen the symptoms. These include the cancer itself, antiemetics, pain medications, age over 50, low hemoglobin or platelet counts, sleep problems, infection, underlying depression, fatigue, hormone changes or hormone treatments, other chronic illnesses such as diabetes or high blood pressure or nutritional deficiencies. As you can see, most of these are easily managed and/or related to the treatment phase of the cancer journey. While this period may be scary and distressing, the majority of patients return to baseline within a short period of time. Patients that receive chemotherapy directly to the central nervous system or radiation directly to the brain are those that seem to suffer long-term effects.

Here are some suggestions from patients that have helped them cope day to day:

- -Tell others what you are dealing with so that those around you can offer support
- -Use a detailed daily planner include "to do" lists, phone numbers, addresses, etc
- -Don't try to multi-task do one thing at a time
- -Exercise your brain word games, puzzles, etc
- -Get enough rest
- -Follow routines
- -Eat more vegetables studies have shown the nutrients really help!
- -Try not to focus on the problem realize that this temporary, use your resources and prioritize most important tasks for your best parts of the day

The cancer community realizes this is a real concern for cancer patients and they are beginning to really focus efforts in its direction. Recent animal studies have shown that some chemotherapy agents do harm nerve cells. Learning which nerve cells are actually damaged may help scientists test new drugs to treat this side effect. Studies are also looking at utilizing drugs that are used for depression, ADHD and Alzheimers to treat chemobrain symptoms. Recognizing the impact on quality of life and sharing information with others is so important for cancer patients. You are never alone in this.



Meet Your Cancer Center Staff (as interviewed by Marcy Poletti)

Nancy M. Smith, RN CPON, Assistant Nurse Manager, Pediatric Hematology/ Oncology, Brenner Children's Hospital

Nancy has been a nurse for more than 36 years. More than 35 of those years have been spent working with children and families in pediatric oncology. When asked why she chose to work in pediatric oncology, Nancy said she "always knew I wanted to be a pediatric nurse. Upon completing nursing school, I believe God opened doors for me in the pediatric oncology department. Dr.

Richard B. Patterson was the only physician in pediatric oncology at the time. I was a night nurse and he needed a nurse and he had a dream. He was my teacher, my mentor, my friend." The most important thing to Nancy about being a nurse is helping her patients and families through the difficult time of facing cancer.

When discussing her more than 36 years spent as a nurse, many of Nancy's most memorable nursing moments took place during the late 1970's while working with our medical center's home and school visitation program. She was able to enter into the families' environment, meet with them and discuss their diagnosis, treatments, going to school, any and all issues—with no interruptions, no beepers—for hours. For Nancy, these were great times. The long term survivor clinic is especially "rewarding" as she sees kids return as adults, and with their own families and lives.

Nancy has been married to her husband and high school sweetheart, Rickie, for 40 years. They have three children (Matthew, Amanda and Melissa) and three grandchildren (Tristan, Rex and Juliet). They are a racing family. Her entire "crew" is involved professionally in some arena of racing, mostly drag racing, but one son-in-law, Scott Speed, is involved in Nascar. Nancy loves running, biking, scuba diving and she has a huge bucket list she is working on. Last summer she learned to wake board. She also helps her husband at the races packing his car parachutes and videotaping his runs.

Nancy is also very involved with her church family. Her Sunday school class, "Sisters in Christ," is very active. She sings with her church choir and assists with special ministries that work with special needs adults. Nancy and her family attend the special ministries retreat, "Happiness Retreat," every year at Camp Caraway. One day each year she goes to Charlotte to work at Operation Christmas child. Nancy shared with me that she has "a heart and desire to become more involved in missions."

Dr. Sharon Castellino, an Associate Professor in Pediatric Hematology and Oncology expressed her deep appreciation for Nancy's commitment to the pediatric oncology program. Dr. Castellino feels that Nancy is a "truly gifted" nurse. The impact of her exceptional work ethic, personal and professional standards can be seen every day as she manages the clinic and provides direct patient care. "The parents and kids really look forward to seeing her when they return, as they recall that she helped them through an especially difficult time."

Websites for Childhood Cancer Survivors

First Descents www.FirstDescents.org

A week long adventure program centered around whitewater kayaking or rock climbing. All young adult cancer fighters and survivors (ages 18-39) are invited to attend. The camp is free. Travel Scholarships are available.

Camp Make a Dream www.campdream.org

A program designed for everyone from children to teens and young adults affected by cancer. It is housed on a Montana ranch, and hosts year-round programs for participants from the United States and Canada. The camp is free. Travel Scholarships are available.

Fertile Hope www.fertilehope.org

Fertile Hope is a national LIVESTRONG initiative to deliver information and support of reproductive options for cancer survivors.

Health Links for Survivors www.survivorshipguidelines.org

Educational handouts for childhood cancer survivors on specific health issues related to their treatment. These educational pieces are published by the Children's Oncology Group Late Effects Committee, based on the current evidence for health surveillance and well being after cancer treatment.

Psychosocial Health after Cancer submitted by Alexandra Boeving Allen, PhD

Surviving childhood cancer involves more than physical survival. There are important psychological aspects of survivorship for children, parents and siblings. We often say "Cancer doesn't happen to a child, it happens to a family." Lengthy hospitalizations, fears associated with the diagnosis, effects of treatment, and loss of control over aspects of daily life can all cause symptoms of distress differently for each member of the family. The good news is that studies show that most kids come through this psychologically healthy and well-adjusted. However, there are certain aspects of the child's functioning after cancer treatment that families and medical providers need to monitor to ensurehealthy development.

Certain treatments for childhood cancer have been associated with "neurocognitive late effects", which refer to a survivor's learning, memory, and attention. Symptoms can manifest several years after therapy and can be especially troubling for adolescents and young adults. Symptoms have most often been reported by those who received radiation to the brain, chemotherapy into the spinal fluid, or large amounts of methotrexate. "Chemo brain" has not been described as well in child/adolescent cancer survivors, but is a concept that is under study. It is therefore important to monitor the child's school functioning and; to talk with the child's school and medical provider if concerned. A comprehensive neuropsychological exam by a clinical neuropsychologist may be appropriate in some survivors.

Emotional functioning can vary tremendously over the course of cancer treatment and in the survivorship period following treatment. This is true for the survivor, parents and siblings. Transition off-treatment can be very anxiety – provoking with a perceived loss of support with less frequent contact with the medical and psychosocial teams. Some symptoms of depression and anxiety can be normal throughout this process. However, when symptoms begin to interfere with life functioning, it is important to talk with a provider, and obtain a referral to a mental health specialist. Family communication is critical during and after treatment for childhood cancer. A warm, open family environment is conducive to children expressing fears, worries, or positive emotions. Adolescent and young adult survivors of cancer face unique challenges as they simultaneously seek independence, yet need the support of family.

Families can – and do – survive childhood cancer. This process is best helped by open communication within the family and with the medical and psychosocial teams.

Websites for All Cancer Survivors

American Cancer Society 800.ACS.2345

www.cancer.org

Aims to lead the fight against cancer through its programs in research, patient services, prevention, detection, treatment and advocacy.

National Cancer Institute

800.4.CANCER

www.cancer.gov

The NCI, established under the National Cancer Center of 1937 is the Federal Government's principal agency for cancer research and training.

National Coalition for Cancer Survivorship 301.650.9127 (toll free) 877.622.7937

www.canceradvocacy.org

To lead and strengthen the survivorship movement, empower survivors and advocates for policy issues that affect their quality of life.

Cancer.Net - Survivorship

703.797.1914

www.cancer.net

Learn about adjusting to changes in your life following treatment, read survivor stories and learn how to be your own advocate.

Back to School and Work submitted by Jeff Ungetheim, MA, MDiv, LPC

Return to school or work after cancer is an important milestone. Children and teens often receive homebound services from hospital based teachers, or from their county's school system while on cancer therapy. Some children return to school during treatment, while others need to wait until treatment has ended. School re-entry can be difficult for both the parent and the child or teen. For the child, fears and anxieties can arise about how classmates will treat them. Teens and children worry about being laughed at and teased, about other kids' misunderstanding of their disease, and about whether they will be included or left out of peer groups. A school visit by a hospital social worker, counselor, or child life specialist can ease the transition, and can help to answer unspoken questions that classmates and teachers often have. A visit can help to dispel myths about childhood cancer, alleviate fears about the disease, and encourage a positive community of support among the child's peers.

School accommodations can help to provide equal access to education services and ease re-entry into school for some survivors. Children can be helped by having a 504 plan or a "medically fragile" designation. These are based on the child's medical condition. Accommodations are individual to the child's need, but may include being allowed to wear a hat, having a water bottle for hydration, or having an extra set of books at home. Academic accommodations may include having extra time on tests, fewer items on homework assignments, or extra time to turn assignments in. When learning abilities have been impacted by chemotherapy or radiation students may apply for "Other Health Impaired" (OHI) certification. Under the OHI, a child will have an individualized education plan (IEP), setting specific goals and strategies to help the survivor perform at his or her full capacity.

Beyond the school years, preparing for the work force can also pose challenges for young adults who have sustained a childhood cancer. These include employment and job limitations, or insurance issues. Various organizations and resources across the country can help with some of these. The National Coalition for Cancer Survivorship has information on employment and insurance issues, along with an explanation of laws affecting cancer survivors. Many public high schools have vocational programs that can help guide and support survivors in getting appropriate training for jobs once they graduate. In addition, each county has a Vocational Rehab office that can do the same for persons who have completed their school years. National resources include the Lance Armstrong Foundation (http:// www.livestrong.org/) and the Ulman Foundation, who focus on the needs of young adult survivors (http:// www.ulmanfund.org).

cancer **trans**i A Program of the Cancer Support Community

and LIVESTRONG"

Cancer Transitions™ is a free 2½-hour, six-week workshop designed to help cancer survivors make the transition from active treatment to post-Moving Beyond Treatment treatment care. The workshops will feature expert panelists including physicians, nutritionists and fitness experts from Wake Forest Baptist

Health. Each week, participants will join in exercise activities tailored to their abilities; receive training in relaxation and stress management as well as tips for nutritious eating. Cancer Transitions will answer many of your questions about cancer survivorship post-cancer treatment. The course covers the following topics:

Session 1: Get Back to Wellness: Take Control of Your Survivorship

Session 2: Exercise for Wellness: Customized Exercise

Session 3: Emotional Health and Well-Being: From Patient to Survivor

Session 4: Nutrition Beyond Cancer

Session 5: Medical Management Beyond Cancer: What You Need to Know

Session 6: Life Beyond Cancer

Eligibility: Adult survivors, 21 years of age and older, of any cancer diagnosis; completed active anti-cancer treatment within the past 2 years

For more details and to register for the six week program, call Teika Holloway, Oncology Outreach, at 713-6985.



Yoga is a wonderful antidote to stress and tension! Join us for an hour of yoga that will leave you feeling relaxed and energized.

September 13, 20, 27 Fall 2011 5:30-6:30 p.m. on Tuesdays November 1, 8, 15, 22, 29

October 4, 11, 18, 25

with Lynn Felder **December** 6, 13

Fall 2011 *September* 15, 22, 29 5:30-6:30 p.m. **October** 6, 13, 20, 27 on Thursdays November 3, 10, 17 with Stephanie Sohl December 1, 8, 15

Winter/Spring 2012 January 17, 24

5:30-6:30 p.m. **February** 7, 14, 21, 28 with Lynn Felder April 3, 10, 17, 24 May 1, 8, 15, 22, 29

June 5, 12, 19, 26 July 3, 10, 17, 24

Where: Comprehensive Cancer Center of Wake Forest University, Meditation Room, 2nd

Cost: FRFF

Who can attend? Classes are open to cancer patients and survivors (whether in treatment or finished,

men or women welcome) and their close family members or friends (bring a buddy!)

Some voga mats and other equipment will be available. The instructor will discuss Materials: where you may buy a yoga mat or other optional props, if you care to have your

Pre-Requisites: None! No experience needed.

Questions? Contact Lynn Felder, RYT from the Yoga Gallery (www.yogagallery.net) at

lynn@artsofyoga.com or (336) 655-7047

To subscribe to the newsletter, to submit your story or if you have suggestions for newsletter content,

please e-mail cccinfo@wakehealth.edu

Wake Forest™ Baptist Health

The National Cancer Institute's (NCI's) Cancer Information Service (CIS) is a federally funded program that was established in 1975 as an essential part of NCI's cancer education and information efforts. NCI's CIS answers questions about cancer, clinical trials, and cancer-related services and helps users find information on the NCI Web site. Provides NCI printed materials.

TO LEARN MORE ABOUT NATIONAL CANCER INSTITUTE RESOURCES:

Contact the National Cancer Institute's Cancer Information Service (CIS)

Toll free: 1-800-4-CANCER (1-800-433-6237)

TTY: 1-800-332-8615

Online: www.cancer.gov

Chat online: www.cancer.gov/help

Other Contributors to our Childhood Cancer Survivors Articles:

Dashea Bowen, LPN, Marcia Wofford, MD, Section Chief, Pediatric Hematology/Oncology

Thomas McLean, MD



Volunteer Services

Get Involved

Wake Forest Baptist Medical Center volunteers play a vital role in supporting the Medical Center's mission of providing comprehensive healthcare services of the highest quality to our patients.

Volunteers serve more than 80 different departments within the Medical Center, assisting staff in providing quality care and service to patients and their families.

Any questions call the volunteer office at 713-3514 or visit our website www.wakehealth.edu/volunteer.