

UNC helps cancer patients, families shift *into* survival mode

Like being dropped off a cliff.

That's how many patients describe the difficult transition from their initial cancer treatment to cancer survivorship, says Marci Campbell, PhD, MPH.

And that's something she and others at UNC's Gillings School of Global Public Health and the Lineberger Comprehensive Cancer Center are addressing. Last year, LIVESTRONG™ chose Lineberger as a LIVESTRONG™ Survivorship Center of Excellence, part of a Network of centers that direct survivorship services and increase the effectiveness of survivorship care through research, the development of new interventions and sharing of best practices.

LIVESTRONG™

SURVIVORSHIP CENTER
OF EXCELLENCE NETWORK

THE  FOUNDATION®
for Cancer Research

Working together, LIVESTRONG™ Survivorship Center of Excellence Network members are examining and transforming how survivors are treated and served in a variety of settings, stimulating survivorship research, and improving the quality and integration of care among health care providers caring for cancer survivors.

Campbell, a nutrition professor, co-directs the Center. "We are very honored to be chosen," she says. "We're only one of eight in the nation and the only one in the southeast."

The Center at UNC Lineberger, Carolina Well, was formed with a five-year \$1.5 million grant co-funded by LIVESTRONG and The V Foundation for Cancer Research. Additional grants will fund three community-based centers that will collaborate closely with UNC Lineberger.

Awareness of the special needs of cancer survivors is growing. Today, more than 65 percent of adults and 75 percent of children who are diagnosed with cancer survive more than five years. It's a phenomenon expected to continue as an aging population brings more cancer



Dr. Marci Campbell

diagnoses, while treatments and early detection bring down death rates. Nationwide, the number of cancer survivors is 12 million. About 300,000 of them live in North Carolina.

Campbell has worked with others, including Paul Godley, MD, PhD, and Donald Rosenstein, MD, to establish community-based centers at hospitals and health care clinics in other locations across the state. Godley is associate professor of hematology and oncology in UNC's School of Medicine and a member of the Lineberger Comprehensive Cancer Center. Dr. Rosenstein is a professor of psychiatry and director of the new UNC Comprehensive Cancer Support Program.

As a result of their efforts, full-time outreach coordinators who specialize in survivorship issues are now in place at the Greensboro Area Health Education Center (AHEC), Tri-County Community Health Center in Sampson County and the Zimmer Cancer Center at the New Hanover Regional Medical Center in Wilmington.

"We didn't want it to be so that everyone had to come to Chapel Hill," Campbell says.

The program also helped establish an off-campus clinic at UNC where survivors can receive follow-up care, such as psychosocial counseling and wellness care. That helps ►►

CANCER SURVIVOR RESOURCES

- LIVESTRONG: www.livestrong.org
- LIVESTRONG Care Plan: www.livestrongcareplan.org
- Carolina Well UNC Lineberger Survivorship Program: www.carolinawell.org
- National Coalition for Cancer Survivorship's "Cancer Survival Toolbox" (a free, self-learning audio program developed by leading cancer organizations; contains a set of basic skills, as well as special topics): www.canceradvocacy.org/toolbox
- National Cancer Institute's Cancer Survivorship information site: <http://dccps.nci.nih.gov/ocs/>

those “who may not want to return to a hospital setting where many people are still very ill and in treatment,” Campbell says.

The goal is for every cancer survivor to leave with a treatment summary and survivorship care plan. The plan would address physical as well as psychological and support needs and include a comprehensive list of medications and treatments used, which can be helpful to a patient’s primary care physician.

In an effort to address survivor needs, Campbell says, questionnaires were given to

cancer patients and caregivers at N.C. Cancer Hospital in the fall of 2008, asking survivors whether they had received enough information (about everything from sexual issues to keeping track of important medical records), and what kind of programs and services they would like to have.

As they return to work and “the new normal,” cancer survivors say they sometimes feel as though the network of family and friends that supported them had now moved on. In addition, many have financial and

work issues that may put tremendous stress on the patient and family.

Clinical caregivers may need some education as well, Campbell says. While some caregivers would say, “Well, that’s done,” the cancer survivor knows that the battle rages on, even without medicine or surgery.

“We heard several stories about cancer patients being given a celebration on the last day of treatment,” Campbell says. This is usually done with the best of intentions – but to the patient, it can seem as though the warm circle of staff and caregivers is leaving, and the patient may feel fearful and alone.

Caroline Huffman, director of patient navigation services at LIVESTRONG, praised Lineberger staff for their progress developing a survivorship center program.

“Lineberger is poised to accomplish great things,” Huffman says. “They’ve got a great team put together and they are incredibly enthusiastic.” ■

– *By Sylvia Adcock*

STEPS OF YOUR OWN

- If you or a loved one is battling cancer, **keep track of all treatments and medications**, including dates and places. This list can be helpful for your primary care physician later.
- Don’t pretend that everything is finished, once treatments are over. The patient needs continuing emotional and possibly physical support beyond chemotherapy or radiation.