

The University of Colorado Cancer Center's Cancer Survivorship Program



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An NCI-designated Comprehensive Cancer Center brings survivorship resources to the community by Alison Faust, RN, ND

LONG-TERM CARE FOR CANCER SURVIVORS requires post-treatment follow-up surveillance, late effects management, rehabilitation, counseling, and health promotion efforts. To help meet these needs, the University of Colorado Cancer Center (UCCC) developed an extensive survivorship program comprised of multiple components, including:

- Enhanced Cancer Resource Centers at UCCC and its three affiliated community-based cancer centers
- Cancer survivor outreach through support groups and classes, including outreach targeting Hispanic and rural cancer survivors
- A telephone counseling and support program
- Ongoing cancer survivorship needs assessment
- Cancer survivor research and dissemination.

In 2006, UCCC joined the LIVESTRONG™ Survivorship Center of Excellence Network, an invitation-only collaborative partnership between the Lance Armstrong Foundation and seven NCI-designated Comprehensive Cancer Centers and their community affiliates.

A \$1.7 million dollar grant from the Lance Armstrong Foundation helped support the creation of the UCCC LIVESTRONG Survivorship Center of Excellence. Today, this program disseminates cancer survivorship research findings, provides professional education, and makes survivorship resources available to patients at UCCC and patients at UCCC's three affiliated community-based institutions:

1. Denver Health Medical Center in Denver, Colorado
2. St. Mary-Corwin Cancer Center in Pueblo, Colorado
3. St. Mary's Regional Cancer Center in Grand Junction, Colorado.

Core components of UCCC's LIVESTRONG Survivorship Center of Excellence include: 1) Cancer Survivor Resource Centers, 2) cancer information and counseling, 3) cancer survivorship educational classes, and 4) cancer treatment summaries and care plans.

Cancer Survivorship Resource Centers

UCCC's Montfort Family Foundation Cancer Resource Center has specially trained volunteers who provide information and resources that match each cancer survivor's needs. Cancer patients, families, and caregivers have access to cancer survivorship-related information and support, including:

- An American Cancer Society (ACS) Cancer Resource Navigator
- Support groups and educational classes
- Computers with Internet access
- Lodging and transportation services near UCCC
- Audio-visual materials for use during treatment at UCCC on topics such as stress release, guided imagery, stories, spirituality, and relaxation
- UCCC tours for new patients, caregivers, and family members and special "Lemonade Tours" for children of cancer patients.

Today, UCCC is working with its three affiliated community-based cancer centers to establish cancer survivorship centers at each location. Modeled after the Montfort Family Foundation Cancer Resource Center, each center will contain a library of print materials, as well as a computer for online access to cancer survivorship information and programs. Grant funds will pay for an onsite coordinator position at each location. The coordinator will serve as the initial contact with cancer survivors:

- Connecting cancer survivors to local and national resources
- Instituting a survivor tracking system
- Training and supervising volunteer staff
- Documenting the activities in the cancer survivorship resource centers using daily logs



- Communicating with other coordinators at UCCC and the other affiliated sites.

Onsite coordinators will also enhance resource options for patients by making community contacts and connections, as well as spread awareness of the survivorship program to the wider community. The end goal is to provide cancer survivors—particularly underserved and rural cancer survivors—with accessible information on all their cancer needs.

Cancer Information and Counseling

UCCC offers a toll free Cancer Information and Counseling Line (800.535.3777) that provides cancer information and counseling to cancer patients, survivors, and family members, as well as to the general public and health professionals. The program uses two service models. The first service model requires that cancer survivors call the line with their questions and concerns. This more traditional format uses a brief, integrative, one-session, caller-initiated, telephone counseling model. Telephone counselors draw from a "theory menu" to identify therapeutic strategies that best match the caller's situation. The Cancer Information and Counseling Line receives about 2,500 patient-initiated calls each year and serves as a professional counseling referral source for the NCI's Cancer Information Service, ACS' National Cancer Information Center, and the Lance Armstrong Foundation.

The second service delivery model, which is being implemented as a demonstration project, reverses this sequence by having counselors make scheduled out calls to participating cancer survivors. This "enhanced" model is a well-articulated, theory-based, four- to six-session program driven by three central themes derived from scientific literature and our own research program conducted by Al Marcus, PhD, and Kathleen Garrett, MA. The specific thematic domains include: 1) living with uncertainty; 2) symptom management post-treatment, defined broadly as physical, emotional, sexual

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Patients and staff at the University of Colorado Cancer Center.

functioning, and the use of complementary and alternative medicine, and finally; 3) behavioral and lifestyle education and counseling appropriate for cancer survivors. Another exceptional feature of this service is that it is preparatory. In other words, issues that commonly arise during the course of re-entry and long-term survivorship will be introduced and explored early on so that participants will be better prepared to deal with them.

Briefly, here's how this enhanced service delivery model works. At their last treatment visit or during a follow-up oncology visit, eligible cancer survivors are invited to participate in the program either by UCCC staff or by onsite coordinators at the affiliated-institutions. The first call is scheduled within one to two weeks post-enrollment, and provides a general orientation as well as reinforcement of routine follow-up and surveillance post-treatment. During this first call, participating cancer survivors will:

- Hear about an adaptive coping model,
- Begin exploring feelings of uncertainty, and
- Create a wellness plan that includes adherence to recommended follow-up care.

During the symptom management sessions (calls two and three), participants identify and prioritize post-treatment physical, psychosocial, and sexual concerns such as pain, fatigue, physical impairment, mood, anxiety, and sexual dysfunction. Participants are encouraged to explore survivorship concerns, identifying what is and what is not within their control to change, and develop action plans as appropriate.

During the behavioral and lifestyle counseling sessions (calls four and five), counselors proactively explore participants' interest in lifestyle and behavior change in such areas as diet and physical activity using MI (motivational interviewing) techniques. This portion of the

intervention mirrors the ACS Guidelines on Nutrition and Physical Activity for Cancer Prevention developed in collaboration with Tim Byers, MD, MPH, Deputy Director of the University of Colorado Cancer Center. Recommended behaviors include: 1) eating a variety of healthful foods, including fruits and vegetables; 2) adopting a physical lifestyle; and 3) maintaining a healthy weight. The goals of sessions four and five: to help participants assess and enhance motivation for healthy living and set small reachable health-related goals.

The final outcall to cancer survivors (call six) is a synthesis and integration of all previous telephone calls. Contingent upon the final evaluation of this demonstration project, UCCC is planning to implement this enhanced counseling program as part of its usual service model for eligible cancer survivors.

Cancer Survivorship Educational Classes

UCCC has also been developing cancer survivorship educational classes, which it is in the process of implementing at its affiliated community-based cancer programs. These classes started in June and will be offered on a monthly basis. The classes are free and open to patients, family members, caregivers, and the community. A variety of UCCC staff will be teaching classes, including dietitians, social workers, physicians, physical therapists, and nurses. Topics include: medical follow-up after treatment; emotional aspects of completing treatment; side effects and after effects of cancer treatments; practical concerns, such as insurance coverage and returning to work; nutrition; physical therapy; and social relationships after treatment.

Cancer Treatment Summaries and Care Plans

Denver Health Medical Center, one of UCCC's community affiliates in the LIVESTRONG™ Network, is

The University of Colorado Cancer Center (UCCC) is the only NCI-designated Comprehensive Cancer Center in the Rocky Mountain Region. Over the past several years, UCCC has developed several new programs of research and service in the area of cancer survivorship.



incorporating cancer patient treatment summaries and survivorship care plans into its ongoing NCI-sponsored Patient Navigation Research Program, *Improving Patient Outcomes Through System Navigation*. The care plan will provide a template for the patient navigator and the patient care team to record specific therapies recommended and received, important disease characteristics, and contact information for the multidisciplinary care team members. In addition, the care plan will incorporate available evidence-based standards of care, including:

- Potential for late side effects
- Signs of possible recurrence
- Recommended cancer screening and other periodic testing and examinations
- Referrals for special issues and concerns
- Other information designed to increase the patient's knowledge and self-efficacy.

This plan will be discussed and shared with patients at key times of treatment initiation and completion. Denver Health Medical Center envisions the process to have a three-fold function: 1) providing initial treatment recommendations to the patient, 2) allowing for monitoring of the treatments received, and 3) evolving into a survivorship plan upon the patient's completion of primary treatments.

Denver Health Medical Center plans on evaluating these cancer care plans with breast and colorectal cancer patients enrolled in the Patient Navigation Research Pro-

gram. This evaluation will include the development of an electronic database to provide and update the information required for the care plans; periodic printouts for patients; and an assessment of satisfaction, usefulness, and ease of use for the patient, the patient navigator, and care providers.

UCCC is conducting a needs assessment study on using similar cancer treatment summaries and care plans for cancer survivorship follow-up care at its location. It is likely that these survivorship programs for surveillance, rehabilitation, and continuing care will be clinic-based rather than centralized in one location, and will focus on dedicated programs for both adult survivors of childhood cancer, as well as adult oncology patients.

A Growing Need

Today, more than 10 million Americans are living with cancer. As the number of people surviving cancer continues to increase, and as their challenges grow in magnitude and complexity, an increasing need exists for new models of survivorship care and new programs for cancer survivorship research. NCI-designated Comprehensive Cancer Centers should be at the forefront in developing these new models and programs in cancer survivorship and bringing these much-needed resources back into the community. 🏠

Alison Faust, RN, ND, is cancer survivorship program manager at the University of Colorado Cancer Center in Aurora, Colo.

Research and Service Programs in Cancer Survivorship

Outside of the LIVESTRONG™ Survivorship Center of Excellence, UCCC has developed and implemented other noteworthy research and service survivorship programs such as:

- **Telephone counseling intervention of head and neck cancer patients.** This innovative pilot study uses specially trained counselors to improve symptom management and psychosocial support for patients being treated for these difficult cancers.
- **Telephone counseling for symptom management in older cancer patients.** This feasibility study uses UCCC's enhanced telephone counseling model with older patients undergoing chemotherapy and/or radiation. Telephone outcalls target symptom management and support during cancer treatment, as well as the transition into the early stages of cancer survivorship.
- **The CARES Project.** CARES is a pilot multidisciplinary case management program that integrates onsite navigation and counselor-initiated phone calls along with the nurse-orientated case management. Eligible patients receive support at strategic points before, during, and after their breast cancer treatment.
- **Community project REGAIN.** This unique collaboration between an existing community-based exercise program and UCCC is designed to provide guidance on nutrition, exercise, and cancer recovery to long-term cancer survivors in the Denver metro area.
- **Survivorship Update Network.** This observational study is following a cohort of nearly 2,000 women who participated in a case/control study of breast cancer. The new survey will gather information about long-term outcomes such as quality of life, adherence to care, and recurrence.