

SURVIVOR AND FAMILY ISSUES



Survivor and Family Issues

Over the past three decades, the number of cancer survivors in the US has more than tripled, from three million survivors in 1971 to almost ten million survivors in 2001. Today, more than half of all people (62 percent) diagnosed with cancer are expected to live at least five years after diagnosis (CDC, 2004).

Along with this extraordinary rise in survival rates, there has been a concurrent shift in public health policy, with a new focus on cancer survivorship. Programs for people living with arthritis, heart disease, and diabetes are commonplace. But we are just beginning to recognize that many people will live for years, and perhaps decades, as cancer survivors. The SCCA has taken the challenge to implement cancer programs with quality of life for cancer survivors as a key component.

Individuals diagnosed with cancer and their caregivers face multi-dimensional and sometimes overwhelming decisions regarding their illness. These issues, which cut across all diagnoses, demographic categories, and cultures, include:

- Access to information and resources about their disease
- Financial and legal issues
- Psychosocial and spiritual issues
- Long-term survivorship issues
- Coping with the loss of a loved one

In addition to these challenges, the SCCA recognizes that poverty, lack of education, and cultural differences can introduce barriers that may require targeted interventions and strategies.

The SCCA objectives and strategies were designed to address these complex issues and recommend ways to alleviate them. The SC Cancer Alliance can harness multi-faceted resources to promote cancer survivor and family empowerment. A key strategy in this regard is the promotion of patient navigators: individuals who are prepared to guide patients through an often confusing and fragmented health care system.

Survivor and Family Issues

The focus of this section is meant to increase the support system for and communication among cancer survivors and families to assist them in obtaining the best possible information and treatment. The SCCA objectives and strategies include the development of written and electronic resources that can be easily accessed by cancer survivors. The goal of these resources is to give South Carolinians the most current medical information available, and at the same time, to help individuals maintain an outlook of personal healing while seeking a cure. These strategies recognize that cancer survivors must often face a barrage of life-or-death decisions, under conditions of tremendous stress.

The strategies in this section focus on cancer as a family issue. As a reflection, this section also addresses end-of-life issues, including the needs of families and supporters of cancer patients who are left to cope after the death of the patient.

Survivor and Family Issues is a new arena in public health planning, grounded in the belief that when we approach cancer, we should embrace the cancer patient as a whole person in the wider context of family and community. The SCCA believes that there is no better resource for current cancer survivors or caregivers than those who have experienced cancer. Members of the Survivor and Family Task Force and other experienced individuals can serve as a valuable resource for support, advice, and information to those currently experiencing cancer-related issues.

“I never dreamed I would have cancer. But I realized there was very little support out there for people who were really thinking longer term about their lives. Not, will I live or die? But how well will I live?”

Doug Ulman, Lance Armstrong Foundation

Survivor and Family Issues

Objective 1. By June 2006, conduct a survey on resources to address cancer rehabilitation services, including location and financial requirements, and quality of life services for those living with cancer, and provide this information to cancer patients, their caregivers, and to cancer care providers.

Strategy 1. Conduct an inventory of current available resources.

Strategy 2. Compile and categorize resources.

Strategy 3. Identify contacts, unmet needs, and possible links for additional information.

Strategy 4. Identify HIPAA issues regarding confidentiality and work to remove barriers to information sharing.

Objective 2. By July 2007, to promote survivor and family empowerment, develop a comprehensive, flexible, electronic database, which is easily accessible, that will provide relevant information and be updated at least quarterly.

Strategy 1. Conduct an inventory of current available resources (include options for treatment and continuing care).

Strategy 2. Compile and categorize resources.

Strategy 3. Identify contacts, unmet needs, and possible links for additional information.

Strategy 4. Identify HIPAA issues regarding confidentiality and work to remove barriers to information sharing.

Objective 3. By September 2007, conduct a survey on resources to address end-of-life issues and publish a database accessible to patients, family, and survivors, which include best practices and end-of-life empowerment resources.

Strategy 1. Conduct an inventory of current available resources.

Strategy 2. Compile and categorize resources.

Strategy 3. Identify contacts, unmet needs, and possible links for additional information.

Survivor and Family Issues

Objective 4. By December 2007, to promote cancer survivor and family empowerment, advocate with the American College of Surgeons (ACOS) to include specific requirements and minimum standards for cancer patient navigation services for cancer treatment centers to obtain and retain ACOS certification.

Strategy 1. Meet with state ACOS representatives to assess current patient navigation services and determine the areas that show need for increased patient navigation services.

Strategy 2. Provide information and data to hospital administrators and physician practices regarding the importance of navigation services, stressing the economic value of trained lay navigators supplementing professional navigators.

Strategy 3. Advocate with government health plans and private insurers to increase reimbursement for patient navigators.

Today, more than half of all people (62 percent) diagnosed with cancer are expected to live at least five years after diagnosis (CDC, 2004). (from report)

Objective 5: By July 2008, to promote cancer survivor and family empowerment, organize a group of lay volunteers who have experience navigating through the medical, financial, legal, and psychosocial systems that cancer patients, caregivers, and survivors must access to ensure quality care, rehabilitation services, and end-of-life assistance.

Strategy 1. Through the survivor and family task force, recruit volunteers to counsel and advise current survivors, care givers, and family members on issues related to the objectives below.

Strategy 2. Provide training on the systems that impact patients, caregivers, and survivors, training on how to access those systems, and training on how to provide support necessary to work through the systems.

Strategy 3. Compile written and electronic information on systems navigation to be provided to hospitals and other healthcare facilities for personal distribution to cancer patients, care givers and survivors to ensure that they have current information on available services and guidance to interpret it.

Survivor and Family Issues is a new arena in public health planning, grounded in the belief that when we approach cancer, we should embrace the cancer patient as a whole person in the wider context of family and community. (from report)