Cancer survivors are growing in numbers as prevention, screening, early diagnosis, and treatment improve. There were 65,524 cancer survivors among the Kansans who were diagnosed with malignant cancer between 1998 and 2008. In Kansas in 2009, 6.5 percent of adults reported ever being diagnosed with cancer (excluding skin cancer). Survivors’ quality of life and quality of care continue to play an important role in addressing the burden of cancer in Kansas. In the last twenty-five years we have thankfully seen a dramatic improvement in the treatment in childhood cancer, and currently the overall cure rate is 82 percent. This means that about 1 out of every 640 adults is a survivor of childhood cancer. It is important to note that 67 percent of childhood cancer survivors will develop at least one late effect and 25% of these will be severe or life-threatening. Health care providers and survivors can learn more about how to manage the late effects of childhood and adult cancers at www.survivorshipguidelines.org.

People who have ever been diagnosed with cancer tend to have risk factors for cancer recurrence, including current smoking and not engaging in leisure time physical activity. In 2009, Kansas cancer survivors were significantly more likely to self-report fair/poor health, to report more physically and emotionally unhealthy days in the past month, and/or report more days where poor health interfered with usual activities. In addition, compared to those who did not report ever being diagnosed with cancer, Kansas cancer survivors were significantly more likely to be older, female, and/or retired. They were also less likely to have more than high school education and/or to be Hispanic than those who did not report ever being diagnosed with cancer. This information can be used to help develop and evaluate interventions aimed at improving the quality of life of cancer survivors.

When the disease is terminal, hospice services, including palliative care, quality of medical delivery, acceptance and assistance with grief processes, and culturally sensitive and compassionate support, are all critical. Terminally ill patients may access hospice services, regardless of age, religion, race, or type of illness. Most private insurance plans, managed care organizations, Medicaid, and Medicare cover hospice services.

**Hospice Care**

The National Hospice and Palliative Care Organization describes Hospice care as follows:

“At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.”

“Hospice focuses on caring, not curing and, in most cases, care is provided in the patient’s home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.”
The Institute of Medicine (IOM) recommends all survivors have a treatment summary and survivorship care plan to describe each survivor’s treatment and plan for ongoing follow-up. The increasing number of cancer survivors underscores the need for medical and public health professionals to address the potential long-term and late effects of cancer on survivors’ physical and psychosocial well-being.\textsuperscript{31} Cancer patients and survivors often need support to deal with issues such as finances, insurance, employment, transportation and simply the tasks of daily living. In 2006, the Kansas LIFE Project engaged Kansas cancer patients and caregivers in Listen and Learn focus groups. Information that participants shared about their cancer journeys was used to identify needed resources, such as TLC in the Workplace\textsuperscript{®} from Hospice and Palliative Care of Greensboro, North Carolina. The Kansas Cancer Partnership (KCP) expanded on the TLC approach, and developed Employee Illness and Survivorship in the Workplace (EISW) training curriculum to specifically address workplace issues for cancer survivors and others with serious chronic illness.

Cancer survivors also benefit from coordinated care, and promotion of 1) healthy behaviors (e.g., smoking cessation and physical activity) to reduce the risk for new or recurrent cancer and 2) early detection to increase the likelihood of survival with new or recurrent cancer.\textsuperscript{31} Strategies outlined in previous sections that address prevention and early detection are relevant to cancer survivors.

“Throughout my ordeal with cancer I have been able to maintain my quality of life.”

With cancer diagnosed three times in eight years, Barbara knows she will live with it the rest of her life. “I am comfortable with my mortality,” the retired teacher said.

Barbara’s cancer journey began in 2001 with cancer diagnosed in her right breast, which was removed along with 19 lymph nodes. In 2003, her left breast was removed when a precancerous lump was found. In 2007, a general feeling of tiredness, bladder problems and distended abdomen led to a diagnosis of Stage IV ovarian cancer.

Subsequently, Barbara had a total hysterectomy with removal of her ovaries. In addition, a colostomy was performed, followed by chemotherapy for seven months, then a surgery to remove tumors from her liver. Her spleen also was removed and she has since had numerous rounds of chemotherapy. She expects to have more surgery in the future as well.

Barbara thinks of cancer as a chronic disease that she lives with each day. She is now an advocate for fellow cancer survivors and states, “We all need someone else to talk to who knows what we’re going through.”
Survivorship and Quality of Life Objective: Physical and Mental Health

1. Improve quality of life for cancer survivors, including physical and mental health

<table>
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<th>Measure</th>
<th>Baseline</th>
<th>Five Year Target</th>
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<tr>
<td>Among adults aged 18 years and older who have ever been diagnosed with cancer, the percent who reported that poor physical or mental health kept them from doing usual activities, such as self-care, work, or recreation, on 14 or more of the past 30 days</td>
<td>20.2% (2009 BRFSS)</td>
<td>19%</td>
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</table>

**Strategies**

1a. Systematically disseminate and support implementation of evidence-based programs, policies, and messages to improve quality of life of cancer survivors to health coalitions, community leaders, health professionals, and worksites.

1b. Improve nutrition and physical activity behaviors among cancer survivors.

1c. Expand availability of workshops (e.g., EISW) in the workplace statewide and among existing health coalitions.

1d. Collaborate with chronic disease prevention programs to leverage resources for promoting healthy behaviors and reducing health risk behaviors among cancer survivors.

1e. Incorporate steps to target identified disparate populations (age, income, disability, rural-urban location, and race or ethnic status) when implementing recommended strategies.

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**Key Accomplishments**

- “Caring Conversations” health care directive training in 2006 for select KCP members served as impetus for development of the EISW module to supplement TLC in the Workplace® training.
- Added Survivorship questions to BRFSS in 2007 and 2009. Data from this telephone survey helps in planning interventions to address behavioral risks and their consequent health outcomes, as well as monitoring progress toward achieving public health program goals and objectives.
- EISW training piloted in 2008 for 125 state employees. EISW won first place at the 2009 National Comprehensive Cancer Control Program Poster session as “an innovative project with an outstanding contribution to cancer programs in the nation.” In 2010, EISW was co-sponsored by KDHE and the Center for Practical Bioethics (CPB) for 11 more employers to take to their workforces. CPB posted a 15-minute related podcast on their website as well as highlighted the training in their weekly electronic E-Alert. The E-Alert posting resulted in 159 downloads, thereby expanding awareness of this critical workplace issue. CPB continues promotion of this course with large employers in the Kansas City area.
- In 2009, a representative of the American Society of Clinical Oncologists (ASCO) provided training to KCP members on use of ASCO Patient Treatment Records to document cancer treatment histories for patients and their primary physicians. Subsequently, a pilot project was conducted at two Topeka hospitals to evaluate use of these forms. Similar forms were examined by KCP members and general consensus was that the forms can be lengthy and cumbersome and until documentation of this information is a billable service, widespread use will be limited.
- Supported establishment of the KU Wichita Breast Cancer Survivorship Clinic in conjunction with Susan G. Komen for the Cure. The clinic serves women in the metro area and central and western Kansas. The clinic opened in late 2009 and marketing of services began in 2010. Efforts are ongoing to educate family practice physicians and other health care providers about services available through the Clinic.
Survivorship and Quality of Life Objectives: Quality of Care

2. Increase the number of cancer centers that work together with patients to develop a comprehensive care summary and follow-up plan to promote physical and mental health after completing treatment

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Five Year Target</th>
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<tbody>
<tr>
<td>Survey to Cancer Centers</td>
<td>To be determined</td>
<td>To be determined</td>
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</table>

**Strategies**

2a. Increase awareness and use among primary care and oncology providers of survivor care plans that include patients in plan development and address both physical and mental health.

2b. Educate cancer patients/survivors about the need for survivor care plans.

2c. Increase the number of patient navigators who include patients in the development of survivor care plans that address physical and mental health.

2d. Develop a methodology for evaluating this objective.

3. Increase use of hospice services

<table>
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<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Five Year Target</th>
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<tbody>
<tr>
<td>Average hospice days per cancer patient in</td>
<td>~10 (2011</td>
<td>≥14</td>
</tr>
<tr>
<td>Kansas during the last month of life</td>
<td>Dartmouth Atlas of Health Care</td>
<td></td>
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**Strategies**

3a. Make available Advance Care Planning tools and resources for those with advanced illness and Goals of Care, incorporating steps to target identified disparate populations (age, income, disability, rural-urban location, and race or ethnic status).

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