

SURVIVORSHIP/END OF LIFE

Cancer survivors are growing in numbers as prevention, screening, early diagnosis and treatment improve. Survivorship and End of Life care is and will continue to play an important role in addressing the burden of cancer in Kansas. Recovery and reintegration into family, society, and workplace are all issues a cancer patient must face. And just as critical, when the disease is terminal, palliative care including quality of the medical delivery, pain management, therapies, acceptance, and culturally sensitive and compassionate support are all important. Cancer patients and survivors often need support to deal with issues such as finances, insurance, employment, transportation and simply the tasks of daily living. The quality of life dimensions cover four issues: physical, psychological, social and spiritual. Patients often need help in navigating the health care system, physical rehabilitation and the control of pain to minimize suffering and ease the side effects of treatment. The barriers for this continuum mirror that of others including physician education, the lack of patient and caregiver information, financial and transportation issues and geographic, social and language concerns.

GOALS

- A-** Better health care professional education is needed for pain and patient care symptom management
- B-** Better rehabilitation and recovery plans for survivors
- C-** Utilization of hospice when appropriate

STRATEGIES

- A-** Professional education
- B-** Information clearinghouse
- C-** Promotion of healthy lifestyle
- D-** Business and industry survivorship standards
- E-** Patient navigators

PROFESSIONAL EDUCATION

Need for better health care professional education in terms of pain and patient care symptom management

Strategy A: Ensure that all health professionals receive standardized end of life, palliative care and survivorship education.

Action/Outcome: Survey nursing and medical schools to determine current end of life, palliative care and survivorship education by January 2006.

Review End of Life Consortium education curriculum and determine best practices by April 2006.

Develop relationship with Kansas Medical Society and State Board of Nursing to assist with development of curriculum and implementation by January 2006.

Develop and/or recommend a standardized professional education curriculum for nurses and physicians by July 2006.

Promote policy to assure appropriate professional educational components are offered by January 2009.

Rationale:

- Lack of physician education in end of life care
- Underutilization of hospice care

STATEWIDE INFORMATION ACCESS POINT

Information for cancer survivors, families and health professionals

Strategy B: Develop a statewide central information access point (one stop for cancer information) for cancer patients, their families and health care professionals.

Action/Outcome: Determine appropriate agency to provide information via toll-free number and website for cancer patients, care-takers and possibly human resource professionals by October 2005.

Promote the toll-free number and website to Kansas through mass media effort by June 2006.

Develop and maintain an annual statewide information exchange session by January 2007 and annually thereafter.

Rationale:

- Accessing credible information often is difficult
- Comprehensive approach needed to provide accurate and timely cancer information

HEALTHY LIFESTYLE FOR SURVIVORS

Promote healthy lifestyle choices for cancer survivors

Strategy C- Promote healthful diet and lifestyle choices to reduce the risk of both recurrence and secondary cancer among survivors.



Sarah-
Cancer Survivor

I was in Jamaica in October 2002 and had gotten sick down there. When I returned to college in Emporia, I was still feeling ill and thought I had a parasite. My stomach was bloated and I had other symptoms. My doctor started treating me for parasites and when I didn't improve he checked me for irritable bowel syndrome. It was during this test that I learned I had colon cancer one week before Thanksgiving in 2002.

I was in major denial about my disease. I wanted to finish school in May and didn't want to have surgery that would have made me miss classes for six weeks. I skipped doctor's appointments and some chemotherapy and radiation treatments. Then about a year and a half later I found out the cancer had spread to my lymph nodes and I thought 'time to get real.' My doctor suggested I enter a clinical trial and I went to the Cleveland Clinic where they did immunotherapy, which uses your own immune system to treat your cancer. It put me into remission for about a month, but when I was checked by my doctor in Kansas City, the cancer had returned. I was then entered into a more aggressive therapy trial and my cancer has now been in remission since November 2003. I continue to have polyps removed from my colon when needed.

My son was only two years old when I was first diagnosed and I kept picturing things like his graduation or wedding day without me there. He was so young; I didn't think he would remember me...

I thank God I had him because he really gave me the willpower to fight the
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...cancer no matter what. I wasn't going to leave him without a mama. He's my world and has been my driving force these last couple of years. He is a very caring child and can sense when I don't feel good or come home from work tired.

My family, friends and church were of tremendous support. I could call my parents in the middle of the night when I was very angry or upset. My church held a fund raiser to help with my medical expenses. My friends were there for whatever I needed.

My maternal grandfather died of colon cancer and I believe there is a genetic tendency in our family. My sister has had a colonoscopy and been tested- not easy for a 15 year old. And my son will be tested too when he is older. I think my fight against cancer has brought my whole family closer together.

Action/Outcome: Increase the consumption of fruit, vegetables and whole grains among Kansans and decrease consumption of high calorie, high fat, low nutrient value foods especially from animal sources and decrease alcoholic consumption.

Increase the percentage of survivors who meet the recommended levels of physical activity and reduce the percentage of survivors who engage in little or no physical activity. Promote safe food handling to reduce the risk of infection and illness.

Rationale:

- Cancer patients and survivors need help with special diets and lifestyle changes
- Safe food sources are a necessity for cancer patients and survivors

BUSINESS STANDARD OF EXCELLENCE

Business and industry survivorship standards

Strategy D: Create a business and industry standard of excellence for cancer survivors.

Action/Outcome: Develop and sponsor a training for human resource professionals by the Fall of 2005 and ongoing.

Explore the possibility of offering a tax credit or incentives to businesses based on the provision of programs of excellence or best practices for employees who are cancer survivors by 2007.

Rationale:

- Financial burden of cancer treatment and recovery often affects employment
- Individuals often lose their jobs and company supplied health insurance
- Geographic and social isolation often occurs with cancer patients

PATIENT ADVOCATE

Patient navigators are needed to assist with cancer care

Strategy E: Every cancer patient will be provided the opportunity to have a patient navigator or advocate assisting in his/her continuum of care.

Action/Outcome: Develop a "society" of cancer patients/survivors to support other survivors and to serve as advocates for survivorship issues by January 2006.

Begin development of a model navigator program for utilization around the state in July 2005.

Rationale:

- Lack of advanced care planning
- Language and transportation barriers/issues