

Colorado Cancer Plan

2010-2015

Chapter: Quality of Life: Survivorship, Rehabilitation, Palliative Care and Hospice

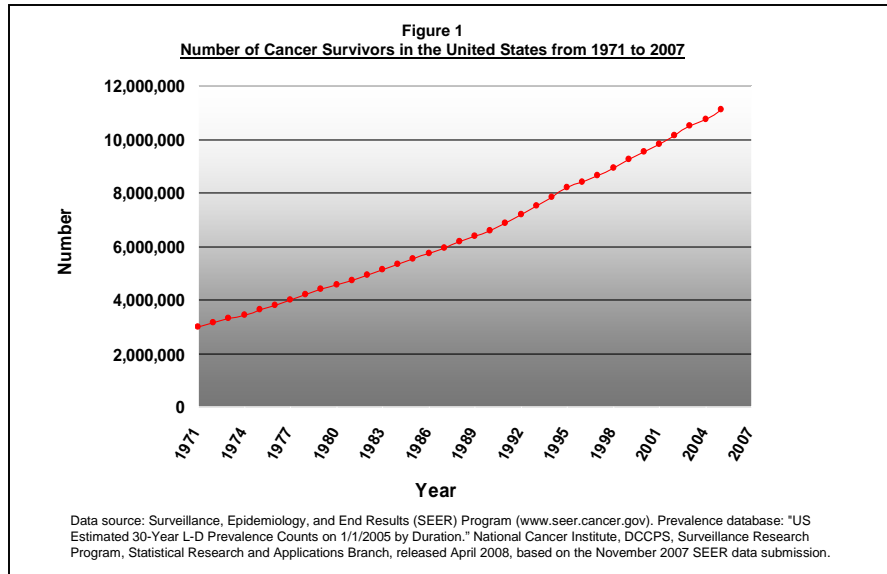
Working Document #1

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Introduction

As shown in Figure 1, recent estimates indicate that there are in excess of 11 million people living with a history of cancer in the U.S., reflecting nearly a four-fold increase from the early 1970s. Given this extraordinary growth in the number of cancer survivors, combined with the many daunting challenges faced by these individuals at the time of diagnosis, during treatment and beyond,



comprehensive state-level cancer control plans must include cancer survivorship, as recommended in a recent report from the Institute of Medicine (IOM). This landmark report, titled *From Cancer Patient to Cancer Survivor: Lost in Transition* (2006), contained 10 key recommendations, one of which recommended that:

“Congress . . . support [the] Centers for Disease Control and Prevention, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation and refinement of existing state cancer control plans” [Recommendation 6, Executive Summary, page 8].

The Colorado Cancer Coalition has been at the forefront nationally in recognizing cancer survivorship as a priority. In the previous Colorado Cancer Plan for 2005-2010, 16 key objectives and over 70 specific strategies were identified in the *Quality of Life* chapter included in this plan. Many of these key objectives and strategies have been updated and retained for 2010-2015, especially those involving cancer rehabilitation, hospice and palliative care. However, several new developments and challenges in cancer survivorship, also identified in the IOM “*Lost in Transition*” report, have likewise been included in this chapter. Especially noteworthy in this regard is the need to provide cancer patients and survivors with treatment summaries and care plans post-treatment. As shown in Table 1, a consensus is now emerging on the essential elements that should be included in these care plans.

Table 1
Essential Elements of a Cancer Survivorship Care Plan

- Specific tissue diagnosis and stage
- Treatment summary and dates of treatment
- Toxicities during treatment
- Expected short- and longer-term effects of treatment
- Surveillance recommendations for toxicity (post-treatment)
- Surveillance recommendations for recurrence or second cancers
- Who will take responsibility for survivorship care
- Psychosocial and vocational needs
- Recommended preventive behaviors/programs

Recommended components include diagnostic information, a comprehensive summary of treatments received and their toxicities, potential short- and longer-term effects of treatment, surveillance recommendations for toxicity, recurrence and second cancers, and recommendations and referrals to address

psychosocial and vocational needs, as well as behavioral programs for cancer survivors. The need to provide cancer survivors with this essential information is so compelling that it has now become one of the organizing themes for this chapter, with several key objectives and strategies designed to provide information, resources and programs to support both the dissemination and utility of these longer-term care plans for cancer survivors.

Also noteworthy is that many organizations and advocacy groups acknowledge that cancer survivorship begins at the time of diagnosis, and that the definition of a cancer survivor should include family members, friends and the caregivers of a cancer patient or survivor. The Colorado Cancer Coalition embraces this definition of cancer survivorship, which is also shared by the National Cancer Institute, the American Cancer Society, the Lance Armstrong Foundation, the Centers for Disease Control and Prevention, and the National Coalition for Cancer Survivorship. Consistent with this definition, the Colorado Cancer Plan now includes several key objectives and strategies that focus specifically on newly diagnosed cancer patients as well as the family members, friends and caregivers of cancer survivors.

By way of summary, XX key objectives have been identified in this chapter to promote, extend and improve cancer survivorship resources and programs in Colorado. These XX objectives and the specific strategies to achieve these objectives have been organized within five broad categories. Three of these categories correspond to the continuum of care for patients diagnosed with cancer, including newly diagnosed cancer survivors, cancer survivors in treatment, and cancer survivors post-treatment. To acknowledge and respond to the many compelling needs and challenges shared by family members, friends and caregivers of a diagnosed cancer patient, the fourth category in this chapter specifically targets this group as a priority concern for the Colorado Cancer Plan. Finally, the fifth category includes several key objectives and strategies to promote additional research in cancer survivorship. As noted in this chapter, such research should serve as a vehicle for developing new and effective resources and programs for cancer survivors that are both evidenced-based and sustainable within Colorado.

NOTE TO COLLEAGUES

- *What follows are the five main categories of objectives identified in the preliminary first draft of the introduction*
- *Within each of these five categories I have listed the objectives from the previous QOL chapter (2005-2010) that seemed most related to that category*
 - *The idea here would be to update and revise these previous objectives as appropriate, identify gaps, and then draft new objectives to address these gaps*
- *It also occurs to me that each of these five categories could have its own working group (i.e., this could be the conceptual framework for organizing our working groups)*
 - *What do you think of this idea?*
- *A complete list of the original 16 objectives for the QOL Task Force (2005-2010) are also attached for your review.*

Newly Diagnosed Cancer Survivors

- Objective 1: Develop, implement, evaluate and maintain cancer survivorship education programs that increase access to state-of-the-art cancer treatment, supportive care and quality of life information and resources
- Objective 10: Ensure that all cancer survivors (including pediatric, geriatric and minorities) have access to palliative care services from the time of diagnosis through the end of life

Cancer Survivors in Treatment

- Objective 1: Develop, implement, evaluate and maintain cancer survivorship education programs that increase access to state-of-the-art cancer treatment, supportive care and quality of life information and resources
- Objective 2: Ensure that all cancer survivors have adequate access to high quality treatment and other post-treatment follow-up services
- Objective 5: Educate health care professionals of the need for and use of rehabilitation throughout the cancer experience
- Objective 6: Ensure that all cancer survivors (including pediatric, geriatric and disparate populations) have access to rehabilitative services and complementary therapies throughout all phases of their cancer experience
- Objective 8: Educate cancer survivors of the importance and availability of on-going access to palliative care. Identify specific palliative programs, resources, and services available to this population
- Objective 9: Educate practicing health professionals, including community-based physicians, nurses, social workers and chaplains on the need and benefits of palliative care services for cancer survivors
- Objective 10: Ensure that all cancer survivors (including pediatric, geriatric and minorities) have access to palliative care services from the time of diagnosis through the end of life
- Objective 11: Identify specific areas of palliative care services that require enhancement (e.g., symptom management, psychosocial care, and/or spiritual care) and develop an action plan to make improvements

Cancer Survivors Post-Treatment

- Objective 1: Develop, implement, evaluate and maintain cancer survivorship education programs that increase access to state-of-the-art cancer treatment, supportive care and quality of life information and resources
- Objective 2: Ensure that all cancer survivors have adequate access to high quality treatment and other post-treatment follow-up services
- Objective 4: Develop, expand and evaluate rehabilitation information and resources for Colorado cancer survivors and their families
- Objective 5: Educate health care professionals of the need for and use of rehabilitation throughout the cancer experience
- Objective 6: Ensure that all cancer survivors (including pediatric, geriatric and disparate populations) have access to rehabilitative services and complementary therapies throughout all phases of their cancer experience
- Objective 8: Educate cancer survivors of the importance and availability of on-going access to palliative care. Identify specific palliative programs, resources, and services available to this population
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- Objective 11: Identify specific areas of palliative care services that require enhancement (e.g., symptom management, psychosocial care, and/or spiritual care) and develop an action plan to make improvements
- Objective 13: Educate cancer survivors and their caregivers about hospice resources available to them in a timely manner
- Objective 14: Educate health care professionals about available hospice resources
- Objective 15: Improve access to hospice care for Colorado cancer survivors

Family Members, Friends and Caregivers of Patients Diagnosed with Cancer

- Objective 4: Develop, expand and evaluate rehabilitation information and resources for Colorado cancer survivors and their families
- Objective 13: Educate cancer survivors and their caregivers about hospice resources available to them in a timely manner

Cancer Survivorship Research

- Objective 3: Develop research interventions to address survivorship issues
- Objective 7: Disseminate, expand and enhance research in cancer rehabilitation
- Objective 12: Encourage collaborative research between and with other palliative care organizations to enhance the development, consistency, and quality of palliative care services offered in Colorado
- Objective 16: Encourage collaborative research between and with hospices to enhance the quality and consistency of care provided at the end of life

List of Objectives from Colorado Cancer Plan, 2005 – 2010

- Objective 1: Develop, implement, evaluate and maintain cancer survivorship education programs that increase access to state-of-the-art cancer treatment, supportive care and quality of life information and resources
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