

VII. ACCESS TO QUALITY CARE AND SERVICES

A. Goals

This section describes prioritized needs and recommended strategies to address access to quality care and services for people living with, through, and beyond cancer. In relation to cancer survivorship, quality care and services include access to quality treatment, effective pain and symptom management, and quality end-of-life care and services. Progress in these key areas is necessary to assure quality service provision for those living with cancer. Goals in this area include the following:

- Establish clinical care guidelines to ensure availability of high-quality care for all cancer survivors.
- Provide access to high-quality care throughout every stage of cancer survivorship.
- Educate survivors on available resources and strategies to enhance informed decision making.
- Ensure coordinated care among all health care professionals involved in delivering services.

For the purposes of cancer survivorship, access to quality treatment, effective pain and symptom management, and quality end-of-life care are defined here and in Section II.C. as follows:

Access to Quality Treatment

Cancer treatment is complex and differs for each individual based on his or her specific situation and needs. All cancer survivors should have timely access to the latest and most effective treatments available. This would include clinical trials, if appropriate.

Pain and Symptom Management

An important part of cancer treatment is the management of pain and other symptoms associated with both disease and treatment. The goal of pain and symptom management is to provide relief so that survivors can tolerate the diagnostic and therapeutic procedures needed to treat their cancer and live comfortably throughout each stage of living with, through, and beyond cancer.

End-of-Life Care

Issues facing survivors and their families during end-of-life are complex and serious. Appropriate end-of-life care affirms life and regards dying as a normal process, neither hastening nor postponing death. The goal of end-of-life care is to achieve the best possible

quality of life for cancer survivors. Although many survivors live many years beyond their diagnosis, the needs and desires of those who are in the process of dying must be addressed.

Prioritized needs and suggested strategies for addressing access to quality care and services are presented in the following section.

B. Prioritized Needs and Suggested Strategies

Quality cancer care means assuring that survivors have access to evidence-based and appropriate treatment and services delivered in a timely and technically competent manner, with good communication, shared decision making, and cultural sensitivity across the continuum of care and throughout the remainder of life. Accountability is an important aspect of quality care (IOM, 1999). Health care providers must be accountable for professional competence, legal and ethical conduct, and accessibility of services (Emanuel & Emanuel, 1996).

Prioritized needs and suggested strategies to address access to quality care and services include the following:

I. Develop, test, maintain, and promote a patient navigation system for cancer survivors.

Patient navigation is a tool that can be used to ensure that survivors understand their care and their process of care as well as to enhance the delivery of optimum care. This need is described in detail in Section III.

2. Educate decision-makers about economic and insurance barriers related to health care for cancer survivors.

Survivorship advocates support the position that cancer survivors should have access to the latest and most effective treatments available and that access to these treatments should be based on the type of care needed and not on the cost of care. Unfortunately, there are many barriers to achieving this ideal of comprehensive access to quality care. The first step toward this ideal is to educate decision makers about the needs of cancer survivors and the financial barriers affecting cancer survivors' access to quality care. Strategies to help assure that decision makers are adequately informed include the following:

- Convene a meeting of health care providers, cancer survivorship experts, researchers, and programmatic staff with the goal of developing strategies to educate policy makers about the unmet needs for cancer treatment of uninsured and underinsured survivors.

- Identify successful policy and legislative language as examples for state programs (and others), and identify key stakeholders (e.g., legislators, governors) needed to improve access to high quality treatment and other post-treatment follow-up services.
- Survey and analyze the insured population to determine the impact the individual's level of coverage has on timely access to care and receipt of follow-up care.
- Develop educational opportunities for decision makers of insurance carriers and health plans regarding policies that promote access to quality cancer care.

3. Establish and/or disseminate guidelines that support quality and timely service provision to cancer survivors.

In their statement, "Principles of Quality Cancer Care," the Cancer Leadership Council emphasized that all people with cancer need to have timely access to care that is based on the best available evidence (NCCS, 2003). A key strategy for meeting this need is to develop a process for establishing clinical care guidelines for each stage of cancer survivorship. This need is discussed in detail in Section III of this National Action Plan.

4. Assess and enhance provision of palliative services to cancer survivors.

The goal of palliative care is to achieve the best possible quality of life for survivors and their families by controlling pain and other symptoms and addressing psychological and spiritual needs throughout each stage of living with, through, and beyond cancer. Strategies to assess and enhance provision of palliative services to cancer survivors include the following:

- Collect baseline **quantitative** and **qualitative data** to assess the current status and location of palliative service provision, and characterize the experiences of survivors, their caregivers, and providers in relation to palliative care.
- Provide professional and public education to teach people about palliative care, how health care providers should administer such services, and how survivors and their caregivers can advocate for this care.
- Establish regulatory policies for licensing and agency responsibility for palliative care oversight.

- Provide training for medical personnel on the topic of substance abuse to help alleviate fears of misuse of pain medications and increase professional acceptance of prescribing pain control medications to cancer survivors.
- Develop targeted therapies to manage cancer pain so that concerns about unintended consequences of pain medication administration can be avoided.

5. Establish integrated multidisciplinary teams of health care providers.

Cancer treatment is complex and differs for each individual based on his or her specific situation and needs. To assure that each cancer survivor receives appropriate and comprehensive treatment, these efforts should be planned, coordinated, and delivered by a multidisciplinary team of providers. Strategies to establish such multidisciplinary teams include the following:

- Create centers of excellence (using pediatric cancer centers as a model) that provide comprehensive care to cancer survivors especially for rarer forms of cancer.
- Formulate policies that will improve access to services provided to survivors from an appropriate provider of choice.
- Promote and provide increased access to clinical trials and longitudinal follow-up through the centers of excellence.
- Develop survivor-oriented Web sites to guide follow-up after completion of primary treatment.
- Develop mechanisms (e.g., password-protected Web forum, telephone, mail) for survivors to have ongoing routine follow-up with their multidisciplinary team after primary treatment. Follow-up should be annual at a minimum.
- Develop survivorship programs through appropriate partner organizations (e.g., the American College of Surgeons Commission on Cancer, NCCS) to provide professional education on cancer survivorship.
- Ensure survivor access to symptom management/palliative care/supportive teams.
- Review management plans from other chronic disease models (e.g., diabetes) and use these as a basis to develop integrated multidisciplinary management plans for cancer survivorship.
- Ensure that integrated multidisciplinary management is available to survivors across the continuum of care.

Section VII Summary: Access to Quality Care and Services

1. Develop, test, maintain, and promote a patient navigation system for cancer survivors.
2. Educate decision-makers about economic and insurance barriers related to health care for cancer survivors.
3. Establish and /or disseminate guidelines that support for quality and timely service provision to cancer survivors.
4. Assess and enhance provision of palliative services to cancer survivors.
5. Establish integrated multidisciplinary teams of health care providers.

Octavio, Cancer Survivor



“Survivorship means coming out of my cancer experience as a whole person and being able to make it an important and positive part of who I am.”