

Goal 5. Optimize Quality of Life for Cancer Survivors

Priority Areas:

1. Psychosocial support services
2. Survivorship services
3. Palliative care
4. Serious Illness/end of life/hospice care

G-5, Priority Area 1: Psychosocial Support

WHY THIS IS IMPORTANT

Psychological distress affects up to 75% of cancer survivors. Although distress screening is recommended by the Commission on Cancer (CoC) and National Comprehensive Care Network (NCCN) Guidelines, fewer than one third of survivors report having talked to their clinicians about their psychosocial concerns.⁹⁷

Since 2019, CoC accredited cancer centers have been required to develop and implement a psychosocial distress screening and referral program, but it is estimated that only about half of patients are screened.⁹⁸

Psychosocial support objectives

- Increase implementation of psychosocial/distress evaluation tools for use in inpatient and outpatient settings (Data: TBD)
- Increase number of available patient and caregiver support groups, focusing on culturally appropriate approaches to encourage access by members of populations of focus



STRATEGIES

- Promote psychosocial distress training of providers through CME opportunities such as that developed by CDC through the National Association of Chronic Disease Directors⁹⁹
- Share best practices through educational events/annual meeting for providers and cancer center staff

Resources

- Journal of National Comprehensive Care Network published Oct. 2019. Distress Management, Version 3.2019, NCCN Clinical Practice Guidelines in Oncology. <https://jnccn.org/view/journals/jnccn/17/10/article-p1229.xml>
- NCCN Guidelines for Patients Distress During Cancer Care, 2020.
- Provider Education Training to Improve Mental Health Care of Cancer Survivors, CDC.
- <https://www.cdc.gov/cancer/survivors/health-care-providers/mental-health-care-prov-ed.htm>
- Provider Education for Mental Health Care of Cancer Survivors. National Association of Chronic Disease Directors. <https://simulations.kognito.com/pemhccs/>

G-5, Priority Area 2: Survivorship Services

WHY THIS IS IMPORTANT

An estimated 16.9 million people with a history of cancer were alive on January 1, 2019. By January 2030, this number will exceed 22 million. Cancer survivors who minimize their exposure to cancer risk factors improve the quality of their lives and reduce the risk of cancer recurrence or progression and the incidence of additional cancers.¹⁰⁰

Survivorship objectives

(Note: Tracking progress on these objectives will depend on data from the continuing inclusion of an optional BRFSS survivorship module.)

- Increase the proportion of cancer survivors who engage in healthy living behaviors
- Increase the proportion of cancer survivors who report that during the past 30 days, poor physical or mental health did not keep them from doing usual activities on any days
- Decrease the proportion of cancer survivors who report that they currently have physical pain from cancer or treatment from 11.6% to 10% (2020 BRFSS Survivorship Preliminary Data)
- Increase the proportion of cancer survivors who report receiving a written summary of all cancer treatments received (from 49.2 % to 54.4%) and written instructions about where to return or who to see for routine cancer checkups after completing treatment (2020 BRFSS Survivorship Preliminary Data)
- Increase awareness of special needs of survivors of childhood and young adult cancers¹⁰¹
- Increase proportion of cancer survivors who, in partnership with their primary care provider, adhere to survivorship guidelines regarding monitoring and screening for late effects
- Increase awareness of special needs of survivors of childhood and young adult cancers
- Improve process of transition from oncology care to primary care, especially for childhood cancer survivors



First Person Point of View

“With the use of navigators, connect survivors to local groups, support systems in person or through social media, annual event to promote survivorship.”

—Participant at CCP Annual Meeting, 2019

STRATEGIES

- Address psychosocial needs of family caregivers through increased supportive services programming by health and community agencies, including the use of community health workers
- Address risk factors for cancer survivors to improve quality of life and reduce risk of cancer recurrence or progression (See Healthy Living objectives in Chapter 2)
- Advocate for continued inclusion of optional Cancer Survivorship modules in state BRFSS
- Analyze results of 2020 BRFSS optional Cancer Survivorship module to identify needs¹⁰²
- Collaborate with YMCAs across the state to increase participation in the LIVESTRONG at the YMCA program for cancer survivors through increased provider referrals and promotion through survivor support groups
- Educate patients on the value of treatment summaries and survivorship care plans
- Encourage community-based self-management workshops for cancer survivors, including promotion of physical activity programs, weight management, and healthy eating
- Promote alcohol behavioral counseling referrals and interventions for cancer patients who continue to use alcohol at any stage during and after cancer diagnosis
- Promote systems changes to integrate survivor care plans into systems of care
- Provide assistance to the largest employers in the state to incorporate and promote evidence-based obesity, nutrition, and physical activity interventions into worksite wellness programs, with a specific focus on cancer survivors
- Provide professional education to providers regarding use of Survivorship Care Plans, including elements such as:
 - psychosocial issues and behavioral counseling interventions, referrals to behavioral counseling services, the availability of support and survivorship groups, the importance of healthy behaviors and the risks of tobacco and alcohol use affecting the reduction of cancer recurrence, and long-term and late effects of cancer and its treatment on survivors' physical and psychosocial well-being
- Support advance care planning for cancer survivors and their families through educational initiatives and including content in survivorship groups
- Train health systems providers to assess, advise, and refer cancer survivors to physical activity programs and to utilize "exercise prescriptions" to improve fatigue, anxiety, depression, physical function, and quality of life
- Work with hospitals, health systems, and cancer centers to establish survivorship priority programs as per CoC guidelines that focus on enhancing survivors' health and quality of life
- Develop or support programs addressing the needs of childhood cancer survivors, including facilitating the transition from oncology care to primary care

REACH FOR THE STARS SURVIVORSHIP PROGRAM AT CONNECTICUT CHILDREN'S MEDICAL CENTER

The team in the Center for Cancer and Blood Disorders at the Connecticut Children's Medical Centers care for patients and families throughout the cancer continuum, from diagnosis through treatment and beyond. This includes care after treatment completion: monitoring for relapse, addressing short- and long-term side effects of cancer and its treatment, and promoting health and wellness throughout the lifespan. By addressing specific concerns, providing anticipatory guidance, and increasing the support given to children and families, nurses and doctors, in collaboration with the psychosocial health care team of social workers, psychologists, and child life specialists, strive to ease survivors' transition to and through cancer survivorship. The aim of the two survivorship programs is to promote survivors' physical and psychosocial well-being and improve reintegration into family life and the community.

A long-term survivorship clinic called "REACH for the STARS" for survivors begins 2 – 5 years after diagnosis and continues through early adulthood. An end-of-treatment transition program for survivors called "Shooting for the STARS" was recently established and is offered in the first weeks to months after completing cancer treatment. Both programs are evidence-based and offer comprehensive multidisciplinary services and support, which include medical, educational, and psychosocial supportive care for survivors and parents.

Resources

- Cancer Survivors. CDC. <https://www.cdc.gov/cancer/survivors/index.htm>
- Information for Health Care Providers. Survivorship Care Plans. CDC. Comprehensive Cancer Control Plans: Addressing Risk Factors for Survivors:
 - <https://www.cdc.gov/cancer/survivors/health-care-providers/index.htm>
 - <https://www.cdc.gov/cancer/survivors/health-care-providers/obesity-wellness.htm>
 - <https://www.cdc.gov/cancer/survivors/health-care-providers/tobacco-use.htm>
- Optimal Resources for Cancer Care 2020 Standards. American College of Surgeons, Commission on Cancer, Effective January 2020 Updated February 2021. [optimal_resources_for_cancer_care_2020_standards.ashx](https://www.facs.org/standards/optimal_resources_for_cancer_care_2020_standards.ashx) (facs.org)
- Comprehensive Cancer Control Plan. Addressing Risk Factors for Cancer Survivors. Comprehensive Cancer Control National Partnership. <https://www.acs4ccc.org/wp-content/uploads/2021/01/CCC-Tip-Sheet-Survivors-v07-FF.pdf>
- REACH for the STARS Survivorship Program - Connecticut Children's

G-5, Priority Area 3: Palliative Care

WHY THIS IS IMPORTANT

- According to the American Society of Clinical Oncology (ASCO), palliative care is used to ease symptoms and side effects and manage any challenges patients experience before, during, and after cancer treatment. ASCO also notes “substantial evidence demonstrates that palliative care—when combined with standard cancer care as the main focus of care—leads to better patient and caregiver outcomes”
- In addition, ASCO reports “earlier involvement of palliative care also leads to more appropriate referral to and use of hospice care and reduced use of futile intensive care”
- Patients with invasive cancers who receive palliative care along with cancer treatments tend to enjoy better quality of life and live longer^{103 104 105 106 107}

Palliative care objectives

- Increase the proportion of cancer patients and survivors who report that their pain is currently under control (2020 BRFSS data to be baseline)
- Maintain Connecticut’s “A” grade on the Center to Advance Palliative Care Report Card

First Person Point of View

“*Though I have good doctors, I ended up losing over 60 pounds and ended up seriously ill in the Hospital. I was treated well for the cancer, though found the Center extremely uninformative (unless you knew the questions to ask) when it came to the various approaches to pain management and adverse body reactions to chemo.*”

–June 2020 response to needs assessment survey

STRATEGIES

- Promote and support a systematic approach to monitor, disseminate, and utilize data trends to advocate for high-quality palliative care
- Promote and support system changes that strengthen the quality of palliative care through partnerships with providers and community members from across the state, including those addressing the needs of pediatric patients
- Build workforce capacity in response to analysis of data tracking the number of healthcare professionals certified in palliative care
- Analyze data trends to identify barriers and advocate for policy and system changes that improve accessibility and quality of palliative care in all settings
- Advocate for increased federal, state, and private funding, resources, and research related to palliative care, especially for populations of focus
- Support development of collaborative initiatives that provide culturally appropriate palliative care education in all settings, including colleges, hospitals, out-patient settings, long-term care, pediatric care, and veteran care, to strengthen the quality and utilization of palliative and hospice care in the state
- Support policy and system changes that increase the use of advanced care planning by residents of Connecticut, including culturally and linguistically appropriate public education programs about end-of-life decision-making (e.g., Medical Orders for Life-Sustaining Treatment or MOLST) and other advanced directive planning efforts
- Align efforts to support recommendations of the Connecticut State Palliative Care Advisory Council
- Encourage state health insurance regulators to support palliative care, such as requiring disability plans to offer optional coverage of palliative care services without the need for beneficiaries to demonstrate that they are homebound
- Advocate for excluding palliative care from opioid prescribing rules¹⁰⁸

Resources

- Advancing Palliative Care for Adults with Serious Illness: A National Review of State Palliative Care Policies and Programs. Rachel Donlon, Kitty Purington, and Natalie Williams. Advancing Palliative Care for Adults with Serious Illness - The ...
- Report to the Commissioner of Public Health and the Connecticut General Assembly on Palliative Care 2017. <https://portal.ct.gov/-/media/Departments-and-Agencies/DPH/Government-Relations/Palliative-Care-Agenda-and-Minutes/Report-2017.pdf>

G-5, Priority Area 4: Serious Illness/End of Life/Hospice Care

WHY THIS IS IMPORTANT

Connecticut is currently ranked 30th among states by percentage of Medicare decedents who receive hospice benefits.

In 2018, a substantial majority of Medicare hospice patients were Caucasian. While improvements have occurred since 2014, Black and Hispanic Medicare beneficiaries who receive hospice services are underrepresented, compared with white Medicare beneficiaries.

End of life/hospice objectives

- Increase the percentage of Medicare decedents (Medicare beneficiaries who die while receiving Medicare benefits) who received hospice benefits from 48.6% (2018 data) to 53%
- Increase the percentage of residents who report having an advance directive in place (Data: TBD)



First Person Point of View

“[We need to] increase hospice services. Families are left to manage this, and they are not healthcare professionals.”

–Participant at Dec. 2019 CCP Annual Meeting

STRATEGIES

- Promote informed decision-making for End-of-Life (EOL) care through consumer and provider education about high-quality EOL care alternatives, such as palliative care and hospice
- Work with the Connecticut Coalition for Serious Illness to identify the current state of resources and support for advance care planning in Connecticut and to make recommendations and initiatives to share best practices
- Work with state partners to support surveying agency and staff needs and gaps in pediatric palliative care
- Work collaboratively with other state initiatives to enhance serious illness care through improved education at the professional level for palliative care and advanced care planning
- Advocate to ensure promotion of appropriate, timely hospice referrals while supporting informed decision-making and choice
- Promote education about MOLST
- Support the Conversation Project, a public engagement initiative with a goal of helping everyone talk about their wishes for care through the end of life¹⁰⁹

MEDICAL ORDERS FOR LIFE SUSTAINING TRAINING (MOLST)

Patients at the end of life or having a serious life threatening and/or progressive illness may have completed living wills and advance directives, but may still benefit from having a MOLST, an optional additional planning document. The MOLST form documents patients' decisions in a clear manner that can be quickly understood by all providers, including first responders and emergency medical services (EMS) personnel.^{110 111 112}

End of Life Resources

- America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals 2019. https://reportcard.capc.org/wp-content/uploads/2020/05/CAPC_State-by-State-Report-Card_051120.pdf
- Connecticut Association for Healthcare at Home (cthealthcareathome.org)
- Connecticut Coalition to Improve End of Life Care. <https://www.ctendoflifecare.org/>
- Connecticut Medical-Orders-for-Life-Sustaining-Treatment. <https://portal.ct.gov/DPH/Medical-Orders-for-Life-Sustaining-Treatment-MOLST/MOLST>
- Connecticut State Hospice Report. Jan. 2020 (ymaws.com)
- End of Life Cancer Care. <https://www.dartmouthatlas.org/interactive-apps/end-of-life-cancer-care/>
- End-of-life quality metrics among Medicare decedents at minority-serving cancer centers: A retrospective study. Jan. 2020. <https://onlinelibrary.wiley.com/doi/full/10.1002/cam4.2752>
- Harris-Kojetin L, Sengupta M, Lendon JP, Rome V, Valverde R, Caffrey C. Long-term care providers and services users in the United States, 2015–2016. National Center for Health Statistics. Vital Health Stat 3(43). 2019. https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf
- Hospice Facts and Figures. 2020 Edition. Alexandria, VA: National Hospice and Palliative Care Organization. August 2020. www.nhpc.org/factsfigures.
- National Hospice and Palliative Care Organization Facts and Figures. 2020 Edition. [NHPCO-Facts-Figures-2020-edition.pdf](https://www.nhpc.org/factsfigures-2020-edition.pdf)
- Palliative & Hospice Care Benchmark Data 2017. <https://portal.ct.gov/-/media/Departments-and-Agencies/DPH/Government-Relations/Palliative-Care-Agenda-and-Minutes/Benchmark-Data--Updated-2017.pdf>