



Top Ten Tips Palliative Care Clinicians Should Know About Survivorship in Oncology

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Abstract

Survivorship in oncology encompasses all individuals with cancer from diagnosis through the end of life. Like palliative care (PC), survivorship care prioritizes an evidence-based, person-centered approach to ensure quality, efficiency, and dignity. While PC clinicians regularly provide supportive and end-of-life care for people with cancer, additional guidance may be needed to address survivorship needs beyond active treatment. We provide our top ten tips aimed to empower interprofessional PC clinicians in addressing the holistic needs of the cancer survivors throughout the full continuum of care.

Keywords

advance care planning; cancer care; caregiver; cancer screening; financial toxicity; medical education; palliative medicine; palliative care; psychological support; sexual health; survivors; survivorship

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Introduction

As new treatments continue to improve outcomes, long-term person-centered care is becoming increasingly nuanced and complex, requiring more specialized survivorship support.¹ Survivorship care is interdisciplinary and interprofessional by both design and necessity, involving oncology clinicians, primary care providers (PCP), medical and surgical specialists, and palliative care (PC) clinicians. The definition of a cancer survivor includes all people with cancer from the time of diagnosis through the end of life.^{2,3}

The characteristic symptoms and support needs of cancer survivors who have completed treatment may vary from the needs of those undergoing intensive treatments for cancer. Further, the needs of cancer survivors can differ across their disease trajectories, including those living with advanced or metastatic cancer, either with continuous or intermittent treatment.⁴ The tips presented here (Table 1) guide PC clinicians to optimize survivorship care in their own practice contexts by attending to the distinctive needs and experiences of cancer survivors, engaging social support networks, and leveraging required clinical skills.

Interdisciplinary and Cross-Team Collaboration Between Medical Oncology, Primary Care, and PC Clinicians Are Essential

PC clinicians may be asked to offer consultative and long-term follow-up supportive care for survivors with newly diagnosed early-stage or advanced/metastatic cancer. PC clinicians continue to enhance interdisciplinary collaboration by supporting and providing expert guidance on the management of late and long-term toxicities.^{5,6}

In particular, PCPs may feel uncertain about their role in caring for survivors living with and beyond cancer. For example, if a survivor is experiencing chronic pain related to cancer treatments, the PC clinician can assist in complex opioid management as the PCP works to manage both chronic disease and health promotion strategies. The involvement of a PC clinician in bridging communication between oncology and PCP teams enhances continuity and support for the survivor.^{7,8} Both PCPs and partnering PC clinicians should involve other supportive services such as rehabilitation, nutrition, and mental health team members to provide a holistic approach to their care.⁹ For instance, the PC clinician can facilitate seamless conversations with subspecialists, such as cardio-oncologists who may be actively involved in assisting with a treatment-related cardiomyopathy. In this scenario, a PC clinician could address refractory dyspnea while the PCP and subspecialist titrate antihypertensive or other disease-directed regimens.¹⁰

Cancer Surveillance Planning Must Be Individualized Due to Increased Risk of Recurrence and Subsequent Cancers in Survivors

Cancer recurrence and subsequent cancers pose significant threats to cancer survivors. Despite comprising only about 6% of the population, cancer survivors contribute to 15–20% of cancer incidence rates due to second primary malignancies.^{11,12} Factors that influence subsequent cancer risk for survivors include certain chemotherapies (e.g., alkylating agents), radiation exposure, age, and tobacco exposure.¹³ As the population of cancer survivors

continues to grow, effective cancer surveillance becomes paramount in ensuring their long-term health.

A PC clinician can use the following U.S. guidelines to assist in the surveillance conversation with their survivors:

- American Cancer Society (ACS) Screening Guidelines—guidelines for early detection of cancers such as breast, cervical, colorectal, lung, and prostate cancer. In addition, the ACS has selected guidelines focusing on cancer survivorship recommendations.
- National Comprehensive Cancer Network (NCCN) guidelines—guidelines on cancer care, including surveillance for various cancer types, like breast, colorectal, and prostate cancer. These guidelines are frequently updated based on new research.
- U.S. Preventive Services Task Force guidelines—guidelines for cancer screening in the general population, particularly for colorectal, cervical, and breast cancer, emphasizing the importance of surveillance intervals based on patient risk.
- American Society of Clinical Oncology (ASCO) guidelines—guidelines for cancer surveillance, including personalized recommendations based on the type and stage of cancer.
- National Cancer Institute (NCI) PDQ[®] Cancer Information Summaries—summaries of cancer surveillance strategies, which include recommendations for follow-up and long-term monitoring.

A PC clinician can partner with survivors to refine the application of these population-based recommendations to the persons' individual goals, resources, and risk factors. Threading this needle between under- and over-surveillance can be challenging.¹⁴ The landscape of cancer care is constantly evolving, with new research shaping recommendations from professional organizations.^{14,15} Not every clinical scenario has a corresponding clinical trial or empirical evidence to guide recommendations, often leaving decisions about surveillance to clinical judgment and expert opinion. PC clinicians should assist survivors in discussing their health priorities, competing comorbidities, and the risks of each surveillance modality to find a goal-concordant surveillance plan.

Late and Long-Term Toxicities of Cancer Therapies Are Frequent and Can Result in Debilitating Symptoms for Survivors

Many survivors are living decades after receiving treatments known to cause long-lasting effects. Current treatments have significantly improved survival rates and are less toxic. Ten years ago, survivors of metastatic non-small cell lung cancer and melanoma may have only experienced the immediate impact of their therapies. Now targeted therapies, such as endothelial growth factor receptor inhibitors and checkpoint inhibitor immunotherapy agents, have extended life by years beyond diagnosis. Despite advances, survivors may experience side effects that may persist over time (i.e., long-term effects). Other toxicities may emerge years after treatment (i.e., late effects), like delayed-onset neuropathy from oxaliplatin. The occurrence of late and long-term effects varies according to the treatment

duration and modality, as well as the specific cancer involved.¹⁶ A recent health-related quality of life survey noted that more than one-third of disease-free cancer survivors reported specific physical, psychological, cognitive, social, and sexual problems four years after diagnosis.¹⁷ Common late effects include cancer-related fatigue, treatment-induced peripheral neuropathy, cognitive impairment, and organ-specific toxicities such as cardiotoxicity and pulmonary toxicity (Table 2).^{18,19}

Recognizing symptoms early and providing tailored pharmacological or non-pharmacologic treatment, including rehabilitation and lifestyle changes, such as smoking cessation, diet, and exercise, can lead to significant improvements. Evidence shows that exercise can improve quality of life, improve survival of some cancers, and help manage fatigue, pain, metabolic syndrome, osteoporosis, and cognitive impairment.^{20,58}

PC clinicians can play a vital role in detecting symptoms early by employing emerging strategies and screening tools such as the distress thermometer, which helps identify specific areas of concern for survivors.^{18,19} In addition to providing pain management support, survivor education, and lifestyle modification guidance, PC clinicians can be focused on alerting other health care providers to ongoing toxicities that might require specialized approaches or treatment. For example, a PC clinician may note a clinical decline in memory, perform a Montreal Cognitive Assessment (MoCA)²¹ to determine the severity of cognitive decline, and refer to a cognitive rehabilitation program to improve symptoms or prevent ongoing deficits.

Causes of Psychological Distress in Survivors Are Common but Often Overlooked

Many survivors experience psychological distress, including symptoms of depression, anxiety, and post-traumatic stress. PC clinicians can partner in the assessment of survivors' distress:

- Routine Assessment
 - Frequency: Regular assessments at key points (post-treatment, follow-up visits, annually).
 - Tools: Use validated tools (Hospital Anxiety and Depression Scale Patient Health Questionnaire-9, General Anxiety Disorder-7)^{22–24} to identify distress, anxiety, and depression.²⁵
- Tailored Screening
 - Risk Factors: Screen more frequently for those with a history of mental illness, high treatment intensity, or lack of social support (including increased social determinants of health).²⁶
 - Specific Concerns: Address issues related to body image, sexual health, cognitive changes, and financial impact.
- Integrated Care
 - Interprofessional Approach: Seek collaboration with social workers, psychologists, chaplains, and other mental health professionals.

- Person-Centered: Ensure screenings are sensitive to individual needs and incorporate person-reported outcomes.

There are distinctive stressors that cancer survivors experience that may not be readily apparent to PC clinicians, including fear of cancer recurrence, survivor's guilt, and body dysmorphia.²⁷⁻³⁰ Screening by PC clinicians and prompt referral to psychologist resources are essential to ensure long-term well-being.^{30,31} Interventions will vary based on the needs of the survivor, but will include partnership with social workers, chaplains, and psychologists (Table 3).³²

Financial Toxicity Is Burdensome on Survivors and Requires Community Resources and Return-to-Work Empowerment Strategies to Address

Financial toxicity can become a significant burden that may negatively impact the cancer survivor.³³ Many survivors have reported that they have utilized either most or all their monetary savings while paying for treatment related to their cancer.³³ Some have reported they can no longer pay for basic needs such as housing, food, and utilities due to financial strain associated with cancer treatments.³³ Survivors can be three times as likely to file for bankruptcy as people without cancer.³⁴ These financial concerns can also exacerbate psychological symptoms.³³

PC clinicians are in a unique position to assess and assist with some of the concerns about financial resources. For example, many PC teams have licensed, dedicated social workers who are well trained and positioned to navigate the financial burden alongside survivors. In addition, PC clinicians can support survivors in advocating with insurance companies, grants, and employers. Select U.S. resources to assist PC clinicians in easing financial toxicity for survivors include:

- Cancer Survivors Network (part of the American Cancer Society)
 - Provides a peer support community for cancer survivors with resources for all tumor sites, including financial assistance.
- Cancer Care
 - Offers financial and co-pay assistance resources for survivors as well as assistance from oncology social workers.
- Cancer Financial Assistance Coalition
 - Represents a coalition of different organizations helping cancer survivors manage finances.
- Cancer Survivor Resources
 - Assists survivors to help find local and national agencies to maintain financial stability.
- Cancer + Careers
 - Educating survivors with information on financial assistance and grants, along with resources for costs associated with cancer.

- Cancer Journeys Foundation
 - Provides information on local and national organizations to help survivors struggling with financial toxicity.
- National Coalition for Cancer Survivorship
 - Creates resources on survivorship issues, including financial strain, housed online at canceradvocacy.org.
- Livestrong
 - Assists with tools and resources for cancer survivors with a searchable database, including financial navigation.

Management of Cancer-Related Pain in Survivorship with Long-Term Opioid Therapy Requires a Risk and Benefit Analysis

Chronic pain can negatively impact the overall well-being of survivors.³⁵ Opioids can be effective for moderate-to-severe pain, but long-term use poses risks, including misuse or dependency.³⁶

Opioid use disorder (OUD) is a long-term risk for cancer survivors who required opioid pain management during their treatment. Long-term opioid therapy should be carefully considered by screening for OUD, assessing the cause and anticipated duration of pain, and treating with evidence-based interventions.³⁷ PC clinicians should set reasonable expectations that the use of opioids for cancer pain is for a set duration, not indefinitely. Opioid de-escalation protocols should be considered after intensive antineoplastic therapies are completed. The goal should be the minimal opioid or utilizing opioid alternatives that allow the survivor to remain functional. Pain management in cancer survivors should incorporate non-opioid analgesics for long-term care whenever possible alongside adjunct approaches such as physiotherapy, stress reduction, and psychological support.³⁸ Partnerships should be forged with pain management and addiction specialists, especially if opioid misuse is suspected.³⁹

PC clinicians are essential for complex pain concerns in survivors. Any new or escalating pain in a cancer survivor must be assessed for recurrent or new cancer.³⁵

Infertility and Sexual Health Are Important Aspects of Survivorship Care

Fertility preservation is an often-overlooked concern for those undergoing cancer treatment. Oncologists are advised to discuss fertility with survivors.⁴⁰ PC clinicians should discuss fertility and sexual health goals with survivors to determine their concerns. There are many measures available for sexual health and intimacy challenges that survivors should be informed of as part of the care plan.

A PC clinician should integrate sexual health screenings for survivors, as these concerns are rarely the primary focus of the clinical encounter. Survivors may experience stigma or shame regarding the impact of cancer or prior treatment on their sexual drive or pleasure. Certain sexual concerns such as vaginal dryness, erectile dysfunction, or impaired intimacy

may be addressed by PC alone with pharmacologic and non-pharmacologic approaches. Others concerns, such as severe vaginal stenosis, denervation injuries, and fistulas, require multidisciplinary approaches involving PCP, gynecology, urology, and psychology with expertise in sexual health.⁴⁰ Sexual orientation and gender identity should be universally assessed by PC clinicians in an unbiased fashion, and counseling tailored accordingly. For instance, while there are over 1 million lesbian, gay, bisexual, transgender, and queer or questioning, intersex, and asexual (LGBTQIA+) individuals in the United States that are living with cancer, many health care clinicians have limited knowledge and comfort in caring for this population.^{41–43}

A PC clinician can utilize the following select U.S. resources to share with their survivors seeking further assistance in fertility and sexual health:

- NCCN Guidelines for Fertility Preservation—provides guidelines addressing sexual health and fertility concerns for cancer survivors, focusing on quality of life, hormone-related symptoms, and fertility preservation. This information is available for both clinicians and patients.
- ASCO Fertility Preservation Guidelines—provides guidelines specifically for fertility preservation in cancer patients, offering recommendations on sperm, egg, and embryo preservation prior to treatment.
- MD Anderson Cancer Center’s Fertility and Sexual Function Clinic—offers a consult service for fertility and sexual health as well as providing both educational resources and medical interventions for survivors.
- American Cancer Society: Fertility and Cancer—provides detailed information about the effects of cancer treatments on fertility and guidance on preserving fertility before treatment.
- Oncofertility Consortium: Michigan State University—offers extensive information on fertility preservation techniques and options available for cancer patients and survivors, providing practical tools for decision-making.

Caregivers Continue to Experience Challenges Related to Supporting Their Loved Ones Even in Long-Term Survivorship

Caregivers of individuals with cancer are essential partners in the cancer care process and arguably the most important member of the care team, yet they often face significant physical, emotional, spiritual, and financial burdens that must be recognized and managed.^{5,44} When caring for individuals with advanced or metastatic cancers, caregivers often encounter higher unmet needs due to the complexity of the survivors’ care.^{5,44}

Caregivers frequently experience uncertainty surrounding cancer survivor prognosis and anticipatory grief.⁴⁴ This refers to the feelings of loss or grief that occur before the actual death of the person they are caring for. PC clinicians should address the caregiver with the same screenings for distress, anxiety, and depression they use for the survivor.⁴⁵ PC clinicians can affirm a caregiver’s effort, comfort a bereaved caregiver, and understand the nuance of a family dynamic or a culturally significant norm facing a caregiver.^{45–47}

Although some bereaved caregivers can show relatively low levels of distress, the majority experience clinically significant distress, which can persist for years after the loss. Distress evolves for caregivers during the survivorship phase, affecting their well-being, quality of life, and daily functioning.^{45,48,49}

PC clinicians should include the caregiver in their clinical conversation and care decisions alongside survivors, providing support for all members of the care support system.

Survivorship is an Opportunity to Re-engage, Clarify, and Refine Advance Care Planning

Advance care planning (ACP) is a discussion between survivors, invested loved ones, caregivers, and clinical professionals regarding anticipated health care decisions. Many of these are codified in advance care documents. Studies suggest that a minority of cancer survivors have completed ACP with their oncologists, PC clinicians, or PCPs at diagnosis or through treatment.⁵⁰

A PC clinician can partner with survivors and their caregivers to address ACP. For individuals who completed ACP prior to a cancer diagnosis or may have never started, PC clinicians are equipped to walk them through its importance in a skilled fashion. For survivors who engaged in advance care planning during a period of clinical uncertainty at the time of their cancer diagnosis, PC clinicians can help revisit and realign those goals and priorities as their circumstances evolve.

Significant barriers to completing ACP discussions with survivors can include expectations of their own prognosis, clinician reluctance to take away hope, and unrealistic physician expectations.⁵¹ PC clinicians can employ their interdisciplinary team members, such as social workers and chaplains, to assist in removing these obstructions. A minority of survivorship programs are integrating ACP into their practice.⁵² With the Centers for Medicare and Medicaid encouraging ACP conversations and compensating clinicians for the time they commit, ACP could help to financially support both PC and survivorship services.⁵³

PC Clinicians Serve as Educators, Teaching Survivorship Concepts to Interdisciplinary Trainees and Primary Care Clinicians

There is a significant gap between the number of cancer survivors who need survivorship care and the availability of dedicated survivorship professionals.^{54,55} Offering training to colleagues could expand the primary care clinical skills in supporting the needs of cancer survivors.

PC clinicians can teach cancer survivorship strategies to interprofessional trainees, PCPs, and resident physicians, and encourage learners to promote integration of survivorship concepts into their practice. This integration normalizes survivorship as a continuity of cancer care.⁵⁵ Grand rounds and clinical rotations can be utilized to teach survivorship care in depth, utilizing case-based learning and teaching resources.⁵⁵ PC clinicians can organize hands on skill workshops and learning seminars as well as quality improvement projects to improve survivorship care education^{56,57} Education at every level is critical in expanding survivorship knowledge and confidence, with PC clinicians acting as pivotal advocates.

Conclusion

With the growing cancer survivor population, PC clinicians play an increasingly important role in addressing the distinctive and evolving needs facing these individuals and their caregivers after the initial diagnosis. Effective survivorship care requires ongoing collaboration, vigilant surveillance, and comprehensive support for caregivers. Long-term and late-onset physical symptoms and psychological impacts must be proactively managed. The survivorship phase also presents a critical opportunity to revisit advance care planning and assess financial stability. To enhance survivorship care, earlier integration of survivorship concepts into medical education at all levels is essential. A strong foundation in these key aspects of survivorship will enable PC clinicians to provide high-quality, effective, and people-centered support for cancer survivors.

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Table 1.
Top Ten Tips Palliative Care Clinicians Should Know About Survivorship in Oncology

<i>Tip 1</i>	Interdisciplinary and cross-team collaboration between medical oncology, primary care, and palliative care clinicians are essential.
<i>Tip 2</i>	Inferility and sexual health are important aspects of survivorship care.
<i>Tip 3</i>	Cancer surveillance planning must be individualized due to increased risk of recurrence and subsequent cancers in survivors.
<i>Tip 4</i>	Caregivers continue to experience challenges related to supporting their loved ones even in long-term survivorship.
<i>Tip 5</i>	Late and long-term toxicities of cancer therapies are frequent and can result in debilitating symptoms for survivors.
<i>Tip 6</i>	Survivorship is an opportunity to re-engage, clarify and refine advance care planning.
<i>Tip 7</i>	Causes of psychological distress in survivors are common but often overlooked
<i>Tip 8</i>	Financial toxicity is burdensome on survivors and requires community resources and return-to-work empowerment strategies to address.
<i>Tip 9</i>	Palliative care clinicians serve as educators teaching survivorship concepts to interdisciplinary trainees and primary care clinicians.
<i>Tip 10</i>	

Table 2.

Select Acute, Long-Term and Late Toxicities¹⁹

Long-term/late toxicity	Clinical manifestation
Chemotherapy induced peripheral neuropathy (CIPN)	Pain, tingling, numbness and increased sensitivity to temperature
Cancer-related fatigue	Persistent physical and mental exhaustion
Cancer-related cognitive impairment	“Brain fog,” loss of memory, impairment in learning, speed, and executive functions
Cardiotoxicity	Arrhythmia, cardiomyopathy, and myocarditis
Chemotherapy-induced pulmonary toxicity	Pneumonitis, diffuse alveolar hemorrhage, non-cardiogenic pulmonary edema
Immunotherapy-related endocrine toxicities	Hypothyroidism, thyroiditis, hypophysitis, and adrenal insufficiency

Table 3.

Recommendations for Treatment of Psychological Distress

Category	Recommendations
Counseling and Psychotherapy	Cognitive Behavioral Therapy (CBT): Effective for anxiety, depression, and coping with cancer-related stress Supportive Psychotherapy: Helps with adjustment issues and enhances coping strategies Mindfulness-Based Stress Reduction (MBSR): Useful for stress management and overall well-being
Medication Management	Antidepressants and Anxiolytics: Consider for clinical depression or anxiety based on evaluation and monitoring Side Effects: Be mindful of potential side effects and interactions with cancer treatments
Support Groups and Peer Support	Facilitate Access: Encourage participation in support groups or peer networks for emotional support and shared experiences Family Support: Include family members in counseling to address dynamics and support systems
Psychoeducation	Informational Resources: Provide education on managing long-term side effects, survivorship, and healthy lifestyle Self-Management: Equip patients with skills for self-care, stress management, and accessing community resources
Lifestyle and Wellness Interventions	Physical Activity: Encourage regular exercise for improved mood and physical health Nutrition: Provide guidance on healthy eating to support recovery and overall health
Financial and Practical Support	Financial Counseling: Assist with navigating financial challenges related to cancer treatment and survivorship Practical Assistance: Connect survivors with resources for transportation, housing, and other practical needs
Monitoring and Follow-Up	Ongoing Care: Regularly review and adjust psychosocial care plans based on changes in the survivor's needs and circumstances Long-Term Planning: Prepare for potential long-term issues and transitions, including late effects of treatment and survivorship care