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Palliative Care for Cancer Survivors

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Synopsis

The palliative care approach for survivors begins with comprehensive assessment of communication and advance care planning needs and the physical, psychological and psychiatric, social, spiritual and religious and cultural domains. Communication and decision-making about difficult issues should include responding to emotions, planning for future communication needs, and considering reasons for miscommunication. Key palliative approaches to symptom management include addressing physical and psychosocial concerns, and the use of first-line nonpharmacologic approaches with the addition of medications as needed. Physicians should address advance care planning in older cancer survivors and those at significant risk of recurrence and mortality, ideally through ongoing conversations in a longitudinal care relationship.

Keywords

Palliative care; survivorship; communication; advance care planning; pain; fatigue; sleep

INTRODUCTION

The palliative care approach focuses on quality of life, emphasizing whole-person care by addressing physical, psychosocial, family and spiritual concerns as well as planning for future care. Palliative care emphasizes the importance of communication about goals of care and patient preferences.¹ Many elements of this care approach (Table 1) are useful for internists and others working with cancer survivors throughout the cancer continuum. This approach may extend from diagnosis through to treatment and recovery, living with cancer as a chronic illness, advanced cancer and end of life care. Systematic reviews support the effectiveness of palliative care for improving quality of life, patient and family satisfaction, and advance care planning for patients with cancer.^{2,3}

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Specialty palliative care and related services can be helpful in complicated situations, where available. However, much of palliative and survivorship care is provided by internists and other primary care practitioners, and patients appreciate the involvement of these clinicians in their care. Internists play a key role in communication about illness, symptom management, psychosocial support, and coordination of cancer and non-cancer of care. Many other disciplines and services may be helpful in providing palliative care to cancer survivors, including social workers, chaplains, pharmacists, rehabilitation professionals, nutritional counselors, home care and community cancer support community programs.

While palliative approaches and survivorship care overlap significantly, the palliative approach needs to be tailored for patients likely to be cured of their cancer. After treatment for early-stage cancer, patients' symptoms and function may improve over time, and patients may be inclined to participate in more time-consuming interventions, such as counseling or exercise. Nonpharmacologic interventions and tapering of medications are therefore often appropriate approaches. In survivors, medications (e.g., steroids, opioids and benzodiazepines) with significant long-term risks must be used with caution and only short-term whenever possible. The focus of support, communication and care planning is generally different as well for survivors than for those with advanced disease, focusing on concerns about cancer recurrence or long-term progression.

In this article, we define cancer survivors as anyone living with or having a history of cancer. The scope ranges from the effects of cancer and treatment, to fears associated with the risk of recurrence and preparation for the potential for advanced disease. As cancer survivors continue to live longer and more survivors live with cancer as a chronic illness, the role of appropriate palliative care for this group will expand and evolve. Palliative care for patients with advanced cancer, hospice, and end of life care are described extensively elsewhere⁴ and are not addressed in detail here, although many of the same principles apply. This article addresses the following key palliative care approaches as adapted for survivorship care:

- Comprehensive assessment of the patient and communication and decision-making about challenging issues;
- An overall approach to physical symptom assessment and management. Nonpharmacologic approaches can be pursued as a first treatment step or delivered in conjunction with pharmacologic approaches. Short-term use of medications, with planned tapering when no longer needed;
- Specific approaches to three common physical symptoms: pain, fatigue, and sleep disturbances;
- Advance care planning when appropriate, including discussion of values and goals of patients and families. Preparation for the possibility of decision-making about advanced cancer and end-of-life care.

STRUCTURE AND PROCESSES

Comprehensive assessment

The palliative care approach to survivors for internists begins with an assessment of biological, psychological, social and spiritual concerns, addressing the appropriate domains and subdomains of each (Figure 1). The domain of structure and process involves assessment of the patient's understanding of the medical situation and communication needs and coordination with other clinicians. The physical assessment includes common symptoms of pain, fatigue, sleep and physical function, as well as other issues appropriate to the patient's specific cancer and stage of survivorship care. The psychological/ psychiatric domain addresses distress, anxiety, and depression.⁵ The social assessment generally includes family relationships, support and burdens. When appropriate, spirituality and religion as well as advance care planning should also be addressed (Box 1).

The different domains and subdomains within the framework interact. For example, all physical symptoms must be assessed in a larger context. For pain, this includes assessments of other physical symptoms, psychosocial issues (e.g., worry that pain implies risk of recurrence), social issues, (e.g., family support to limit painful activities), spiritual issues, (e.g., the meaning of pain), and cultural views about pain and its management.

Communication and decision-making

Caring for cancer survivors often includes challenging communication tasks. Discussions of treatment options, prognosis, patient goals, and consequent shared decision-making requires frank and honest conversations. Cancer patients often rely on their internists for direction in these areas. Physicians should use a systematic approach to communication. This includes having a plan for each time important issues are discussed with a patient, and using good skills for eliciting information and communication. For example, starting with open-ended questions— such as, “What have you been told about your illness?” and, “How is treatment going for you?”—is non-threatening and allows a patient to express concerns.⁶ Providing guidance to patients and families on how to approach communication and preparing questions can also improve communication.

When patients share emotions, clinicians should respond with validating statements, rather than shifting the topic or retreating into technical discussions. Clinicians should provide information simply and clearly, prefaced by statements such as, “I’m afraid I have some bad news.” Good communication should address what is known, as well key possible outcomes, and acknowledge uncertainty. Clinicians should assess for understanding, with gentle repetition, as patients may not hear or understand the first time. Clinicians should tailor communication to patients’ preferences for communication. Involving other specialties and disciplines can improve consistent communication and help address issues that may complicate good communication, such as family relationships and caregiver stress. Open-ended general inquiries throughout the encounter—such as “Do you have any concerns?”—may encourage discussion of difficult topics and nonmedical issues, such as caregiving needs.⁷

To improve communication and decision-making process, physicians can employ history-taking skills to further clarify difficult questions or statements. For example, rather than answering the question, “What are my chances?” with an estimate of prognosis, it may be helpful to ask, “Can you explain a little more about what you are asking?” and then ask more about why they want to know. Although some patients may indeed want precise statistical estimates, others may be asking the question as a way to articulate concerns about the future or their current situation or to better plan for caregiving needs or upcoming events.

When communication and decision-making are not progressing, or there is conflict, evaluating potential underlying reasons for miscommunication can help clinicians improve the process.⁸ Misunderstanding or lack of information is common, and it may be helpful to ask patients or families what they have been told by other clinicians. Key approaches to address potential misperceptions about cancer status and care include: asking about the underlying reasoning or beliefs behind a decision; listening to and validating emotions; and asking about the role of the family, often a source of challenging decision-making. Clinicians should also attempt to avoid further complicating challenging decision-making by communicating ineffectively or giving conflicting information.

PHYSICAL DOMAIN

Almost half of cancer patients, even at early stages, have at least one moderate to severe symptom related to cancer or its treatment, such as pain, fatigue, nausea, or vomiting.⁹ Although many symptoms improve over time, some may persist. The etiology of long-term symptoms is often unclear or may be multifactorial. Patients often have multiple symptoms related to their cancer or treatment as well as other non-cancer-related symptoms. These may intertwine with psychosocial stressors, which can contribute to the impact of physical symptoms.

In terms of treatment, little research exists for long-term symptoms in survivorship, and chronic symptoms in cancer survivors can be challenging to manage. Few large, high-quality randomized clinical trials (RCTs) exist for long-term oncology symptoms. Addressing the etiology of symptoms such as pain (e.g., lymphedema) and associated issues (e.g., distress) and nonpharmacologic approaches are often therefore the best initial approach. However, the time and energy level needed for interventions such as education or counseling may be challenging for some patients with cancer.

When pharmacotherapy is used, given decreased functional reserve and coexisting symptoms, survivors may be more susceptible to side effects. Key principles in pharmacotherapy for symptoms in survivors involve considerations about side effects, adverse consequences, polypharmacy, and short-term use of medications. Interactions between symptoms may make overall suffering worse, as medications used to treat one symptom may cause or exacerbate another. Issues of caregiving, spiritual or psychosocial distress, or financial worries often underlie or complicate physical complaints. Trials of interventions supported by evidence in non-cancer populations (e.g., peripheral neuropathy) may be warranted, with consideration of potential risks and adverse effects. (Box 2, 3)

Below, we discuss three key symptoms experienced by cancer survivors: pain, fatigue, and sleep disturbances.

Pain

Cancer and its treatments cause a variety of pain syndromes, including chemotherapy-induced peripheral neuropathy, hormonal-related arthralgias, dyspareunia and myalgias, postmastectomy pain and lymphedema related to surgery or radiation.¹⁰ Addressing pain involves the following: comprehensive assessment of other symptoms, sources of distress, and barriers to pain management; and investigating potential related etiologies and oncologic emergencies. While it is beyond the scope of this article to address the vast array of pain syndromes, we advise that the initial approach, when possible, should include supportive modalities (e.g., rehabilitation, lymphedema management) or lifestyle modifications to daily activities, as first line treatment or in conjunction with medications. The initial approach may also include education and psychosocial interventions, as appropriate. Such interventions are supported by systematic reviews of numerous RCTs, with effect in reducing pain intensity by 1 point on a 10-point scale,^{11,12} a difference equivalent to or greater than most pharmaceutical or interventional studies. A systematic review of RCTs also supports the efficacy of relaxation or other cognitive behavioral interventions and supportive counseling.¹³

Chemotherapy-induced peripheral neuropathy (CIPN), one specific pain syndrome where medications may be effective, is a common adverse effect of many chemotherapeutic agents. Chemotherapy dose adjustment or switching to another agent may need to be considered in severe cases. CIPN tends to improve after cessation of therapy, but approximately half of patients who received chemotherapy affiliated with causing CIPN have long-term symptoms.¹⁴ Patients may also have components of neuropathy related to other treatments, such as surgery or chronic cancer. RCTs of prophylactic agents for CIPN, including minerals, vitamins, and anticonvulsants, have shown no effect.¹⁵ In addition, for patients whose pain did not improve sufficiently after chemotherapy, there is insufficient evidence specifically for CIPN to support nonpharmacologic approaches.¹⁶ RCTs of tricyclic antidepressants and the anticonvulsants gabapentin and lamotrigine showed no effect, although these trials were generally small.¹⁵ A single RCT of the antidepressant duloxetine demonstrated effectiveness, although the dropout rate due to adverse effects was high.¹⁵ Many other agents have not been evaluated for cancer-related neuropathic pain specifically, and although the pathophysiology may be different from other types of neuropathic pain where other agents are effective, medications with evidence for effectiveness for non-cancer-related neuropathy, such as pregabalin and gabapentin,¹⁷ can be considered. Patients with CIPN should also be reassessed periodically, as the neuropathic symptoms often improve over time and these medications have significant side effects and can often be reduced or stopped.¹⁵

Although opioids have sometimes been used for cancer survivors' chronic pain, the growing literature regarding the negative impact of opioids on both patients and society warrants rethinking this approach. Guidelines for chronic pain and neurological conditions increasingly recommend a range of nonpharmacologic approaches and no longer recommend chronic opioids, except in select refractory cases after full discussion of risks.

18,19 A 2015 systematic review on long-term opioid therapy for chronic pain across conditions for a National Institutes of Health Workshop found no evidence of long-term effectiveness and significant adverse events, including dependence (ranging from 3% to 26%), abuse (0.6% to 8%), misuse (6% to 37%), increased risk for overdose, sexual dysfunction, and motor vehicle crashes.²⁰ Addictive illnesses are also common in both patients and caregivers, and are often challenging to screen for and identify. Weaning off opioids started in the acute cancer and treatment phase is often an important component of survivorship care. The internist's cautious, attentive approach to opioid prescribing and management can help avoid the risks of long-term use. Evidence-based guidelines on tapering of opioids are available,²¹ and similar approaches can often be used to wean benzodiazepines or sedative-hypnotics used during the acute cancer treatment phase.

Fatigue

Cancer-related fatigue (CRF) is defined by the National Comprehensive Cancer Network as a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion that is related to cancer or cancer treatment, interferes with usual functioning, and which is not proportional to recent activity. Cancer-related fatigue significantly affects the physical, psychosocial, and economic status of patients and caregivers, as well as patients' overall quality of life.²² Fatigue usually occurs alongside and interacts with other issues, particularly pain, distress, and decreased functional status. Symptoms generally improve after treatment, but improvement is often slow, and fatigue and associated issues frequently persist after completion of therapy.^{23,24}

The approach to and treatment of fatigue are extensively described elsewhere²⁵ and summarized briefly here. Although fatigue is often multifactorial or is related to cancer or its treatments, the challenge to the internist is to determine whether fatigue indicates progression of underlying disease, the onset of a new medical condition, interaction with other symptoms or issues, or side effects from current treatment. It is important to identify any contribution from sleep disturbances; deconditioning, depression, anxiety, psychosocial distress, dyspnea, and uncontrolled pain or other symptoms may be factors.²⁶

Meta-analyses²⁷ and guidelines^{28,29} support a small but significant impact of aerobic exercise programs and yoga for fatigue, particularly in early-stage disease. For some patients, due to the burden of disease, treatment, or complications, exercise may be challenging or impossible. In these situations, the approach should focus on energy conservation and rest to achieve goals; rehabilitative programs can sometimes assist with maximizing function. Psychosocial interventions including educational programs on fatigue, training in self-care and coping, and activity management, may also be effective.³⁰ Trials of pharmacologic agents and supplements for fatigue have not generally shown evidence of benefit for cancer patients or survivors, particularly multiple RCTs of methylphenidate, dexamphetamine and modafinil, and adverse effects are common, particularly anxiety and insomnia.^{29,31}

Sleep disturbances

Poor sleep can be detrimental to survivors' quality of life and affects other symptoms, and deserves careful evaluation and treatment. Insomnia is considered difficulty falling asleep or awakening during the night, which should be distinguished from general complaints about fatigue, distress or depression. Other sleep disturbances also impact survivors, such as sleep apnea or restless leg syndrome. Insomnia often predates the cancer diagnosis, but may be related to or exacerbated by cancer or its treatments, and may persist throughout survivorship. Insomnia may be exacerbated by excessive sleeping during the day, uncontrolled symptoms (e.g., pain or dyspnea), medications, caffeine or alcohol. Psychosocial and spiritual issues and anxiety can be most bothersome in the evening and may contribute to patients being unable to sleep, and interventions such as counseling may be helpful. If patients need medications for other purposes (e.g., depression, neuropathy), clinicians can consider whether medications have a side effect of drowsiness, can be taken at night, and can be effective as a dual aid for insomnia.

An evidence-based review of RCTs of interventions for sleep disturbances in cancer patients found substantial evidence to support cognitive behavioral therapy, with some evidence for exercise and mindfulness-based stress reduction.³² There is insufficient evidence for use of medications for sleep disturbances in cancer patients.³² Both the Oncology Nursing Society's Putting Evidence into Practice³² and evidence-based non-cancer practice guidelines from the American College of Physicians (strong recommendation)³³ recommend the use of cognitive behavioral therapy for insomnia as initial treatment. Cognitive behavioral therapy includes a combination of cognitive therapy, behavioral interventions (e.g., daytime sleep restriction and reducing stimuli), and education on sleep hygiene, and is available through print materials, individual or group therapy, or web-based methods. Engaging cancer survivors in therapy for sleep disturbances may be challenging, and in-person cognitive behavioral therapy for insomnia is not widely accessible, although evidence-based online programs are now available.³⁴

Given the significant adverse effects of medications for insomnia (e.g., amnesia, drowsiness, and rebound insomnia), they are best used as second-line therapy and for acute episodes rather than chronically. When necessary for short term use, evidence-based clinical practice guidelines from the American Academy of Sleep Medicine and the American College of Physicians (weak recommendation) agree on use of selected non-benzodiazepine hypnotics (zaleplon, zolpidem, and eszopiclone) and the tricyclic antidepressant doxepin.^{33,35}

ETHICAL AND LEGAL DOMAIN

Advance Care Planning (ACP)

Advance care planning is the process of communication between a patient, family/health care proxy/decision maker, and/or healthcare providers to clarify treatment preferences and to develop goals of future care. Improving concordance between patient preferences and the care patients receive at end-of-life is crucial for patient-centered and quality care.³⁶ The goal of ACP is to improve the likelihood that cancer survivors receive medical care that is consistent with their values, goals and preferences, if their illness recurs or progresses.³⁷

Physicians should have ACP discussions with older cancer survivors and those at significant risk of recurrence, complications, or mortality. Advance care planning often involves completing advance directive forms to document patients' preferences about the choice of one or more surrogate decision makers (i.e., the durable power of attorney), preferences for life-sustaining treatments (i.e., the living will), and, ideally, more broadly, patients' other preferences, values, and goals.

Importance of ACP in Primary Care—Many patients receive more intensive treatment at the end of life than they would choose if they had the opportunity to more fully discuss their care options and preferences.³⁶ Research demonstrates that ACP discussions increase the likelihood that patients will receive care consistent with their preferences. For example, ACP discussions are associated with less use of intensive life-sustaining treatment and more use of hospice care.^{38,39} Contrary to physicians' frequent concerns, ACP discussions are not generally associated with increased anxiety.³⁸ ACP discussions decrease patient stress while increasing patient satisfaction.^{40–45} For health care proxies, ACP decreases anxiety, depression, and stress, while increasing satisfaction with quality of care.^{38,40,46,47}

Goals of care discussions between a patient and clinician can include goals and preferences for future care, quality of life, decision-making preferences, fears or anxieties, palliative care options, do-not-resuscitate orders, and surrogate decision-making in future disease stages.⁴⁸ These discussions can be helpful to patients and for future care even if they do not lead to discussions of documentation of an advanced directive or appointment of a surrogate decision-maker.⁴⁹ Research suggests that there is a need to improve prevalence and quality of these goals for care discussions. Only a small percentage of hospitalized patients have a discussion with their physician about their future care or goals.⁵⁰ When ACP is inadequate, patients may not receive care consistent with their preferences.^{36,38,51,52}

Patient-Provider ACP and Goals of Care Discussions—Patients' long-term relationships with primary care physicians facilitate high-quality ACP.⁵³ ACP is an iterative process and professional societies recommend clinicians have multiple ACP discussions with patients over time,¹ providing adequate opportunities for patients to think about their future care through their changing health experience.⁵⁴ Patients with cancer frequently receive care from multiple clinicians across different healthcare settings, which challenges consistency and sharing of ACP information.⁵⁵ As primary care clinicians involved in survivorship often have longitudinal relationship with patients and are the liaison between other involved clinicians, they are often the best to engage in ACP and goals of care discussions.

Improving Prevalence and Quality of ACP Discussions—A review of communication about serious illness for the American College of Physicians found that best practices included: sharing prognostic information, eliciting decision-making preferences, understanding fears and goals, exploring views on trade-offs and impaired function, and wishes for family involvement.⁵⁶ A study asking patients which components of these discussions were most important generally concurred, with patients noting preferences for care in the event of life-threatening illness, values, prognosis, fears, and questions about goals of care.⁵⁰

Successful physician interventions for improving ACP discussions include physician training, reminders for clinicians or patients, appointments targeting ACP, interactive patient education seminars, and longer times for annual visits.^{57–59} However, resource and time constraints are frequent barriers to implementing or sustaining these interventions.⁶⁰ There are also initiatives to improve ACP involving non-physician professionals and trained laypersons, such as implementing models that encourage multiple ACP conversations and communication guides.^{40,61,62} Other interventions target patients through paper, web-based,^{63,64} or video tools.^{65–70} A systematic review⁴⁵ on the efficacy of ACP interventions concluded that interventions can improve the frequency of advance care planning discussions and documentation between patients and health care professionals. Interventions that focused on communication about end-of-life care in addition to completion of ADs improved concordance between preferences and the care patients received.⁴⁵

Documenting ACP—Advance directive (AD) completion rates remain low at only about a third of adults in the US.⁷¹ Many patients who discuss preferences for care with family or physicians have not documented their preferences, and physicians often do not document discussions in the medical record. For example, one study found that agreement between expressed preferences and medical record documentation of wishes was only 30%.⁷²

States have customized ACP documentation forms and these are generally applicable across states. Several other ACP guides that have been developed for the clinical setting are also legal documents in most states. One of the most popular is the Five Wishes document, designed by Aging with Dignity, which addresses values and preferences more broadly, as well as decision making regarding treatment at the end of life.⁷³ The document has been translated into multiple languages.⁷³ Research suggests that adolescent and young adult patients with cancer might benefit more from tailored documents⁷⁴ that incorporate language and terminology reflecting their values and beliefs.⁷⁵ Voicing My Choices is another Aging with Dignity planning guide designed for adolescent and young adult patients.⁷⁶ The guide aims to help patients communicate their end-of-life preferences to family and health professionals.^{75,77–79}

In many states, when patients have preferences but do not want to complete forms, physicians can document and create a witnessed oral advance directive. Advance care planning can also include appropriate discussion and completion of resuscitation orders, if consistent with patients' preferences. Examples of these include the newer POLST or MOLST forms (Physician or Medical Orders for Life-Sustaining Treatment). Ideally, these conversations and documents are shared with care teams and family members. Documentation should be placed in easily accessible areas, such as the electronic medical record and the patient's home.

SUMMARY

In summary, the palliative care framework as applied to survivorship includes comprehensive assessment of communication needs, the physical, psychological, social, cultural and spiritual domains, and advance care planning when appropriate. Key principles include techniques to maximize the quality of communication and decision-making about

difficult issues. Key palliative approaches to symptom management include addressing associated symptoms and psychosocial concerns, using nonpharmacologic approaches first or alongside medications, and carefully considering side effects. Clinicians should assess interactions between symptoms and other issues that affect patients, as this often affects management; symptoms should be prioritized; and clinicians should consider side effect profiles carefully, as medications often exacerbate other symptoms. Finally, physicians should address advance care planning in older cancer survivors and those at significant risk of mortality, ideally through engaging in conversations about values and goals over time. When possible, physicians should document preferences for end-of-life care and surrogate decision makers, including in the medical record, and encourage discussions between patients and families.

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BOX 1. Palliative Care Principles for Physicians in Cancer Survivorship⁴**Care for Patients and Family Members**

Provide guidance and support as patients make transitions between stages of illness (treatment, recovery, recurrences, cancer as a chronic illness)

- Provide comprehensive and competent assessments of patient and family needs
- Listen and offer caring presence
- Communicate effectively and compassionately about cancer status and its effects, prognosis and treatment options and effects
- Engage in shared decision-making, including families when desired
- Respect patient and family beliefs, values, and goals
- Support the patient's and family's search for meaning and hope
- Provide ongoing emotional support and reassurance

Provide skilled, effective interventions that meet the patient's needs

- Refer to other disciplines and supportive services to help address needs when appropriate
- Serve as an advocate to help patients and families receive needed services
- Adjust therapies to meet the capabilities of family members, and teach patient care techniques

Data from Dy SM, Grant M. UNIPAC #1: The hospice and palliative care approach to serious illness, American Academy of Hospice and Palliative Medicine. ed 4, Glenview, Illinois, 2012.

BOX 2. Palliative care approach to physical symptoms, adapted for survivorship

- **Prioritize:** what is most affecting patients' quality of life and keeping them from doing what they want to do?
- **Assess:** Thoroughly assess symptoms and commonly associated coexisting symptoms (e.g., fatigue, depression, and sleep disturbance), for potential treatable causes, and consider diagnostic testing where likely benefits exceed burdens/harms
 - Is anything being caused by treatments or medications that can easily be adjusted?
- **Treat:** Discuss and respect patient preferences
 - Consider several possible options
 - If there is a procedure or treatment, what are the side effects/ risks? Side effects are and risks often higher in cancer patients, especially with chronic cancer and comorbidities
 - Balance treating a symptom with side effects and other current concerns. Is it worth it?
 - Use nonpharmacologic approaches first whenever appropriate (e.g., talking about distress instead of prescribing an antidepressant)
 - **Keep it simple:** change one thing at a time if possible
 - **Time-limited trial:** try something regularly for a few days
- **Support:** Always consider psychological and social aspects, and how to work with and support the family
- **Followup:** Discontinue or taper treatments as soon as no longer needed

BOX 3**Web resources for patients and families**

National Comprehensive Cancer Institute - Guidelines for patients – treatments of different cancers and supportive care, including fatigue and distress <https://www.nccn.org/patients/guidelines/cancers.aspx>

American Cancer Society – Resources on living with cancer as a chronic illness, nutrition and activity, worry about and dealing with recurrence <https://www.cancer.org/treatment/survivorship-during-and-after-treatment.html> (Also has published specific survivorship guidelines for various cancers, which address a variety of palliative care domains)

National Cancer Institute – Guidance on many symptoms and other sources of distress <https://www.cancer.gov/publications/patient-education/life-after-treatment.pdf>

Local cancer support organizations - Provide many services, including support and exercise programs, often for free – search for “cancer support community” and your state or local area

Key Points

- The palliative care approach begins with comprehensive assessment of domains of an individual's life including the physical, psychological, social and spiritual arenas.
- Communication and decision-making for difficult issues should include responding to emotions, planning ahead for communication needs and considering reasons for communication challenges
- Key palliative approaches to symptom management include addressing associated symptoms and psychosocial concerns, using nonpharmacologic approaches first or together with medications, and carefully considering side effects
- Advance care planning includes addressing values, goals and preferences for care with family involvement, and written or oral documentation

Definitions	Domains	Key Subdomains
<p><u>Cancer survivors</u> are anyone living with or with a history of cancer</p> <p><u>Palliative care</u> emphasizes communication about goals of care and patient preferences and support for the best quality of life for patients and their families, regardless of the stage of illness or use of other interventions</p>	Structure and Processes	Comprehensive assessment Communication, decision-making Coordination
	Physical	Pain Fatigue, physical function Sleep disturbances Nutrition, weight, body image
	Psychological and Psychiatric	Adjustment Distress, worry Anxiety, depression
	Social	Social function, employment issues Family involvement, strain, burden Family/ social support
	Spiritual and religious	Forgiveness, gratitude Meaning Connections to religion/ religious community
	Cultural	Cultural values and preferences
	Ethical and Legal	Advance care planning Patient preferences

Adapted from: National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. Third Edition, 2015. www.nationalconsensusproject.org. Accessed on February 15, 2017.
 Note that key subdomains are listed, but many other issues, particularly in the physical domain, may be important and need to be tailored for specific cancer types

Figure 1.
 Framework for Palliative Care in Cancer Survivors

Table 1

National Consensus Project Clinical Practice Guidelines for Palliative Care key elements, adapted for survivorship¹

Key Elements	Description
Patient-family centered care	The personal needs and preferences of each patient and family is respected, and the patient and family constitutes the unit of care.
Timing of care	Ideally, survivorship care begins at the time of diagnosis and continues throughout the trajectory, including managing long-term treatment effects and recurrences, treating cancer as a chronic illness, and the end of life and family bereavement.
Comprehensive care	Palliative care uses a multidimensional assessment to identify and address quality of life issues through the prevention of or alleviation of physical, psychological, social, and spiritual distress. Palliative care requires regular assessment, diagnosis, planning, interventions, monitoring, and follow-up.
Collaboration with other disciplines	Palliative care encourages collaboration with other disciplines and services (e.g., social work, nutrition, rehabilitation, support groups).
Attention to addressing patient and family needs	A key goal of palliative care is to prevent and address the burdens imposed by disease and its treatments, including pain and other symptoms.
Communication and shared decision-making	Effective communication about symptoms, treatments, goals of care and preferences, along with shared decision-making, are critical.
Delivery of palliative care	Palliative care for survivors is generally provided by internists and oncologists, but in complicated situations, palliative care specialists or teams may be helpful.

From National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, Third Edition. 2015; with permission.