

HEALTHCARE PROFESSIONALS

No. 12 in a series providing the latest information

Facts About Facilitating Optimal Survivorship Care for Blood Cancer Survivors

Introduction

Transitioning to life beyond active treatment can be challenging for blood cancer survivors. All survivors in remission, or those whose disease has been deemed cured, have an adjustment period. Many experience life-long challenges because of their disease and treatment. Additionally, some survivors may be managed with active surveillance and not offered active treatment right away. These survivors must adjust to the uncertainty of living with chronic cancer. Some may be in remission, but have a recurrence or progression of disease, and may have to undergo additional treatment.

Regardless of their unique situation, all blood cancer survivors and their families need ongoing support related to all aspects of health, including physical, emotional, financial, and occupational.

This fact sheet is aimed at helping healthcare professionals facilitate a smoother transition into survivorship care for all blood cancer survivors. It specifically addresses: survivorship care planning; recurrence and subsequent malignancies; psychosocial, emotional, and cognitive effects of treatment; physical long-term and late effects of treatment; comorbidities; health promotion and disease prevention; survivorship guidelines; patient and caregiver education; care coordination among healthcare professionals; and preparing patients and caregivers for the survivorship phase.

It is important to remember that blood cancer survivors have been through trauma and may be facing lifelong effects from their disease and treatment. The content and resources shared in this fact sheet are aimed at helping clinicians deliver optimal survivorship care to all blood cancer survivors.

What is Cancer Survivorship?

"In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience."

- National Cancer Institute

Highlights

- Survivorship care planning is an essential aspect of quality cancer care and should be started as early as possible, preferably before the end of active treatment.
- Blood cancer survivors are at increased risk for physical and emotional long-term and late effects of their disease and treatment. They also may require special considerations related to early detection and health promotion activities.
- Actions taken by clinicians can help facilitate a smoother transition from oncology-led to PCP-led delivery of survivorship care, when appropriate.
- Blood cancer survivors have been through trauma and need ongoing support.

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Survivorship Care Planning

Survivorship care planning is an essential aspect of quality cancer care. Because the survivor's primary disease and treatment may place them at increased risk for serious long-term and late effects, a patient-specific plan should be developed, and delivery of care should be coordinated between the patient, caregivers, oncology team, primary care practitioner (PCP), and other healthcare professionals.

Below is an overview of the components of survivorship care. The domains are aligned with the Cancer Survivorship Care Quality Framework¹ and tailored to the unique needs of blood cancer survivors.

Table 1. Components of Survivorship Care¹

Monitoring for and management of recurrence and subsequent malignancies	Monitoring for and management of psychosocial, emotional, and cognitive effects of treatment	Monitoring for and management of physical long-term and late effects of treatment	Monitoring for and management of comorbidities	Health promotion and disease prevention
 History and physical exam Risk/exposure-based monitoring Laboratory tests and studies Patient and caregiver education regarding signs and symptoms they should report Referral to a specialist as needed 	Psychosocial, emotional, and cognitive assessment Patient and caregiver education Treatment, including psychotropic medication, as needed Referral to a social worker, psychologist, neuropsychologist, or psychiatrist, preferably with experience helping survivors of cancer or chronic illness, as needed Referral for peer support, such as through a support group	History and physical exam Risk/exposure-based monitoring Laboratory tests and imaging studies Patient and caregiver education regarding signs and symptoms they should report Referral to a specialist as needed	 History and physical exam Age, sex, and risk-based monitoring Management of comorbidities Patient and caregiver education Continuation with PCP for primary care services 	 Document vaccine status Administer seasonal, risk-based, and catch-up vaccines, as appropriate Patient and caregiver education about infection prevention Promote a healthy lifestyle (including nutrition, exercise, smoking cessation, limiting alcohol use, etc.) Continuation with PCP for primary care services

Individual risk can vary based on the patient's age and exposure, but notable long-term and late effects for blood cancer survivors include:

- Anxiety and depression
- Body image concerns
- Bone disorders, possibly requiring joint replacement
- Cardiotoxicity

- Cognitive impairment
- Dental complications and possible tooth loss
- Fatigue
- Inability to work or return to school
- Infertility
- Neuropathy
- Pain
- Pulmonary toxicity
- Subsequent malignancy or diseases

Survivors should receive treatment exposure-based monitoring for long-term and late effects because side effects vary based on the specific types of therapy received. For more information about late and long-term effects of agents commonly used in the treatment of blood cancer, please visit:

www.LLS.org/HCPbooklets (search for "Facts About Blood Cancer Survivorship Treatment and Ongoing Patient Care")

Monitoring for and Management of Recurrence and Subsequent Malignancies

Recurrence

Monitoring for disease recurrence for those who are in remission or have been cured is a critical component of survivorship care and can facilitate prompt intervention if recurrence is detected. Monitoring for blood cancer recurrence is usually the responsibility of the oncology team.² The oncology team may continue this monitoring for around ten years, but the exact duration varies based on a number of factors. If a patient transitions to a PCP for monitoring, the oncologist should provide specific recommendations based on the patient's disease, treatment, and prognostic factors. Recommendations for monitoring, depending on the diagnosis, may include:^{2,3,4,5}

- History and physical exam, which should incorporate the survivorship guidelines developed by the Children's Oncology Group (COG) and/or the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®), as appropriate
- Laboratory tests, which may include complete blood count (CBC) with differential, chemistries, liver function tests, coagulation profile, reticulocyte count, immunoglobulin serum levels, lipid panel, LDH, HgbA1c, and/or vitamin D 25-OH
- Minimal/measurable residual disease testing, which may include flow cytometry, polymerase chain reaction (PCR), and/or next-generation sequencing (NGS)
- Imaging studies, which may include chest X-ray and computed tomography (CT) of the chest, abdomen, and/or pelvis
- **Bone marrow biopsy,** especially if the peripheral blood smear is abnormal or cytopenia develops

Patients with indolent or chronic forms of blood cancer may be managed with active surveillance, which used to be known as "watch and wait." In this case, patients are monitored for disease recurrence or progression. Examples of blood cancers that may be managed with this approach include chronic lymphocytic leukemia (CLL) and myelodysplastic syndromes (MDS).

All patients being monitored for recurrence or progression should be educated about the signs and symptoms they should report to their healthcare professional. Patients should also be clearly informed which clinician is responsible for monitoring their disease status and who they should

contact regarding concerns or symptoms they need to report. If the PCP is responsible for monitoring, the oncologist should provide clear recommendations and criteria for referral.⁶

Resources are available to help clinicians determine the specific testing and monitoring intervals recommended based on the patient's disease and treatment. COG and NCCN Guidelines both offer guidance regarding monitoring for disease recurrence, and The Leukemia & Lymphoma Society (LLS) published a fact sheet on measurable residual disease, which includes recommended testing intervals for blood cancer survivors. Additionally, MD Anderson Cancer Center publishes cancer survivorship algorithms for common forms of leukemia and lymphoma, including specific recommendations related to monitoring for recurrence.

Visit:

- www.survivorshipguidelines.org to view COG Long-term Follow-up Guidelines
- www.NCCN.org (search for "Survivorship" in upper right search box)
- www.NCCN.org (search for "Treatment by Cancer Type" in the upper right search box to view disease-specific guidelines)
- www.LLS.org/HCPbooklets (search for "Facts About Measurable Residual Disease")
- www.mdanderson.org/for-physicians/clinical-toolsresources/clinical-practice-algorithms/survivorshipalgorithms.html to view Cancer Survivorship Algorithms published by MD Anderson Cancer Center

Subsequent Malignancies

Blood cancer survivors are at increased risk for subsequent malignancies, including blood cancers and solid cancers. These malignancies are new primary cancers and are not a recurrence or progression of the first primary cancer. Approximately 15–20% of cancer diagnoses in cancer registries are subsequent malignancies.⁷

Subsequent malignancies may be secondary to treatments the survivor received for their primary blood cancer or related to shared etiologic factors, such as genetic susceptibility, smoking, environmental exposures, and lifestyle factors. Individual risk varies based on the survivor's risk factors, age at the time of treatment for the first cancer, and type and intensity of treatment. Blood cancer treatments that increase the risk of a subsequent cancer include:^{2,4,8}

Alkylating Agents

Examples include: carmustine (BiCNU°), chlorambucil (Leukeran°), cyclophosphamide (Cytoxan°), melphalan (Alkeran°), and procarbazine (Matulane°)

Antitumor Antibiotics

Examples include: bleomycin (Blenoxane®), daunorubicin (Cerubidine®), doxorubicin (Adriamycin®, Doxil®), idarubicin (Idamycin®), and mitoxantrone (Novantrone®)

DNA-repair Enzyme Inhibitors

Examples include: etoposide (VP16, Etopophos®, Toposar®, VePesid®), and teniposide (Vumon®)

Heavy Metals

Examples include: carboplatin (Paraplatin®) and cisplatin (Platinol®)

Hematopoietic Stem Cell Transplantation

Radiation Therapy

Examples include: chest radiation for the treatment of Hodgkin lymphoma and total body irradiation administered prior to stem cell transplantation

Subsequent cancers may present several years, or decades, after treatment for the first primary cancer. This can pose challenges for monitoring as some patients may no longer be under the direct care of their oncologist. To facilitate long-term monitoring, a clear plan should be developed by the oncology team and shared with the patient and PCP. The PCP and oncologist should share the responsibility for monitoring, with the oncologist providing risk-based recommendations.

Cancer screenings may need to begin much sooner than recommended by standard age-based guidelines, especially among survivors of childhood, adolescent, or young adult blood cancers.⁴ As one example, female survivors of Hodgkin lymphoma who received chest radiation at a young age have a five to twenty times increased risk of developing breast cancer and therefore need more intensive surveillance.^{4,8} Clinicians are encouraged to consult the guidance developed by COG and NCCN Guidelines to facilitate patient-specific survivorship care planning.

Learning about the increased risk for a subsequent cancer can be distressing to survivors and their caregivers. Survivors and their caregivers can benefit from referral to a mental health specialist or cancer support group, including the support services offered through LLS.

Visit:

- www.survivorshipguidelines.org to view COG Long-term Follow-up Guidelines
- www.NCCN.org (search for "Survivorship" in upper right search box)
- www.mdanderson.org/for-physicians/clinical-toolsresources/clinical-practice-algorithms/survivorshipalgorithms.html to view the Cancer Survivorship Algorithms published by MD Anderson Cancer Center
- Refer your patients to <u>www.LLS.org/IRC</u> to chat with an Information Specialist for personalized information and support

Monitoring for and Management of Psychosocial, Emotional, and Cognitive Effects of Treatment

Anxiety and Depression

Anxiety and depression are common among cancer survivors and can negatively affect quality of life, decrease immune function, and potentially shorten survival times. ^{2,10,11} Survivors' experiences can vary greatly depending on their age, diagnosis, and treatment, but many survivors experience a range of difficult emotions due to factors including:

- Survivorship guilt
- Uncertainty about the future
- Coping with changes to their body
- Social isolation
- Feelings that no one understands what they are experiencing
- Feelings of aloneness due to decreased appointments with the oncology team
- Anxiety about follow-up appointments
- Fear of recurrence (or progression, in patients with chronic or indolent cancer)
- Pressure to "get back to normal"
- Distress about the potential for serious long-term and late side effects from their treatment
- Mourning what their life was or could have been

Clinicians should routinely assess every patient's emotional health and promptly refer patients for support. Referrals for support should occur while the patient is still in treatment

so they can have support throughout the transition to survivorship care. Some recommended practices to monitor and manage survivors' emotional health include:

- Regularly screen and assess survivors for anxiety, depression, and distress. Also, encourage survivors to talk with healthcare professionals about their emotional health and the emotional challenges they are experiencing.
- Provide information about emotional health, which can help survivors understand the challenges they are experiencing and feel less alone. Information can also help patients learn strategies for managing their mental health and understand when they need professional help.
- **Include caregivers and loved ones in discussions** so they know what to expect for the survivor and themselves.
- **Provide counseling regarding fertility loss,** if relevant for age and disease.
- Provide information and referrals to peer support groups and support services, which may include services offered through the survivor's treatment center and/or through LLS. It is important for survivors to connect with others who have experienced, or are experiencing, similar challenges. This normalizes and validates their experience and helps them feel less alone.
- Refer patients to a mental health specialist, preferably one who has experience helping survivors of cancer or chronic illness navigate survivorship issues.
- Prescribe pharmacologic and nonpharmacologic interventions, which may include dietary interventions, mindfulness-based interventions, yoga, tai chi, qigong, and reflexology.^{12,13}

NCCN Guidelines and the American Society of Clinical Oncology (ASCO) both offer guidance on the management of anxiety and depression in cancer survivors. LLS offers numerous support services, including LLS Community, an online social network and registry for patients, caregivers, and healthcare professionals.

Visit:

- www.NCCN.org (search for "Survivorship" in upper right search box)
- society.asco.org/practice-patients/guidelines/patient-andsurvivor-care (search for "Anxiety")
- www.LLS.org/community to join LLS Community

Fatigue

Fatigue is common among blood cancer survivors and can severely affect quality of life. Cancer-related fatigue is often described as persistent exhaustion that is not relieved by sleep. Some patients find that fatigue is the most bothersome side effect of their disease and treatment. Fatigue can persist for years after the end of treatment. It can also affect emotional health and lead to depression.

Survivors should be educated about the symptoms of fatigue and encouraged to report symptoms to their healthcare team. Survivors should also be informed that treatments are available to help alleviate fatigue, including:

- **Treating contributing factors,** such as treatment of anemia, pain, hypothyroidism, sleep apnea, and depression
- **Lifestyle interventions,** such as exercise, nutrition, and mindfulness-based interventions

Visit:

• <u>society.asco.org/practice-patients/guidelines/patient-and-survivor-care</u> (search for "Fatigue")

Changes in Cognition

Changes in cognition are common among cancer survivors and, in some cases, can substantially impact daily life. Depending on the survivor's age and situation, clinicians should assess the impact of neurocognitive deficits on education, employment, and/or their ability to live independently.

Modifiable contributing factors, such as fatigue and depression, should be identified and treated. Clinicians should also validate the survivor's experience, teach strategies for managing the symptoms, and refer the patient to a specialist as needed.^{2,4}

If nonpharmacologic interventions are insufficient, pharmacologic treatments may be considered.² NCCN Guidelines offers detailed recommendations on how to assess and manage cognitive dysfunction in adults, and COG offers guidance specific to the management of pediatric cancer survivors.

Visit:

- www.NCCN.org (search for "Survivorship" in upper right search box)
- <u>www.survivorshipguidelines.org</u> to view COG Long-term Follow-up Guidelines

We're Here to Help

LLS offers community support and services in the United States and Canada, including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups, and other great resources. For more information about these programs or to contact your region:

• Call: (800) 955-4572

· Visit: www.LLS.org/ChapterFind

Monitoring for and Management of Physical Long-term and Late Effects of Treatment

Long-term and late effects are a major cause of morbidity and mortality among blood cancer survivors and, therefore, necessitate close management and monitoring.¹⁴

Long-term effects are side effects that continue for an extended period after treatment. **Late effects** refer to side effects that do not appear until after treatment. Both long-term and late effects can persist, and sometimes increase, over time. ¹⁴ Sometimes these effects continue for the remainder of the survivor's life.

Recommendations for monitoring should be specified in the survivor's plan of care. Additionally, patients should be educated about their potential increased risk for long-term and late effects and also understand which clinician is responsible for monitoring these effects. In addition to verbal education, patients should receive a written copy of their treatment summary and survivorship recommendations.

COG and NCCN Guidelines both offer guidance related to monitoring and management of long-term and late effects. LLS has also published a fact sheet with information that is specific to blood cancer survivors.

Visit:

- www.survivorshipguidelines.org to view COG Long-term Follow-up Guidelines
- www.NCCN.org (search for "Survivorship Guidelines" in upper right search box)
- www.LLS.org/HCPbooklets (search for "Facts About Blood Cancer Survivorship Treatment and Ongoing Patient Care")

Monitoring for and Management of Comorbidities

Many blood cancer patients have one or more comorbidities at the time of their cancer diagnosis.¹⁵⁻¹⁷ These include diabetes, cardiac disease, renal disease, chronic obstructive pulmonary disease (COPD), prior malignancy, obesity, and/ or other comorbidities.^{16,18} The presence of comorbidities can affect treatment options, outcomes, and overall survival.¹⁸⁻²⁰

Additionally, blood cancer survivors are also at increased risk for experiencing exacerbation of comorbidities and developing new comorbidities due to the effects of their disease and treatment. One study found that nearly half of all cancer survivors were diagnosed with an additional chronic condition following cancer treatment.¹⁷

Survivors require close monitoring and management of comorbidities. Not only are comorbidities associated with poor treatment outcomes and survival, but in some cases, a comorbidity itself may pose greater risk to the patient than the cancer diagnosis. For example, cardiovascular disease is a leading cause of morbidity and mortality in survivors of leukemia, lymphoma, and multiple myeloma. Other important comorbidities for blood cancer survivors include diabetes, COPD, subsequent malignancies, cerebrovascular disease, and anxiety and depression. 16,17,22

Management of comorbidities can be distressing for patients due to the conditions themselves and also because of potential fragmentation in post-treatment care. Many patients report not knowing who is responsible for their care following the conclusion of cancer treatment.²³

For best outcomes, patients should be encouraged to routinely see their PCP throughout, and beyond, their cancer treatment period. This is important because patients who exclusively see an oncologist are less likely to receive primary care services, such as bone densitometry, cholesterol screening, and influenza vaccination.²³ Maintaining contact with their PCP will also help patients transition from active treatment to survivorship care.²³

Health Promotion and Disease Prevention

Immunizations

Vaccine recommendations for blood cancer survivors often differ from the general population, especially for patients who were treated with B-cell-depleting therapy, chimeric

antigen receptor T-cell therapy, or hematopoietic stem-cell transplantation.²⁴

Clinicians should document the patient's vaccine status at their first visit and administer recommended vaccines, which may include seasonal vaccines, risk-based vaccines, and catch-up vaccines. For patients to produce a protective immune response, vaccination should occur at least 2 weeks before initiation of treatment.^{2,24} Vaccination is still advised if treatment must be started sooner, although the response may not be as robust.²⁴

Live vaccines are typically contraindicated in actively immunocompromised survivors and their close contacts.² These vaccines include varicella; measles, mumps, and rubella (MMR); rotavirus; nasal influenza vaccine; yellow fever; and oral typhoid. Non-live vaccines are generally considered safe, but immunocompromised patients may not mount an adequate response.² Some blood cancer patients will also require revaccination or have vaccine requirements that are specific to their disease or treatment history.

ASCO and NCCN Guidelines have both developed detailed vaccination guidelines, including recommendations specific to survivors who have long-standing B-cell dysfunction or received B-cell-depleting therapy, chimeric antigen receptor T-cell therapy, or hematopoietic stem-cell transplantation.^{2,24}

Additionally, immunocompromised survivors may experience a range of emotions and feelings of isolation if they are unable to mount an adequate response to vaccines. This is especially true of survivors who need to make lifestyle changes because of their increased risk for infectious diseases. Survivors and their caregivers can be referred to an LLS Information Specialist for personalized information and support, including recommendations regarding LLS's support groups, online chats, and peer-to-peer support services.

Visit:

- <u>society.asco.org/practice-patients/guidelines/supportive-care-and-treatment-related-issues</u> (search for "Vaccination of Adults with Cancer")
- www.NCCN.org (search for "Survivorship Guidelines" in upper right search box)
- Refer your patients to www.LLS.org/IRC to chat with an Information Specialist for personalized information and support

Prevention of Infections

Survivors who completed treatment or are being managed with active surveillance should be informed if they are still considered immunocompromised, and if so, for how long they are expected to remain immunocompromised. Immunocompromised survivors and their caregivers should be educated about their risk for infection and infection-prevention measures.

Some precautions that may be advised are listed in **Table 2**.

Table 2.

Precautions for Immunocompromised Survivors

Personal Hygiene:

Wash hands thoroughly, bathe daily, and prevent abrasions by using a soft-bristle toothbrush and electric shaver.

Medical Device Care:

Careful management of medical devices such as indwelling ports and catheters.

Food Safety:

Cook all meat thoroughly, wash all produce, and avoid raw and unpasteurized foods.

Prevention of Injuries:

Avoid cuts and burns and carefully monitor the healing of any wounds.

Hobbies and Lifestyle:

Avoid large crowds and individuals who are sick, wear gloves and a mask while gardening, and do not handle pet/animal feces.

Travel:

Speak with the health team regarding potential need for pre-travel vaccination and/or prophylaxis, especially if traveling internationally.

Early Detection:

Screen for infectious diseases, including hepatitis ${\bf B}$ and ${\bf C},$ as clinically indicated.

Immunocompromised survivors may feel negative emotions related to their increased risk for infection. This can be especially difficult for survivors who will be immunocompromised for an extended period of time or the rest of their lives. LLS Information Specialists can help by providing personalized information and support to survivors and their caregivers.

 Refer your patients to <u>www.LLS.org/IRC</u> to chat with an Information Specialist for personalized information and support.

Healthy Lifestyle

Nutrition: A healthy diet can help cancer survivors stay strong, maintain a healthy body weight, and improve their quality of life. Some survivors struggle with nutrition due to changes in appetite, changes in weight, food insecurity, and side effects related to their disease and treatment. Individuals struggling with eating or nutrition may benefit from personalized support from a nutrition specialist.

LLS offers survivors of any cancer type and their caregivers free one-to-one nutrition consultations with a registered dietician. During the consultation, survivors can have their questions answered, receive help with issues related to nutrition, and develop a wellness plan personalized to their needs.

- Refer your patients to www.LLSnutrition.org to schedule a nutrition consultation.
- Visit <u>www.LLS.org/HCPbooklets</u> to learn more about food insecurity and identify patients at risk (search for "Food Insecurity").

Exercise: Exercise offers a number of physical and emotional benefits and is associated with improved quality of life among cancer survivors. ²⁵⁻²⁷ Exercise recommendations should be tailored to the individual's abilities and preferences. Additionally, survivors should be encouraged to start slow and progress incrementally.

Some blood cancer survivors may need supervision or professional support related to exercise. This includes survivors with peripheral neuropathy, lymphedema, bone loss, and other conditions that place them at increased risk for injury. These individuals should be referred to physical and/or occupational therapy.²

Even survivors without significant physical limitations may find it difficult to return to physical activity following treatment. To help with this, Livestrong and the YMCA partnered together to offer a 12-week physical activity program specific for cancer survivors. Studies have found that participation in the program is associated with an increase in physical activity and quality of life.²⁸

Refer your patients to www.livestrong.org/how-we-help/livestrong-at-the-ymca/ to learn more about the physical activity program offered by Livestrong and the YMCA

Healthy Habits: In addition to the health promotion behaviors discussed above, patients should also be encouraged to regularly follow-up with their PCP, receive routine health screenings, get adequate sleep, practice sun safety, limit alcohol use, and avoid tobacco products.

To help with smoking cessation, survivors can be referred to <u>Smokefree.gov</u>, which is a program created by the National Cancer Institute (NCI) to help individuals stop smoking. Survivors can also call 1-800-Quit-Now to connect with their state's helpline.

 Refer your patients to <u>Smokefree.gov</u> for help with smoking cessation or call 1-800-Quit-Now to be connected with your state's helpline.

Survivorship Guidelines

Because survivor needs will vary based on their specific disease and treatment, clinicians are strongly encouraged to consult the comprehensive guidelines developed by COG and NCCN Guidelines.

COG has developed extensive guidelines and exposure-based recommendations to guide the care of survivors who were treated for cancer as a child, adolescent, or young adult. NCCN Guidelines has developed survivorship guidelines and disease-specific guidelines focused on adult survivors, including those with chronic cancers. Additionally, survivors being managed with active surveillance may benefit from the LLS information booklet on the topic.

Visit:

www.survivorshipguidelines.org to view COG Long-term Follow-up Guidelines

www.NCCN.org (search for "Survivorship" in upper right search box)

www.NCCN.org (search for "Treatment by Cancer Type" in upper right search box to view disease-specific guidelines)

Refer your patients to www.LLS.org/booklets (search for "Watch and Wait Fast Facts")

Table 3. Survivorship Guidelines

Comprehensive recommendations can be found in the guidelines published by the NCCN Guidelines[®], Children's Oncology Group (COG), and American Society of Clinical Oncology (ASCO).

NCCN Guidelines	www.NCCN.org (search for Guidelines Survivorship in upper right search box)	
COG	www.childrensoncologygroup.org/survivorshipguidelines	
ASCO	www.asco.org/practice-patients/guidelines/patient-and-survivor-care	

NCCN=National Comprehensive Cancer Network® (NCCN®)

Patient and Caregiver Education about Survivorship Care

Patient and/or caregiver education is a crucial element of effective survivorship care planning. Patients and their caregivers should be educated about the survivor's potential increased risk for long-term and late effects and informed which clinician will be responsible for each aspect of their survivorship care. They should also be informed about support services that are available to both survivors and their families to help them cope with the ongoing emotional and psychological impact of the disease and treatment.

To help facilitate the survivor's transition, care planning should begin early and incorporate patient education about what to expect following active treatment. Survivors or their caregivers should also be given written copies of their records, treatment summary, and plan for follow-up care.

Healthcare professionals may also consider providing additional tools to facilitate patient knowledge. For example, one study found that a credit card-sized "Survivor Healthcare Passport" helped survivors of childhood cancer demonstrate improved and sustained knowledge when distributed at their first survivorship clinic visit. The card includes information about the treatments administered, systems at risk, and follow-up care needed (see Figure 1).²⁹



Care Coordination Among Healthcare Professionals

Care Delivery Models

There are multiple models for providing ongoing survivorship care, and no model will fit every circumstance. Examples of current models include:³⁰

- Oncology-led: This approach may be used for a patient currently in active treatment, with ongoing management by the oncology team. A PCP manages acute non-oncology concerns, addresses chronic disease management, and oversees health promotion services, including routine screenings, as indicated.
- **Primary Care-led:** This approach may be suitable for a long-term survivor of childhood leukemia who was treated with a regimen that carries a low risk of long-term and late effects. In transitioning such patients, the following preparation (see section below) would be helpful.
- **Shared Care:** This model may be best for those living with a hematological malignancy such as CLL or MDS where ongoing cancer-related monitoring by an oncologist is occurring. A PCP manages chronic medical conditions and addresses disease-preventive strategies.
- Multidisciplinary Survivorship Clinics: This model may be best for a long-term survivor of childhood or young adult hematological malignancy who was treated with an aggressive regimen that poses high risk for long-term and late effects. This patient may be best transitioned to a program that includes a survivorship clinician as well as those trained to screen for and manage late and long-term effects. Primary care would also be involved in shared care.

Regardless of the model used, it is important that all blood cancer survivors receive high-quality survivorship care, as described in this fact sheet.

Transition From Oncologist to Primary Care Practitioner

When survivorship care is being transitioned from an oncology-led to PCP-led model, there are some strategies that may help the transition proceed more smoothly. Most importantly, oncologists should provide clear recommendations related to surveillance of cancer recurrence and risk-based monitoring for long-term and late effects of the survivor's disease and treatment.²

Some recommended practices to help facilitate the transition of care are listed below, but it is important to note that survivorship care delivery is still an active area of research:

- Shared Care During Active Treatment: Sharing care throughout the active treatment phase may help facilitate survivors' future transition to PCP-led care and result in more robust care throughout the cancer journey.²³
- Early Planning Before the Transition: Advanced coordination between the oncology team, patient, and PCP can help facilitate a smoother transition to PCP-led care. This is important because cancer survivors often report not knowing which clinician is responsible for their care following active treatment.²³ It is important that patients and clinicians know who is responsible for each aspect of care. It is also important that patients feel confident in the ability of the clinician their care is being transitioned to. If they do not, the patient should be informed about other options available to them, including referral to a clinician with more experience in cancer survivorship care.
- Oncology-Specific Appointment With PCP: Around the time of transition, patients should be encouraged to schedule an appointment with their PCP to exclusively discuss their oncology history and survivorship needs. This will allow for a more focused conversation about the patient's survivorship care, as opposed to incorporating the conversation within their annual exam.
- Oncologist-Prepared Recommendations: When the PCP is responsible for monitoring for disease recurrence and/or long-term and late effects, the oncologist should provide evidence-based recommendations that are specific to the survivor's disease and treatment. This information, which may be communicated in a progress note, should preferably include the rationale for the recommendation. For example, an oncologist might state, "The patient received doxorubicin, which is cardiotoxic. Based on the dose administered, the patient should be monitored with an echocardiogram every five years and a cardiovascular history and physical exam annually."

The COG Long-term Follow-up Guidelines and the cancer survivorship algorithms developed by MD Anderson Cancer Center both provide helpful guidance regarding long-term monitoring (see links below).

• Sharing Patient Records: Sharing patient records between the oncologist, PCP, and other subspecialists is important for continuity of care. Clinicians have reported that having access to the same electronic health record systems (EHR) can help facilitate a positive partnership between clinicians.³¹

- Use of Survivorship Assessment Tool(s): Using survivorship assessment tools can help facilitate quality survivorship care. NCCN Guidelines developed a guideline-specific screening tool based on the NCCN Guidelines for Survivorship. This tool can help clinicians assess common areas of concern related to cancer survivors and includes questions related to: 1) Cardiac health; 2) Anxiety, depression, trauma, and distress; 3) Cognitive function; 4) Fatigue; 5) Lymphedema; 6) Pain; 7) Hormone-related symptoms; 8) Sexual health; 9) Fertility; 10) Sleep disorder; 11) Healthy lifestyle; 12) Immunizations and infections; and 13) Employment/ return to work.²
- Cancer and Survivorship Training for PCPs: PCPs may benefit from general education about cancer survivorship issues. One recommended resource is the Cancer Survivorship E-learning Series for Primary Care Providers. This free series was developed through collaboration between the American Cancer Society and GW Cancer Center and funded by the CDC.

Visit:

- www.survivorshipguidelines.org to view COG Long-term Follow-up Guidelines
- www.mdanderson.org/for-physicians/clinical-toolsresources/clinical-practice-algorithms/survivorshipalgorithms.html to view Cancer Survivorship Algorithms published by MD Anderson Cancer Center
- www.NCCN.org to access the Survivorship Assessment tool within the NCCN Guidelines for Survivorship (search for "Survivorship" in the upper right search box)
- <u>cme.smhs.gwu.edu/gw-cancer-center-/content/cancer-survivorship-e-learning-series</u> to access the *Cancer Survivorship E-learning Series for Primary Care Providers*

Coordination with Non-Physician Professionals

Advanced practice clinicians, nurses, and other specialists play an important role in survivorship care. In some survivorship care delivery models, advanced practice clinicians are responsible for directly delivering the survivorship care. Additionally, nurses, social workers, and patient navigators are often involved in care coordination and planning. These clinicians are also important in educating patients and identifying concerns related to physical and emotional health.

To provide the best possible care, it is important that all members of the healthcare team receive education about survivorship issues and survivorship care planning strategies. These individuals may benefit from some of the informational resources developed by LLS, including those linked below:

Visit:

- <u>www.LLS.org/HCPbooklets</u> to view Facts About Blood Cancer Survivorship Treatment and Ongoing Patient Care
- www.LLS.org/CE to participate in free education programs

Preparing Patients and Caregivers for the Survivorship Phase Before and After Treatment Ends

Adjusting to life after active treatment can be a challenging transition for blood cancer survivors and their families. Although treatment may be over, many blood cancer survivors will continue to experience challenging effects from their disease and treatment. Survivors should be educated about these potential effects and offered information about possible interventions.

Also, when discussing these topics, it is important to remember that what you say matters. For example, there is no "good kind" of cancer. Clinicians should help normalize that everyone will have some kind of adjustment period after treatment ends.

Preparing Patients and Caregivers for Physical Changes

Changes in Physical Characteristics

Clinicians should talk with survivors about the physical changes they may be experiencing because of their disease and treatment. Survivors may experience visible changes, including hair loss, changes to their skin, and weight gain or weight loss. Survivors may also cope with invisible changes, such as "chemo brain," fatigue, neuropathy, and changes in sexual health and fertility.

Survivors may feel self-conscious and grieve their previous body and identity. Clinicians should remind survivors that it can take time to adjust to these changes and encourage survivors to be kind and patient with themselves. Survivors may benefit from including their significant other in these conversations for information and support, especially regarding sexual health and fertility, to ensure the burden does not fall solely on the survivor.

Survivors can also be offered medical interventions, support services, and therapy as appropriate. They should also be encouraged to participate in activities that make them feel good, including exercise, which has many proven benefits.

Sexual Dysfunction

Sexuality is an important aspect of quality of life but is often overlooked in survivorship care. Sexual dysfunction among cancer survivors is very common, with prevalence estimates ranging from 40–100%,³² and may arise from the physical and/or emotional aspects of the disease and treatment.

Clinicians should discuss the potential impact of cancer on sexual health with survivors and, when appropriate, their partner. Conversations about sexuality should include discussing if the survivor or partner has concerns about their sexual health or sex life and recognizing that sexual dysfunction can impact many aspects of a survivor's life, including emotional health, intimate relationships, dating, and having a family in the future.

Patient concerns should be taken seriously. When needed, the survivor should be referred to an appropriate specialist, which may include a therapist, urologist, gynecologist, endocrinologist, pelvic floor therapist, sex therapist, or other professional.

NCCN Guidelines and ASCO have both offered detailed guidance regarding sexual health and dysfunction in cancer survivors. Additionally, LLS has a fact sheet for patients regarding sexual health and intimacy.

Visit:

- www.NCCN.org (search for "Survivorship" in upper right search box)
- society.asco.org/practice-patients/guidelines/patient-andsurvivor-care (search for "Sexual Problems")
- www.LLS.org/booklet/sexual-health-and-intimacy to access the Sexual Health and Intimacy fact sheet for your patients

Preparing Patients and Caregivers for Socioeconomic Challenges

Financial Concerns

As a result of their cancer, approximately 33% of workingage survivors in the United States have gone into debt, and more than half have experienced financial hardship. 33,34 Financial burdens can severely affect survivors' emotional health and lead to poor clinical outcomes, especially when patients delay or forgo care. 35 Many oncologists report feeling uncomfortable about discussing financial concerns with patients, and most receive little training about the financial burden of cancer.³⁵ However, it is important that issues related to finance are discussed with the survivor and, if appropriate, their caregivers. Support with financial navigation can result in real, tangible help for cancer survivors. For example, one study funded by NCI found that a financial navigator intervention saved blood cancer participants an average of about \$2,500 per patient.^{36,37}

Practical ways to support survivors include:

- **Screen for financial burden** using a validated tool such as the FACIT-COST, which is a free tool developed in conjunction with the University of Chicago to assess financial toxicity in cancer patients.³⁸
- **Refer survivors to a specialist,** such as a financial navigator, social worker, or patient navigator, who can help them navigate financial issues.
- **Provide information** about financial toxicity and available resources.
- Direct survivors to the LLS Patient Financial Assistance Team to learn more about the various financial assistance programs LLS has available for blood cancer survivors. These programs include co-pay assistance programs, travel assistance programs, programs for non-medical expenses, an education scholarship for blood cancer survivors, and a partnership with Dollar For to help reduce or eliminate medical debt. The LLS Patient Financial Assistance Team can also recommend financial services offered by other organizations.

Visit:

• www.LLS.org/support-resources/financial-support or contact the Patient Financial Assistance Team directly by calling (877) 557-2672 or emailing FinancialAssistance@LLS.org

Occupational Concerns

Approximately one-third of all cancer survivors in the United States are working age. ^{39,40} With regard to blood cancers, the median age at diagnosis of Hodgkin lymphoma is 39 years, and the median age at diagnosis of all blood cancers is 68 years. ⁴¹

For many survivors, employment is necessary for income, health benefits, and emotions related to normalcy, productivity, and identity. A large number of survivors either stop working or make changes to their work.³⁹

Clinicians should have routine discussions with survivors about employment, and if issues are identified, assistance should be offered. As part of the discussion, clinicians should screen survivors regarding their concerns about how the cancer and treatment have affected their ability to work. Clinicians should also help survivors identify goals and expectations surrounding work.

The LLS website has a section that details important information about employment discrimination laws, medical leave laws, and other important information, such as if and when a blood cancer survivor needs to tell their current or future employer about their medical history. Additionally, LLS Information Specialists are available to provide personalized information and direct survivors and their caregivers to additional resources.

Clinicians may benefit from reviewing NCCN Guidelines' recommendations related to employment issues and return to work, which include specific recommendations related to assessing survivors' current status, treating contributing symptoms (such as fatigue and pain), counseling survivors and their families about employment, and other interventions/referrals.² The National Coalition for Cancer Survivorship (NCCS) offers a comprehensive free booklet entitled *Working It Out: Your Employment Rights as a Cancer Survivor.* The survivor may also benefit from referral to a therapist or support group to help them navigate the challenges of employment after blood cancer.

Visit:

- www.LLS.org/managing-your-cancer/employment-rightscancer-survivors-and-caregivers to access LLS webpage on employment rights of cancer survivors and caregivers
- www.canceradvocacy.org/product/working-it-out-youremployment-rights-as-a-cancer-survivor-english/ to access NCCS's free booklet, Working It Out: Your Employment Rights as a Cancer Survivor
- Refer your patients to www.LLS.org/IRC to chat with an Information Specialist for personalized information and support.

Preparing Caregivers for the Survivorship Phase

Caregivers also need support during the transition to survivorship care. Sometimes caregivers do not understand why the patient cannot go back to life exactly like it was before the diagnosis and treatment. Clinicians can help facilitate understanding by educating the caregiver about the effects of the disease and treatment and including the caregiver in patient education.

Clinicians can also recommend support groups and other professional services to help caregivers work through their emotions and readjust to their new normal. Caregivers often experience challenges related to emotional health, employment, finances, and the need to readjust their goals due to the blood cancer diagnosis.

Additionally, the caregiver's role may change during the survivorship phase, depending on the age and needs of the survivor. Clinicians can help by educating caregivers about how to support the survivor both physically and emotionally after treatment ends. Some ways the caregiver can support the survivor include:

- Learn about the possible long-term and late side effects of the survivor's disease and treatment
- Offer emotional support to their loved one
- Talk with their loved one about their continued needs after treatment ends
- Support their loved one in obtaining survivorship care, which may include: understanding the ongoing survivorship plan of care, helping the survivor manage their screening/testing schedule, attending follow-up appointments and scans, understanding side-effect management, knowing which clinicians are responsible for each aspect of care, and obtaining copies of the survivor's medical records and treatment summary

LLS offers numerous support services for caregivers, including informational resources, peer support, online chats, and information about financial support programs.

- Refer caregivers to <u>www.LLS.org/IRC</u> to chat with an Information Specialist for personalized information and support
- Refer caregivers of children and adolescents to www.LLS. org/FamilyWorkbook to access Caring for Kids and Adolescents with Blood Cancer: A Workbook for Families, which includes information about survivorship
- Refer caregivers of adult patients to www.LLS.org/
 Caregiver Workbook to access the Caregiver Workbook, which includes information about survivorship

Barriers to Follow-up Care

High-quality survivorship care is associated with higher quality of life and allows for earlier detection and treatment of long-term and late effects of blood cancer and its treatment. ⁴² However, many survivors do not have access to the care they need and deserve.

Barriers to care include cost,⁴² lack of insurance or transportation, difficulty navigating the healthcare system,⁴² confusion about which clinicians are responsible for providing survivorship care,²³ knowledge about the importance of survivorship care,⁴³ anxiety about going for follow-up testing, and, in the case of survivors of childhood cancer, transitioning from pediatric to adult-focused survivorship care.⁴³

To help address these barriers, clinicians can:

- Educate survivors and caregivers on topics related to survivorship, including those discussed in this fact sheet.
- Ensure survivors understand which physician is responsible for each aspect of their care.
- Provide survivors with written copies of their records, treatment summary, and plan for follow-up care, and make sure they understand these documents.
- **Refer patients for psychosocial support,** both through a therapist and/or a peer support group.
- **Direct survivors to support services,** including those listed in this fact sheet.

Providing Education, Support, and Resources to Survivors and Caregivers

Providing education, information, and support to survivors and their caregivers is critical to ensuring they receive the care they need and do not become lost to follow-up. Survivorship care planning should begin as early as possible so all aspects of care can be coordinated and the survivor has time to ask questions and understand this new phase of their cancer journey. Below are additional recommended resources for providing education and support.

Visit:

- www.LLS.org/booklets to access free publications, including:
 - A Teen's Guide to Everything Cancer
 - Blood and Marrow Stem Cell Transplantation
 - Cancer-Related Fatigue Facts
 - Chimeric Antigen Receptor (CAR) T-Cell Therapy
 - Communicating with Your Healthcare Team: Survivorship
 - Fertility and Cancer
 - Immunotherapy
 - Learning to Communicate Effectively and Ask Important Questions
 - Managing Stress: How Stress Affects You and Ways to Cope
 - Measurable Residual Disease (MRD)
 - Oral Treatment Adherence Facts
 - Pain Management Facts
 - Post-Transplant Lymphoproliferative Disorders
 - Sexual Health and Intimacy
 - Side-Effect Management: Managing Peripheral Neuropathy (Nerve Damage)
 - Side-Effect Management: Memory and Concentration Problems in Adults
 - Side-Effect Management: Reducing Your Risk of Infection
 - Survivorship Workbook for Adults
 - Survivorship Workbook for Children and Adolescents
 - Survivorship Workbook for Young Adults
 - Watch and Wait Fast Facts

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We're Here to Help

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. LLS has regions throughout the United States and Canada. To find the region nearest to you, visit our website at www.LLS.org/ChapterFind or contact

The Leukemia & Lymphoma Society

3 International Drive, Suite 200 Rye Brook, NY 10573 Phone Number: (800) 955-4572 (M-F, 9 a.m. to 9 p.m. ET)

Website: www.LLS.org

LLS offers free information and services for patients and families touched by blood cancers as well as for healthcare professionals. The resources listed below are available to you and your patients and are meant to be a compliment to the HCP team and an additional source of support.

Consult with an Information Specialist. Information Specialists are highly trained social workers and nurses who assist through treatment, financial, and social challenges. They offer up-to-date disease and treatment information. Language services are available. For more information, please:

- Call: (800) 955-4572 (M-F, 9 a.m. to 9 p.m. ET)
- Visit: www.LLS.org/IRC
- Email or Live chat: www.LLS.org/InformationSpecialists

Clinical Trials Support Center (CTSC). Work one-onone with an LLS clinical trial nurse navigator who will personally assist throughout the entire clinical trial process. A nurse navigator will help identify potential clinical trials and overcome the barriers to enrollment (navigators help HCPs and patients). For more information about this free service, please:

- Call an Information Specialist: (800) 955-4572 to be referred to the CTSC
- Visit: www.LLS.org/CTSC
- Complete a referral form for your patient at: www.LLS.org/CTSCreferral

Nutrition Consultations. Nutrition Education Services Center (NESC) provides one-on-one *free* nutrition education and consultations to patients and caregivers of all cancer types with registered dietitians who have expertise in oncology nutrition.

• Visit: www.LLSnutrition.org

Free Information Booklets. LLS offers free education and support publications that can either be read online or downloaded. Free print versions can be ordered. For more information, please:

• Visit: <u>www.LLS.org/booklets</u>.

Información en Español. (LLS information in Spanish) Para mayor información por favor:

• Visite: www.LLS.org/espanol.

LLS Community. LLS Community is an online social network and registry for patients, caregivers, and healthcare professionals. It is a place to ask questions, get informed, share your experience, and connect with others. To join:

• Visit: www.LLS.org/community

LLS Regions. LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups, and other great resources. For more information about these programs or to contact your region, please:

• Call: (800) 955-4572

• Visit: www.LLS.org/ChapterFind

Patti Robinson Kaufmann First Connection® **Program.** A free peer-to-peer support program that connects patients and their loved ones to a trained peer volunteer who has gone through a similar experience.

• www.LLS.org/FirstConnection

Resources for Healthcare Professionals: Webinars, Podcasts, In-person Education Programs, Videos, and Fact Sheets:

- <u>www.LLS.org/CE</u> (free accreditation)
- www.LLS.org/HCPpodcast
- www.LLS.org/HCPvideos
- www.LLS.org/HCPbooklets

Resources for your Patients:

- www.LLS.org/programs
- www.LLS.org/EducationVideos
- www.LLS.org/podcast

Additional Resources

The National Cancer Institute (NCI)

www.cancer.gov (800) 422-6237

The National Cancer Institute, part of the National Institutes of Health, is a national resource center for information and education about all forms of cancer. The NCI also provides a clinical trial search feature, the PDQ® Cancer Clinical Trials Registry, at www.cancer.gov/clinicaltrials, where healthcare professionals and patients can look for clinical trials.

Children's Oncology Group (COG)

www.survivorshipguidelines.org www.childrensoncologygroup.org/survivorshipguidelines

The Children's Oncology Group (COG), a National Cancer Institute supported clinical trials group, is the world's largest organization devoted exclusively to childhood and adolescent cancer research. The COG unites more than 10,000 experts in childhood cancer at more than 200 leading children's hospitals, universities, and cancer centers across North America, Australia, New Zealand, and Europe in the fight against childhood cancer. COG provides important information for children and their families from the time of diagnosis, through treatment and following cure.

National Comprehensive Cancer Network (NCCN)

www.NCCN.org

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 32 leading cancer centers devoted to patient care, research, and education. NCCN Guidelines is dedicated to improving and facilitating quality, effective, equitable, and accessible cancer care so all patients can live better lives.

American Society of Clinical Oncology (ASCO)

www.asco.org/practice-patients/guidelines/patient-and-survivor-care

The world's leading professional organization for physicians and oncology professionals caring for people with cancer.

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