



CLINICIAN STRATEGIES AND RESOURCES: CARING FOR AYAS AS THEY TRANSITION TO CANCER SURVIVORSHIP

MAY 9, 2024

AMERICAN CANCER SOCIETY: WWW.CANCER.ORG

THE LEUKEMIA & LYMPHOMA SOCIETY: WWW.LLS.ORG



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WELCOMING REMARKS

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Rye Brook, NY



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TARGET AUDIENCE

This activity is intended for hematologist/oncologists, APPs, nurses, social workers, and other healthcare professionals involved in the care of adolescent and young adult (AYA) patients with cancer and cancer survivors.

EDUCATIONAL OBJECTIVES

After completing this accredited activity, the participant should be better able to:

- Describe care challenges for AYAs as they transition to survivorship
- Explain the importance of survivorship care, including late effects and how to access long-term follow-up guidelines
- Identify interdisciplinary care team roles in supporting AYA cancer survivors
- Review resources to support AYAs with cancer, their caregivers, and healthcare professionals



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FACULTY

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DISCLOSURES

Brittany Hall, PhD, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

Rebecca Eary, DO, MPH, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

Michelle Rajotte, LMSW, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

Michael Roth, MD, has a financial interest/relationship or affiliation in the form of:
Research Grant: Pfizer, HebeCell

Danielle Friedman, MD, MS, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

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Accreditation, Credit and Support



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Physician Continuing Medical Education

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Registered Nursing Credit Designation

Approval for nurses has been obtained by the National Office of The Leukemia & Lymphoma Society under Provider Number CEP 5832 to award 1.0 continuing education contact hour through the California Board of Registered Nursing.

Nurse Practitioner Continuing Education

This activity is approved for 1.0 contact hour(s) of continuing education (which includes 0 hour(s) of pharmacology) by the American Association of Nurse Practitioners®. Activity ID# 24076719. This activity was planned in accordance with AANP Accreditation Standards and Policies.

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Interprofessional Continuing Education Credit



This activity was planned by and for the healthcare team, and learners will receive 1.0 Interprofessional Continuing Education (IPCE) credit for learning and change.

IPCE CREDIT™ There is no commercial support associated with this CE activity.

Providers

This activity is provided by The Leukemia & Lymphoma Society and Medical Learning Institute, Inc., in collaboration with The American Cancer Society.



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METHOD OF PARTICIPATION

There are no fees for participating in or receiving credits for this CE activity. For information on applicability and acceptance of continuing education credit for this activity, please consult your professional licensing board.

Learners must participate in the entire CE activity, complete, and submit the evaluation form to earn credit. Once submitted, the certificate will be generated. If you have questions regarding the receipt of your certificate, please contact via email at ndane@mlieducation.org.



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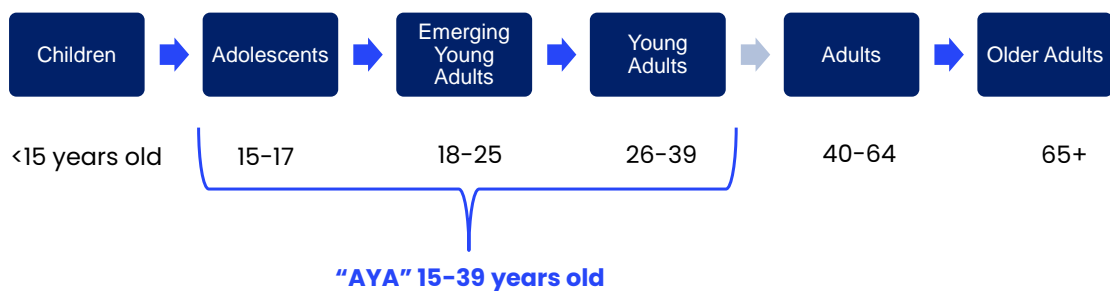
Overview of AYA Cancer



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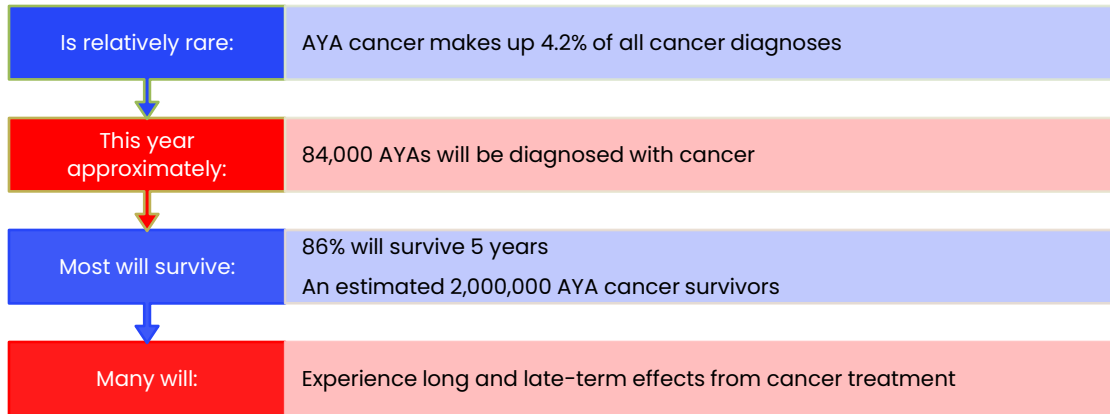
Adolescent and Young Adult (AYA)

refers to individuals diagnosed with cancer between the ages of **15 and 39**



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AYA Cancer



National Cancer Institute: Cancer Stat Facts: Cancer Among Adolescents and Young Adults (AYAs) (Ages 15–39)



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POLLING QUESTION 1

Which of the following are long-term psychosocial issues that AYA survivors of cancer experience?

- A. Financial toxicity
- B. Anxiety and depression
- C. Less likely to have children
- D. More likely to use drugs and alcohol
- E. All of the above



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Importance of Survivorship Care



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What Do We Know about Long-Term and Late Effects among AYA Cancer Survivors?



Physical Issues:

- 2nd Malignancies
- Cardiovascular Disease
- Endocrine Dysfunction
- Neurocognitive Deficits
- Fertility
- Sexual Dysfunction
- Body Disfigurement
- Physical Condition



Psychological Issues:

- Distress
- Anxiety & Depression
- Posttraumatic Stress
- Fear of Recurrence
- Body Image Concerns
- Cognitive Impairment
- Loneliness
- Survivor's Guilt
- Drug and Alcohol Use

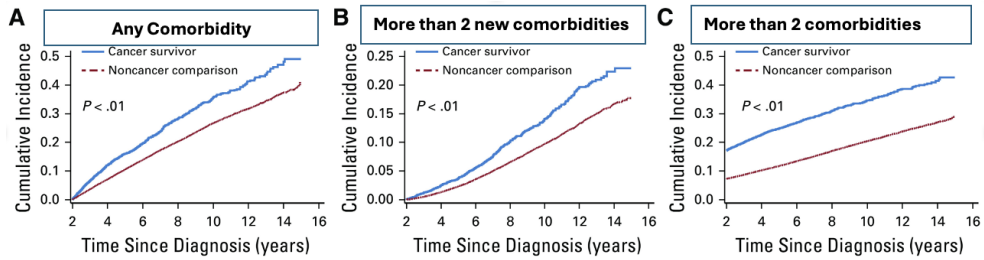


Social Issues:

- Education
- Employment Challenges
- Financial Toxicity
- Relationships (romantic and friendships)
- Access to Supportive Services

References: Janssen et al, Cancers, 2021
The Leukemia & Lymphoma Society
American Cancer Society

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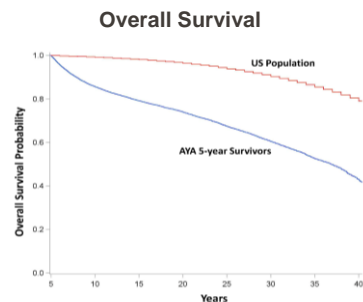
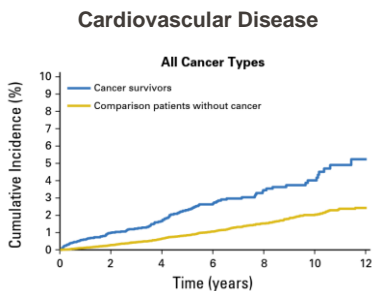
Long-Term Outcomes for Survivors of AYA Cancer

- High risk of developing severe and chronic health conditions due to their cancer treatment exposures
 - Nearly 100% of survivors by age 50 will have 1 or more chronic condition
- Treatment-related late effects are often compounded by the emergence of age-associated chronic conditions

References: Bhakta, 2017; Chao et al. JCO 2020



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Long-Term Outcomes for Survivors of AYA Cancer

- Increased risk of cardiovascular disease compared to patients without cancer
- Increased risk for early mortality due to late side effects of treatment including cardiovascular disease and subsequent malignancies

References: Abrahao, 2020; Meadows, 2009; Armenian et al. Cancer 2020; Chao et al. JAMA Network Open 2019; Berkman et al. Cancer 2020; De et al. JCO 2021



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Long-Term Psychosocial Outcomes

Compared with the general population, survivors of AYA cancer are:

- More likely to have mood and anxiety disorders
- More likely to have lower income
- Less likely to be married
- Less likely to have children
- More likely to use tobacco products and/or alcohol



De et al. JCO 2021
Kaul et al. Cancer 2017
McGrady et al. JCO 2024



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Understanding the Psychological Landscape

- Coming out of the fog
 - Less focus on practical concerns & increased awareness of psychosocial needs
- High levels of daily life needs negatively associated with health (Zhang et al, 2023)
 - Acute medical concerns managed, now living with chronic concerns
- Life not returning to pre-diagnosis
 - Reduction of social support compared to active treatment
 - Reduction in communication with medical team
- Top Concerns: Worry about a new cancer & recurrence (Vandraas et al, 2021)



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Accessing Long-term Follow-up Guidelines



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Publicly accessible at:
www.survivorshipguidelines.org

This webpage also includes:

- **Health Links:** Patient education materials to accompany the guidelines.
- **Program Resource Guide:** A comprehensive guide designed for institutions interested in establishing and enhancing long-term follow-up programs for childhood cancer survivors.
- **Directory of Long-Term Follow-Up Services**



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CHEMOTHERAPY			ANTHRACYCLINE ANTIBIOTICS (CONT)																		
Sec #	Therapeutic Exposure	Potential Late Effects	Periodic Evaluation	Health Counseling/ Further Considerations																	
34	<p>Anthracycline Antibiotics Doxorubicin Epirubicin Idarubicin Mitoxantrone</p> <p>Dose Conversion Use the following formulas to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracycline dose.</p> <p>To estimate cumulative anthracycline dose in doxorubicin isotoxic equivalents:</p> <ul style="list-style-type: none"> 1.0 x (doxorubicin total dose) + 0.5 x (epirubicin total dose) + 0.87 x (idarubicin total dose) + 5.0 x (mitoxantrone total dose) 	<p>Cardiac toxicity Cardiomyopathy Subclinical left ventricular dysfunction Congestive heart failure Arrhythmia</p>	<p>HISTORY Shortness of breath Dyspnea on exertion Orthopnea Chest pain Palpitations If under 25 yrs: nausea, vomiting</p> <p>Yearly</p> <p>PHYSICAL Blood pressure Cardiac exam</p> <p>Yearly</p> <p>SCREENING Echo (or comparable imaging to evaluate cardiac function)</p> <table border="1"> <thead> <tr> <th>Anthracycline Dose**</th> <th>Radiation Dose**</th> <th>Recommended Frequency</th> </tr> </thead> <tbody> <tr> <td><100mg/m²</td> <td><15Gy</td> <td>No screening</td> </tr> <tr> <td>100 to <250mg/m²</td> <td>15Gy to <30Gy</td> <td>Every 5 years</td> </tr> <tr> <td>>100 to <250mg/m²</td> <td>>15Gy</td> <td rowspan="2">Every 2 years</td> </tr> <tr> <td>Any</td> <td>>30Gy</td> </tr> <tr> <td>Any</td> <td>≥ 250mg/m²</td> <td>Every 2 years</td> </tr> </tbody> </table> <p>**Based on doxorubicin isotoxic equivalent dose ***Based on radiation dose with potential impact to heart (radiation to chest, abdomen, spine [thoracic, whole], TB). See section 77.</p> <p>EKG (include evaluation of QTc interval) Baseline at entry into long-term follow-up, repeat as clinically indicated</p>	Anthracycline Dose**	Radiation Dose**	Recommended Frequency	<100mg/m ²	<15Gy	No screening	100 to <250mg/m ²	15Gy to <30Gy	Every 5 years	>100 to <250mg/m ²	>15Gy	Every 2 years	Any	>30Gy	Any	≥ 250mg/m ²	Every 2 years	<p>HEALTH LINKS Heart Health Cardiovascular Risk Factors Nutrition and Physical Activity</p> <p>COUNSELING Traditional CVR's significantly increase survivors' risk of cardiomyopathy. Counsel regarding the importance of maintaining blood pressure, BMI, lipids, and glucose levels within goal ranges per general population guidelines.</p> <ul style="list-style-type: none"> Exercise is generally safe and encouraged for patients with normal LV systolic function Consult cardiology for survivors with asymptomatic cardiomyopathy to define physical activity limits and precautions. Consider cardiology consultation to define physical activity limits and precautions for high risk survivors (i.e., those requiring an echo every 2 years) who plan to participate in intensive exercise. <p>QTc interval is prolonged. Caution use of QTc prolonging medications (e.g., tricyclic anti-depressants, anti-fungals, macrolide antibiotics, metronidazole).</p> <p>POTENTIAL CONSIDERATIONS FOR FURTHER TESTING AND INTERVENTION Cardiac MRI as an adjunct imaging modality when echo images are suboptimal. Cardiology consultation in patients with subclinical abnormalities on screening evaluations, LV dysfunction, dysrhythmia, or prolonged QTc interval. For patients who are pregnant or planning to become pregnant, additional cardiology evaluation is indicated in patients who received:</p> <ul style="list-style-type: none"> >250 mg/m² anthracyclines >30 Gy chest radiation, or Anthracycline (any dose) combined with chest radiation (≥15 Gy) <p>Evaluation should include a baseline echo (pre- or early-pregnancy). For those without prior abnormalities and with normal pre- or early-pregnancy baseline echos, follow-up echos may be obtained at the provider's discretion. Those with a history of systolic dysfunction or with pre- or early-pregnancy systolic dysfunction are at highest risk for pregnancy-associated cardiomyopathy, and should be monitored periodically during pregnancy, labor and delivery due to increased risk for heart failure.</p> <p>SYSTEM = Cardiovascular SCORE = 1</p>
Anthracycline Dose**	Radiation Dose**	Recommended Frequency																			
<100mg/m ²	<15Gy	No screening																			
100 to <250mg/m ²	15Gy to <30Gy	Every 5 years																			
>100 to <250mg/m ²	>15Gy	Every 2 years																			
Any	>30Gy																				
Any	≥ 250mg/m ²	Every 2 years																			
<p>Additional Information</p> <p>Although mitoxantrone is an anthraquinone, it is related to the anthracycline family and is included in this section because of its cardiotoxic potential. Childhood cancer survivors exhibit clinical and subclinical toxicity at lower levels than adults. In patients with abnormal LV systolic function, certain conditions (such as isometric exercise and viral infections) have been anecdotally reported to precipitate cardiac decompensation. Prospective studies are needed to better define the contribution of these factors to cardiac disease risk. Abdominal symptoms (nausea, emesis) may be seen more frequently than exertional dyspnea or chest pain in younger patients.</p> <p>CCO LTFU Guidelines – Page 30</p>																					

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Significant Gaps in Provider Knowledge of Guidelines

Hodgkin Lymphoma Survivor Vignette	General Internists (N=1,110; US only)	Family Physicians (N=1,124; US & Canada)	Pediatric Oncologists (N=665; US only)
Responses Concordant with COG Guidelines			
Breast cancer screening	9%	16%	66%
Thyroid screening	76%	74%	76%
Cardiac screening	15%	10%	57%
Total	5%	2%	33%

Suh E et al, Ann Intern Med 2014; Nathan P, et al. J Cancer Surv 2013; Henderson T, et al. J Clin Oncol 2010.

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Transition Challenges



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POLLING QUESTION 2

What is the most common barrier you or your patients experience when an AYA patient transitions to survivorship care?

- A. Lack of provider clarity
- B. Fear and avoidance
- C. Cost or lack of Insurance
- D. Lack of survivorship programs to refer to
- E. Providers not asking the right questions
- F. Other



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"Research has shown that without a structured transition process, youth and young adults are more likely to have problems with medical complications, limitations in health and wellbeing, difficulties with treatment and medication adherence, discontinuity of care, preventable emergency department and hospital use, and higher costs of care."

- Updated Clinical Report on Health Care Transitions for Youth and Young Adults from the American Academy of Pediatrics



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Barriers to Survivorship Transition

Lack of provider clarity

Skepticism about follow-up care

Autonomy and moving forward

Competing responsibilities

Fear and avoidance

Cost or Lack of Insurance

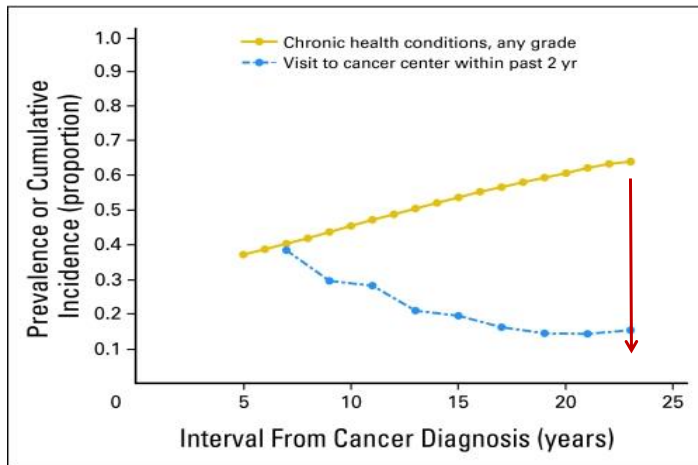
Lack of survivorship programs to refer to

Providers not asking the right questions

Smits-Seeman et al, J Cancer Surviv, 2017
Effinger, K., J Cancer Surviv, 2022

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Less than Half of Adult-Aged Survivors Remain Actively Involved in Survivorship Care



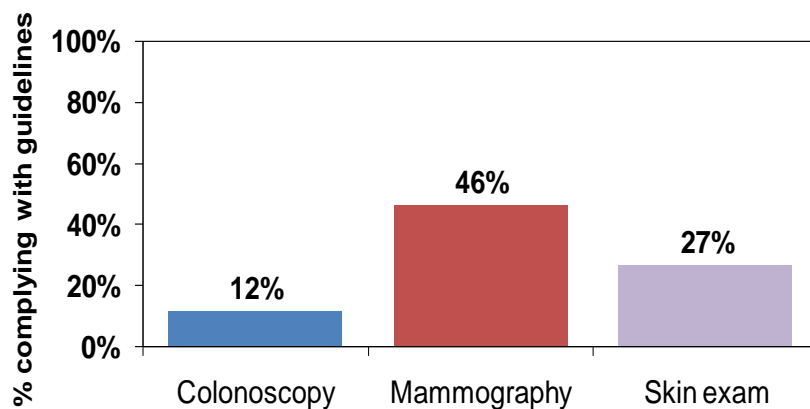
Among 975 adult cancer survivors, **27.3%** had a cancer-related medical visit within the last 2 years

Nathan PC, et al. J Clin Oncol. 2009
Ford JS, et al. Cancer 2020



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High-Risk Survivors Are Not Receiving Recommended Screening Tests



Nathan et al. Ann Intern Med. 2010.



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POLLING QUESTION 3

What transition strategies do you implement to optimize the transition to survivorship care? Select all that apply.

- A. Provide education and encouraging self-advocacy
- B. Coordinate and collaborate with multidisciplinary health care teams
- C. Provide patient navigation services to guide AYA survivors through the transition process
- D. Offer psychosocial support services to address the needs of AYA survivors
- E. Provide a personalized survivorship care plan
- F. Refer survivors to specialized survivorship clinics
- G. All of the above
- H. Other



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Transition Strategies

Education and Empowerment

- Educate AYA cancer survivors about the importance of survivorship care and need for long-term follow-up.
- Empower survivors to advocate for their needs.

Care Coordination

- Coordinate care among multidisciplinary health care teams.
- Establish clear communication channels.
- Share treatment summaries and collaborate on care plans.

Patient Navigation

- Provide patient navigation services to guide AYA cancer survivors through the transition process.
- Navigators can assist with understanding care plans, scheduling follow-up appointments, accessing services, and navigating the health care system.

Psychosocial Support

- Offer psychosocial support services to address the needs of AYA survivors during transition to survivorship care.
- Provide counseling, facilitate support groups, and incorporate psychosocial management into care plans.

Survivorship Care Plans

- All survivors should have personalized care plans that outline recommended follow-up care, screening schedules, and strategies for managing late effects.
- Know where specialized survivorship clinics are to refer survivors to.



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Interdisciplinary Care Team Roles



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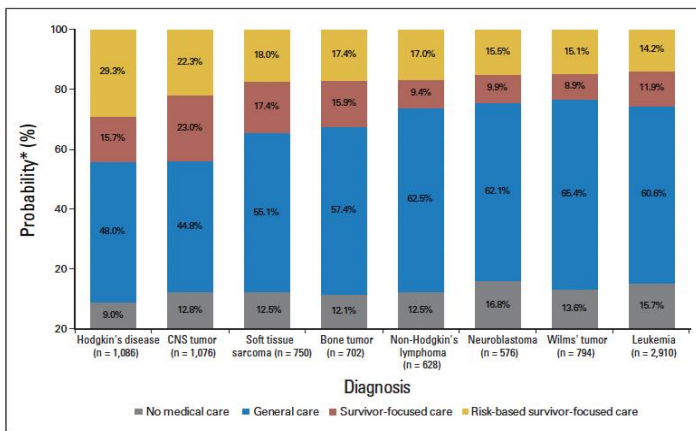


Fig 1. Probability of reporting a particular level of medical care according to initial cancer diagnosis. (*) Probabilities adjusted for sex, age at diagnosis, and age at time of interview using a generalized logit model.

Primary Care Utilization among survivors

- Nearly all cancer survivors will return to primary care at some point in their lifetime (Pinheiro, 2022)
- Survivors more likely to access care in community primary care practices versus survivorship focused clinics (Nathan, 2008)
- In a large cohort of AYA survivors, nearly 30 percent of patients had no follow up with oncology or primary care within the first year completing treatment (Hahn, 2023)



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Need for Primary Care

Reduction of modifiable risks and health promotion

Screening for second primary cancers

Optimizing control of chronic conditions

Addressing late effects

Linking to specialist care – referrals

Assessing psychological and mental health needs

Patients who have a PCP live longer and have decreased mortality from cancer, cardiovascular, and respiratory disease compared to those who only receive specialty care (Basu, 2019).



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Role of Psychosocial Providers

Individual & Group Therapy

- Referrals to peer support

Referrals To Appropriate Providers

Program Development & Evaluation

- Screening & Intervention programs
- Identifying & supporting referrals to meet psychosocial needs
- Increasing optimization of services



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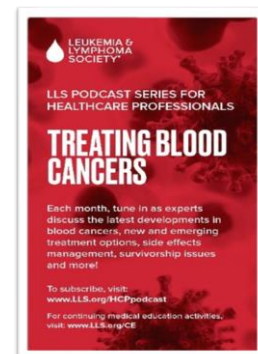
RESOURCES



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FREE LLS RESOURCES FOR HEALTHCARE PROVIDERS

- CME and CE courses: www.LLS.org/CE
- Staying Connected®: www.LLS.org/StayingConnected
- Fact Sheets for HCPs: www.LLS.org/HCPbooklets
- Videos for HCPs: www.LLS.org/HCPvideos
- Podcast series for HCPs: www.LLS.org/HCPpodcast



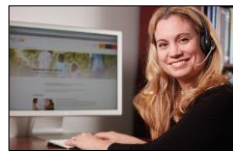
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FREE LLS RESOURCES FOR PATIENTS

- ❑ **Information Specialists** – Personalized assistance for managing blood cancer treatment decisions, side effects, and dealing with financial and psychosocial challenges (IRC).
- ❑ **Clinical Trial Nurse Navigators** – RNs and NPs provide a personalized service for patients with blood cancer seeking treatment in a clinical trial, sift through the information and provide information to bring back to their HC team (CTSC).
 - www.LLS.org/CTSC
- ❑ **Nutrition Education Services Center (NESC)** – LLS provides **Nutrition Education Services** to patients and caregivers of all cancer types. *Our registered dietitians have expertise in oncology nutrition.* To schedule a free consultation:
 - visit www.LLSnutrition.org
 - call 877-467-1936

❑ Reach out Monday–Friday, 9 am to 9 pm ET

- Phone: (800) 955-4572
- Live chat: www.LLS.org/IRC
- Email: infocenter@LLS.org
- HCP Patient Referral Form: www.LLS.org/HCPreferral



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FREE LLS RESOURCES FOR PATIENTS AND CAREGIVERS

- ❑ www.LLS.org/YoungAdults
- ❑ **Webcasts, Videos, Podcasts:**
 - www.LLS.org/Webcasts
 - www.LLS.org/EducationVideos
 - www.LLS.org/Podcast
- ❑ **Support Resources**
 - ❑ Financial Assistance: www.LLS.org/Finances
 - ❑ Other Support: www.LLS.org/Support
 - LLS Regions
 - Live Online Weekly Chats: "Young Adults"
 - Facilitated by Oncology SW
 - LLS Community Social Media Platform
 - First Connection Peer to Peer Program



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FREE LLS RESOURCES FOR YOUR PATIENTS



BOOKLETS AND FACT SHEETS

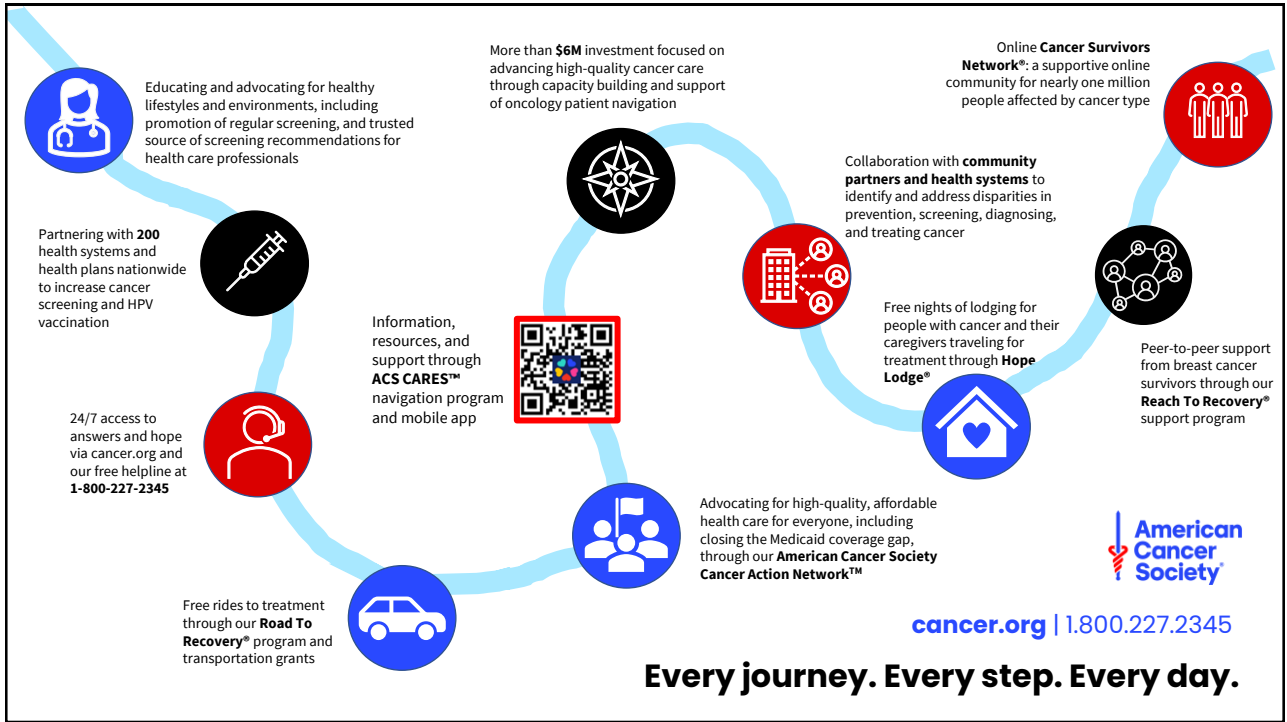
English – www.LLS.org/Booklets
 Spanish – www.LLS.org/Materiales



Vision: End cancer as we know it, for everyone.

Mission: Improve the lives of people with cancer and their families through advocacy, research, and patient support, to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer.

cancer.org | 1.800.227.2345



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American Cancer Society

ACS LION™
Transform care through a new navigation training and credentialing program

The American Cancer Society Leadership in Oncology Navigation (ACS LION) is a standardized training and credentialing program that helps patient navigators deliver essential nonclinical support to individuals, caregivers, and families facing cancer.

Now available, the program meets the Centers for Medicare & Medicaid Services (CMS) training requirements for "Principal Illness Navigation" reimbursement, as introduced in the 2024 CMS Physician Fee Schedule, and is aligned to professional oncology navigation (PONT) standards.

[Learn more about the program and enrollment](#)

Visit cancer.org/NavigationCredential or scan the QR code to learn more about ACS LION and how to enroll.

The program is \$495 per learner. Opportunities for program access assistance are available. Please email ACSLION@cancer.org for more information.

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SAVE THE DATE

Orientation | June 26th, 2024 | 1:00–2:00 PM EST

Pediatric, Adolescent, and Young Adult Cancer Survivorship ECHO

Four Principles of the ECHO Model



Use technology to leverage scarce resources



Apply case-based learning to master complexity



Share best practices to reduce disparities



Evaluate and monitor outcomes



Learn more at
echo.cancer.org

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Additional Resources for Healthcare Providers:

- Relevant Training and Educational Programs for HCPs (some providing CE)
 1. GW School of Medicine & Health Sciences: [Cancer Survivorship E-Learning Series](#)
 2. Harvard University: [Cancer Survivorship: Optimizing Care and Outcomes](#)
 3. Cancer Support Community: [Cancer Transitions: Moving Beyond Treatment™ Program](#)
- National Cancer Institute [Pediatric and Adolescent and Young Adult Cancer Survivorship Information](#)
- Canteen's [Adolescent and Young Adult Oncology Psychosocial Survivorship Care Process Manual](#) (includes *Psychosocial Survivorship Screening Tool* on page 20)
- [Six Core Elements of Health Care Transition](#) from Got Transition: for use by clinicians to assist youth and young adults as they transition to adult health care
- COG's [Directory of Long-term Survivorship Programs](#)



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Questions?



Ask a question on Zoom:
Please type them in the Q&A
box and submit.



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THANK YOU

Instructions For Credit

Participants must complete the evaluation to receive credit.
After completing this process, your certificate will automatically generate.

Link to complete evaluation: <https://lls.link/ayaeval>

OR scan the QR code:



For questions or concerns, please contact Profeducation@lls.org



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