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
WELCOMING REMARKS

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Associate Director
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The Leukemia & Lymphoma Society
Rye Brook, NY
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
FACULTY

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

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

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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.

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Ask a question:
Please type them in the Q&A box and submit.
Overview of AYA Cancer
Adolescent and Young Adult (AYA)

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

Is relatively rare: AYA cancer makes up 4.2% of all cancer diagnoses

This year approximately: 84,000 AYAs will be diagnosed with cancer

Most will survive: 86% will survive 5 years
An estimated 2,000,000 AYA cancer survivors

Many will: Experience long and late-term effects from cancer treatment

National Cancer Institute: Cancer Stat Facts: Cancer Among Adolescents and Young Adults (AYAs) (Ages 15–39)
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
Importance of Survivorship Care
What Do We Know about Long-Term and Late Effects among AYA Cancer Survivors?

Physical Issues:
- 2<sup>nd</sup> 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
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
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

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
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)
Accessing Long-term Follow-up Guidelines
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**
### Chemotherapy

**Therapeutic Exposure**

<table>
<thead>
<tr>
<th>Sec #</th>
<th>Anthracycline Antibiotics</th>
</tr>
</thead>
<tbody>
<tr>
<td>34</td>
<td>Doxorubicin</td>
</tr>
<tr>
<td></td>
<td>Daunorubicin</td>
</tr>
<tr>
<td></td>
<td>Epirubicin</td>
</tr>
<tr>
<td></td>
<td>Idarubicin</td>
</tr>
<tr>
<td></td>
<td>Mitoxantrone</td>
</tr>
</tbody>
</table>

**Potential Late Effects**

- Cardiac toxicity
- Cardiomyopathy
- Subclinical left ventricular dysfunction
- Congestive heart failure
- Arrhythmias

**Periodic Evaluation**

- **HISTORY**
  - Shortness of breath
  - Dyspnea on exertion
  - Orthopnea
  - Chest pain
  - Palpitations
  - If under 25 yrs: nausea, vomiting

- **PHYSICAL**
  - Blood pressure
  - Cardiac exam

- **SCREENING**
  - Echo (or comparable imaging to evaluate cardiac function)
  - Recommendations for frequency of echocardiogram:
    - **Anthracycline Dose**:
      - <100 mg/m²
      - 100 mg/m² to 250 mg/m²
      - >250 mg/m²
    - **Radiation Dose**:
      - <15 Gy
      - 15 Gy to <30 Gy
      - ≥30 Gy
    - **Recommended Frequency**:
      - Every 5 years
      - Every 2 years

- **Health Counseling/Further Considerations**

  **HEALTH LINKS**
  - Heart Health
  - Cardiovascular Risk Factors
  - Nutrition and Physical Activity

  **NURSING**
  - Traditional CRFs 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.

- **Exercise**:
  - Exercise is generally safe and encouraged for patients with normal LV systolic function.
  - Counsel cardiomyopathy with asymptomatic cardiomyopathy to define physical activity limits and precautions.

- **Screening**: 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.

- **Potential consensuses for further testing and intervention**
  - Cardiomyopathy as an adjusted 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:
    - >250 mg/m² anthracyclines
    - >20 Gy chest radiation, or
    - Anthracycline (any dose) combined with chest radiation (>15 Gy)
  - Evaluation should include a baseline echo (pre- or early-pregnancy). For those without prior abnormalities and with normal pre- or early-pregnancy baseline echo, follow-up echo 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.

**Additional Information**

Although mitoxantrone is an anthracycline, 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. Additional symptoms (nausea, emesis) may be seen more frequently than exertional dyspnea or chest pain in younger patients.

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**Version 5.0 - October 2023**

**American Cancer Society**

**Leukemia & Lymphoma Society**
Significant Gaps in Provider Knowledge of Guidelines

### Hodgkin Lymphoma Survivor Vignette

<table>
<thead>
<tr>
<th>Responses Concordant with COG Guidelines</th>
<th>General Internists (N=1,110; US only)</th>
<th>Family Physicians (N=1,124; US &amp; Canada)</th>
<th>Pediatric Oncologists (N=665; US only)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer screening</td>
<td>9%</td>
<td>16%</td>
<td>66%</td>
</tr>
<tr>
<td>Thyroid screening</td>
<td>76%</td>
<td>74%</td>
<td>76%</td>
</tr>
<tr>
<td>Cardiac screening</td>
<td>15%</td>
<td>10%</td>
<td>57%</td>
</tr>
<tr>
<td>Total</td>
<td>5%</td>
<td>2%</td>
<td>33%</td>
</tr>
</tbody>
</table>

Transition Challenges
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
"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
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
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.
High-Risk Survivors Are Not Receiving Recommended Screening Tests

- Colonoscopy: 12%
- Mammography: 46%
- Skin exam: 27%
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
### Transition Strategies

<table>
<thead>
<tr>
<th>Education and Empowerment</th>
<th>Care Coordination</th>
<th>Patient Navigation</th>
<th>Psychosocial Support</th>
<th>Survivorship Care Plans</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Educate AYA cancer survivors about the importance of survivorship care and need for long-term follow-up.</td>
<td>• Coordinate care among multidisciplinary health care teams.</td>
<td>• Provide patient navigation services to guide AYA cancer survivors through the transition process.</td>
<td>• Offer psychosocial support services to address the needs of AYA survivors during transition to survivorship care.</td>
<td>• All survivors should have personalized care plans that outline recommended follow-up care, screening schedules, and strategies for managing late effects.</td>
</tr>
<tr>
<td>• Empower survivors to advocate for their needs.</td>
<td>• Establish clear communication channels.</td>
<td>• Navigators can assist with understanding care plans, scheduling follow-up appointments, accessing services, and navigating the health care system.</td>
<td>• Provide counseling, facilitate support groups, and incorporate psychosocial management into care plans.</td>
<td>• Know where specialized survivorship clinics are to refer survivors to.</td>
</tr>
</tbody>
</table>
Interdisciplinary Care
Team Roles
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)
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).
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
RESOURCES
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
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](http://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](http://www.LLSnutrition.org)
  ➢ call 877-467-1936

- **Reach out** Monday–Friday, 9 am to 9 pm ET
  
  o Phone: (800) 955-4572
  o Live chat: [www.LLS.org/IRC](http://www.LLS.org/IRC)
  o Email: infocenter@LLS.org
  o HCP Patient Referral Form: [www.LLS.org/HCPreferral](http://www.LLS.org/HCPreferral)
FREE LLS RESOURCES FOR PATIENTS AND CAREGIVERS

- [www.LLS.org/YoungAdults](http://www.LLS.org/YoungAdults)
- Webcasts, Videos, Podcasts:
  - [www.LLS.org/Webcasts](http://www.LLS.org/Webcasts)
  - [www.LLS.org/EducationVideos](http://www.LLS.org/EducationVideos)
  - [www.LLS.org/Podcast](http://www.LLS.org/Podcast)

- Support Resources
  - Financial Assistance: [www.LLS.org/Finances](http://www.LLS.org/Finances)
  - Other Support: [www.LLS.org/Support](http://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
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.
Every journey. Every step. Every day.

Partnering with 200 health systems and health plans nationwide to increase cancer screening and HPV vaccination.

Information, resources, and support through ACS CARES™ navigation program and mobile app.

More than $6M investment focused on advancing high-quality cancer care through capacity building and support of oncology patient navigation.

Free rides to treatment through our Road To Recovery® program and transportation grants.

24/7 access to answers and hope via cancer.org and our free helpline at 1-800-227-2345.

Advocating for high-quality, affordable health care for everyone, including closing the Medicaid coverage gap, through our American Cancer Society Cancer Action Network™.

Collaboration with community partners and health systems to identify and address disparities in prevention, screening, diagnosing, and treating cancer.

Free nights of lodging for people with cancer and their caregivers traveling for treatment through Hope Lodge®.

Peer-to-peer support from breast cancer survivors through our Reach To Recovery® support program.

Online Cancer Survivors Network®: a supportive online community for nearly one million people affected by cancer type.

Online Cancer Survivors Network®: a supportive online community for nearly one million people affected by cancer type.
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.
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
• 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
THANK YOU

Instructions For Credit

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

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