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

Michelle Rajotte, LMSW
Associate Director
Information Resource Center
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

Rebecca Eary, DO, MPH
Assistant Professor, Department of Family and Community Medicine
UT Southwestern Medical School
Medical Director, Primary Care Cancer Survivorship Clinic and the After Cancer Experience (ACE) Adult Program for Adolescent and Childhood Cancer Survivors
Dallas, TX

Danielle Friedman, MD, MS
Associate Member
Department of Pediatrics, MSK Kids
Director, Pediatric Long-Term Follow-Up Program
Director, Pediatric Survivorship Fellowship
Memorial Sloan Kettering Cancer Center
New York, NY

Brittany Hall, PhD
Associate Professor
UT Southwestern Medical Center
Dallas, TX

Michelle Rajotte, LMSW (Moderator)
Associate Director
Information Resource Center
The Leukemia & Lymphoma Society
Rye Brook, NY

Michael Roth, MD
Professor of Pediatrics
Medical Director, Cancer Survivorship
Co-Director, Adolescent and Young Adult Oncology Program
Director, Childhood Cancer Survivorship Program
University of Texas M.D. Anderson Cancer Center
Houston, TX

Angela Yarbrough, DNP, APRN, FNP-BC, CPHON
Nurse Practitioner
University of Texas M.D. Anderson Cancer Center
Houston, TX
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.

Angela Yarbrough, DNP, APRN, FNP-BC, CPHON, has no relevant financial relationships with ineligible companies to disclose for this educational activity.

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Medical Learning Institute, Inc. (MLI) designates this live activity for a maximum of 1.0 AMA PRA Category 1 Credit™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

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. 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.

METHOD OF PARTICIPATION

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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.
Overview of AYA Cancer

Adolescent and Young Adult (AYA)

refers to individuals diagnosed with cancer between the ages of \textbf{15 and 39}

\begin{itemize}
  \item Children
  \item Adolescents
  \item Emerging Young Adults
  \item Young Adults
  \item Adults
  \item Older Adults
\end{itemize}

\begin{itemize}
  \item <15 years old
  \item 15-17
  \item 18-25
  \item 26-39
  \item 40-64
  \item 65+
\end{itemize}

“AYA” 15–39 years old
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

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
Importance of Survivorship Care

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
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**
Hodgkin Lymphoma Survivor Vignette

Responses Concordant with COG Guidelines

<table>
<thead>
<tr>
<th></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</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>

Significant Gaps in Provider Knowledge of Guidelines

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

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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
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

12% compliance with guidelines for Colonoscopy, 46% for Mammography, and 27% for Skin exam.
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>
<tr>
<td></td>
<td>• Share treatment summaries and collaborate on care plans.</td>
<td></td>
<td></td>
<td></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
  - Phone: (800) 955-4572
  - Live chat: [www.LLS.org/IRC](http://www.LLS.org/IRC)
  - Email: infocenter@LLS.org
  - 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.

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

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.

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

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

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

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

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

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](#)
Questions?

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

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