

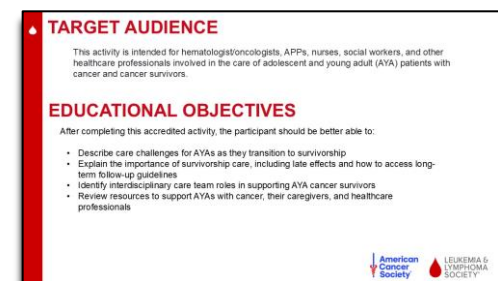
**Slide 1: Clinical Strategies and Resources: Caring for AYAs as They Transition to Cancer Survivorship**  
**Michelle Rajotte, LMSW:** Welcome to *Clinical Strategies and Resources: Caring for AYAs as They Transition to Cancer Survivorship*.



**Slide 2: Welcoming Remarks**  
 I'm Michelle Rajotte, Associate Director of the Information Resource Center at The Leukemia & Lymphoma Society. I'll be your moderator today for the program. On behalf of The Leukemia & Lymphoma Society and the American Cancer Society, thank you for joining us.

Our organizations are committed to improving patients' quality of life through webinars such as this one for healthcare providers and education and support resources for patients and caregivers. The webinar and panel discussion will focus on adolescent and young adult patients with cancer as they tradition, transition into survivorship, emphasizing interdisciplinary care and long-term support. A review of resources you can provide to your patients, as well as additional education resources for you, will also be provided.

To help make this webinar engaging, polling questions seeking responses from all of you will be asked; and our fas-, faculty will share and discuss your responses.



**Slide 3: Learning Objectives**  
 The learning objectives for today's webinar are listed on the slide.



**Slide 4: Faculty**  
 I am honored to introduce our panelists. Dr. Rebecca Eary, Assistant Professor, Department of Family and Community Medicine and Medical Director of The Primary Care Cancer Survivorship Clinic and the Aftercare Experience Adult Program for Adolescent and Childhood Cancer Survivors at UT Southwestern in Dallas, Texas.

Dr. Danielle Friedman, Associate Member, Department of Pediatrics, MSK Kids Director, Pediatric Long-Term Follow-Up Program Director, pediatric survivorship fellowship at Memorial Sloan Kettering Cancer Center in New York.

Dr. Brittany Hall, Adolescent & Young Adult Psychologist and Associate Professor at UT Southwestern Medical Center in Dallas, Texas.

Dr. Michael Roth, Professor of Pediatrics, Medical Director, Cancer Survivorship Co-Director, Adolescent & Young Adult Oncology Program, Director Childhood Cancer Survivorship Program at the University of Texas MD Anderson Cancer Center in Houston, Texas. He also is Chair of the Children's Oncology Group AYA Oncology Discipline Committee.

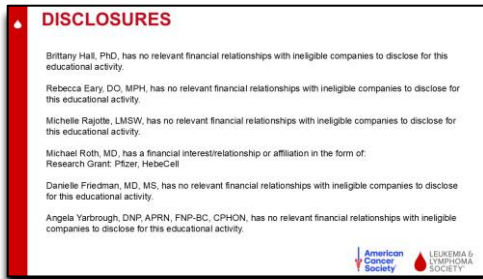
Dr. Angela Yarbrough, Nurse Practitioner at the University of Texas MD Anderson Cancer Center in Houston, Texas.

Thank you for volunteering your time and expertise with us.



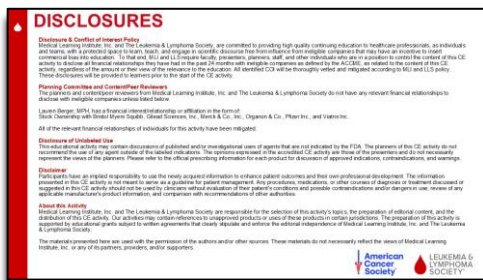
**Slide 5: Resources**

Following the discussion, we will share information about resources from The Leukemia & Lymphoma Society and the American Cancer Society.



**Slide 6: Disclosures**

Faculty and planner disclosures are listed here.



**Slide 7: Disclosures**

**CE DESIGNATION**

**Accreditation, Credit and Support**  
 In support of ongoing patient care, this activity has been planned and implemented by Medical Learning Institute, Inc. and The Leukemia & Lymphoma Society. Medical Learning Institute, Inc. is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.


**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 5632 to award 1.0 continuing education contact hour through the California Board of Registered Nursing.

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 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.

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




**Slide 8: CE Designation**

Continuing education information is listed here.

**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 [mlina@mlieducation.org](mailto:mlina@mlieducation.org).



**Slide 9: Method of Participation**

To receive credit for participating, please complete the evaluation at the end of the program. Once submitted, a certificate will be generated. Your feedback is important to help us plan future programs and is also required for you to receive continuing education credit.

**Overview of AYA Cancer**

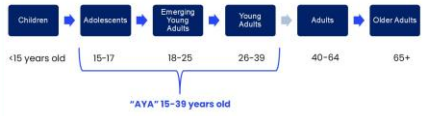



**Slide 10: Overview of AYA Cancer**

Now, I'm pleased to begin the panel discussion. Dr. Roth, can you tell us what AYA cancer is?

**Adolescent and Young Adult (AYA)**

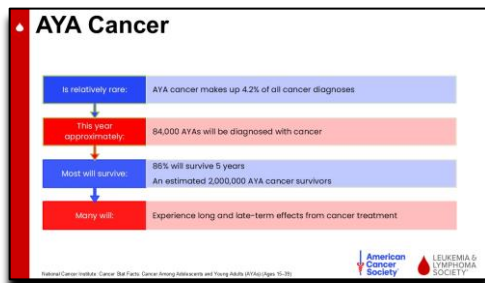
refers to individuals diagnosed with cancer between the ages of 15 and 39

**Slide 11: Adolescent and Young Adult (AYA)**

**Michael Roth, MD:** Thanks, Michelle, very much for the introduction; and welcome everyone. So, when we talk about the AYA cancer population, we're talking about patients between the ages of 15 to 39 years of age, and it's important to recognize that this is a pretty wide and heterogeneous age population. And we know that a 15-year-old has very different lived experiences than a 39-year-old.

So, we generally think about life in terms of developmental milestones, and we subgroup this population to three main categories. So, those who are adolescents between the ages of 15 to 17 years of age, those who are emerging young adults between the ages of 18 to 25, and those who we consider as young adults between the ages of 26 to 39 years.



**Slide 12: AYA Cancer**

So, who are our AYA cancer patients? So, we do know that, fortunately, cancer in the AYA population is relatively rare; and approximately 4% of all cancer diagnoses will occur within this population. That does amount to approximately 90,000 individuals diagnosed with cancer between the ages of 15 to 39 each year in the United States. Fortunately, cure rates have improved over the past few decades, and approximately 85% of all

individuals diagnosed with cancer during this age range today will be cured of their cancer and go into long-term survivorship. Unfortunately, many of our survivors will encounter many long-term and late side effects of their treatment, which will require screening and treatment for those chronic health conditions as you will soon hear in the rest of this presentation.

**POLLING QUESTION 1**

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

- Financial toxicity
- Anxiety and depression
- Less likely to have children
- More likely to use drugs and alcohol
- All of the above

Reference: American Cancer Society. LEUKEMIA & LYMPHOMA SOCIETY

**Slide 13- Polling Question**

**Michelle Rajotte:** Thank you, Dr. Roth. Now we have our first polling question. "Which of the following are long-term psychosocial issues that AYA survivors of cancer experience?" So, yes, all of the above is the correct answer.

**Importance of Survivorship Care**

Reference: American Cancer Society. LEUKEMIA & LYMPHOMA SOCIETY

**Slide 14: Importance of Survivorship Care**

In terms of late effects used when talking about this population, Dr. Yarbrough, Dr. Early, and Dr. Roth, please provide more information on the long-term and late effects of AYA cancer.

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

<p><b>Physical Issues:</b></p> <ul style="list-style-type: none"> <li>• 2<sup>nd</sup> Malignancies</li> <li>• Cardiovascular Disease</li> <li>• Endocrine Dysfunction</li> <li>• Neurocognitive Deficits</li> <li>• Fertility</li> <li>• Sexual Dysfunction</li> <li>• Body Disfigurement</li> <li>• Physical Condition</li> </ul>	<p><b>Psychological Issues:</b></p> <ul style="list-style-type: none"> <li>• Distress</li> <li>• Anxiety &amp; Depression</li> <li>• Post-traumatic Stress</li> <li>• Fear of Recurrence</li> <li>• Body Image Concerns</li> <li>• Cognitive Impairment</li> <li>• Loneliness</li> <li>• Survivor's Guilt</li> <li>• Drug and Alcohol Use</li> </ul>	<p><b>Social Issues:</b></p> <ul style="list-style-type: none"> <li>• Education</li> <li>• Employment Challenges</li> <li>• Financial Toxicity</li> <li>• Relationship (Health) and Access to Supportive Services</li> </ul>
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Reference: Johnson et al. Cancer, 2011. The American Cancer Society. LEUKEMIA & LYMPHOMA SOCIETY

**Slide 15: What Do We Know about Long-Term and Late Effects among AYA Cancer Survivors?**

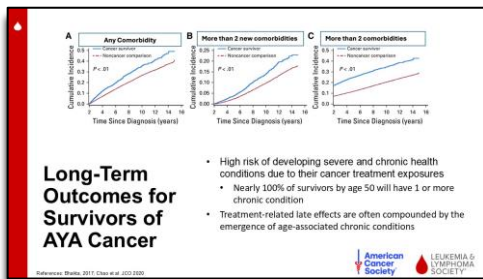
**Angela Yarbrough, DNP, APRN, FNP-BC, CPHON:**

Yes, so late effects are health problems that occur months to years or after a disease is diagnosed or after treatment is ended. So, we know that late effects can be physical issues, as well as social issues. So physical issues can be in the form of secondary malignancies that they may develop, cardiovascular disease that can occur after

certain types of treatments, endocrine dysfunction, neurocognitive deficits, fertility issues, sexual dysfunction, body disfigurement, and other physical conditions. Psychological issues can consist of just emotional distress, anxiety or depression, post-traumatic stress. Fear of recurrence can be a really common theme, cognitive impairment, body image concerns, loneliness and survivor's guilt, as well as drug and alcohol abuse.

And then social issues can include difficulty with education and just completing that if they're in the midst of college or what that looks like in the future and how they're able to get through that. Employment challenges, if they're trying to manage, treatment and dealing with work.

Financial toxicity is a big term that we hear now. We know the financial impacts of cancer therapy is huge. And then relationships, like, how do they deal with sharing a cancer diagnosis or potential infertility with future partners and then access to supportive services.



**Slide 16: Long-Term Outcomes for Survivors of AYA Cancer**

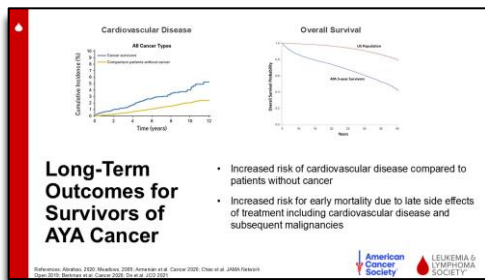
**Rebecca Eary, DO, MPH:** So, on this slide, I'm really going to talk for a minute here about the relationship between late effects and chronic conditions. And so I think taking a step back and thinking about, even if you have no experience working with patients who've had an AYA cancer or even a cancer survivor in general, to think of it through the lens of their exposure from their

treatment. You know, did they have chemotherapy? Did they have surgery? Did they have radiation?

If they had radiation, what part of the body was radiated? Was that their chest where their heart could be or their lungs could be? And so when you think of it in terms of what those late effects could potentially do to a person as they age, an age-related illness develops, I think that's what this slide demonstrates.

It shows that patients who have a history of AYA cancer are more likely to have a chronic condition as they age. And that's something, no matter what your position is as a clinician, is good information because what can you control? You can't control the late effects from those treatments, but you can help control those chronic conditions that may develop. And so looking at this study, I think this demonstrates this well.

Most patients by the age of 50 would have at least one chronic condition. And, again, that relationship between the treatment and the chronic conditions, I think, is an important one to have when we're thinking about patients as they age.

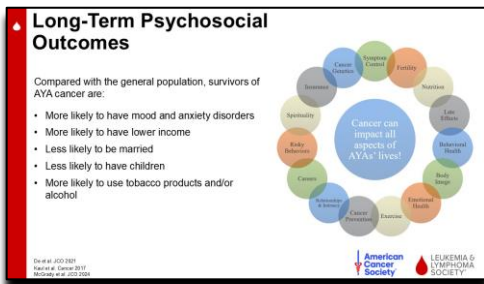


**Slide 17: Long-Term Outcomes for Survivors of AYA Cancer**

**Dr. Roth:** So, we also know that many of these patients will experience specific late effects when we look at different organ systems, and cardiovascular toxicity is one that we are deeply concerned about. The figure on the top left here shows that compared to the general population, our survivors of AYA cancer have a significantly increased risk of developing cardiovascular disease, and this risk increases as they get further and further away from treatment.



We also know that our patients are at high risk for shortened lifespan or early mortality, so that risk of death at a younger age doesn't go away once they're cured of their cancer. But, unfortunately, some of these health challenges such as cardiovascular disease and renal disease and liver disease, these can contribute to early mortality in our cancer survivorship population which makes it even more important that we ensure all patients get access to important and also high-level survivorship care.



**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

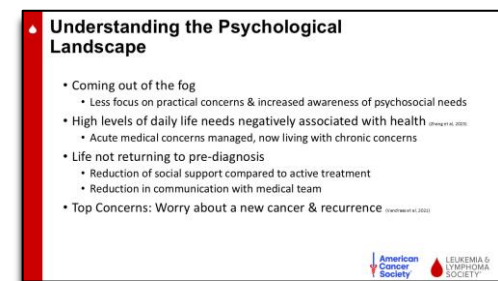
Dr. H. et al. JCO 2011  
 American Cancer Society  
 LEUKEMIA & LYMPHOMA SOCIETY

**Slide 18: Long-Term Psychosocial Outcomes**

In addition to the medical and the chronic physical health conditions, our patients are at risk for developing poor psychosocial health outcomes. And this is not only during the cancer experience and during treatment, it's, also goes to the post-treatment experience.

The figure on the right shows that, as many of you know, that cancer can impact any and all areas of an AYA's life, and it's important to know that these issues don't go away necessarily when treatment ends. From the literature, we know that our survivors of AYA cancer are more likely to have mood disorders and anxiety disorders, more likely to have financial distress during and after treatment, as well as they're less likely to achieve some life goals such as, perhaps forming sustained and long-term relationships, growing and expanding a family, and they're also more likely to participate in higher risk health activities such as using tobacco or alcohol products.

**Michelle Rajotte:** Dr. Hall, can you share more about where AYA survivors are psychologically when they finish with active treatment?



**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 (Hwang et al. 2012)
  - 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 (Hwang et al. 2012)

American Cancer Society  
 LEUKEMIA & LYMPHOMA SOCIETY

**Slide 19: Understanding the Psychological Landscape**

**Brittany Hall, PhD:** Yeah. We know that, Dr. Roth just did a great job of kind of introducing the idea that AYA survivors are at higher risk of mental health difficulties, anxiety, depression, mood disorders. But if we think about the different psychological responses at different stages during the cancer continuum, we know that initial diagnosis and there's that initiation of treatment, we see this spike in anxiety and distress because they don't know

what's coming. Fear about side effects from treatments that are more immediate.

But then we find that the majority just settle into that treatment process. It becomes more familiar. It's almost like a safety net because it's very predictable in many ways. We see that people can be significantly impacted by other variables during this time like transportation, insurance, stable social support to drive them to and from appointments, or caregivers at home.

These are things that make some AYAs more vulnerable. But the majority really settle in, and then the practical and physical concerns really take precedence during this period of time, and the emotional concerns or other psychosocial concerns take more of the back seat. So once the majority of patients that we see will enter into a form of surveillance, maintenance for their treatment, or they enter no evidence of disease, this starts the beginning of post-treatment

survivorship. They've been working towards entering into or crossing this finish line; and they've been racing towards it, and then they cross it a lot and they look around and they don't recognize where they are. They don't feel as if the race is over; it can be anticlimactic.

And life requirements and responsibilities return full force, but maybe the AYA energy levels, they don't go back to the same extent. And socially many of our patients feel isolated. They don't know quite how to reconnect with peers after this very intense experience.

Now, this is true for all survivors, survivors 40+ and pediatric, potentially, when they enter into this survivorship phase. But it's particularly relevant for our young people, our AYAs because their peers, they're running at a faster pace of life; and the majority haven't experienced slowing down due to medical problems, and their life expectations in young adulthood remain very high as related to career or maybe family planning or relationships. And the patient returns to that fast-paced life, but their functioning isn't the same as it was pre diagnosis anymore.

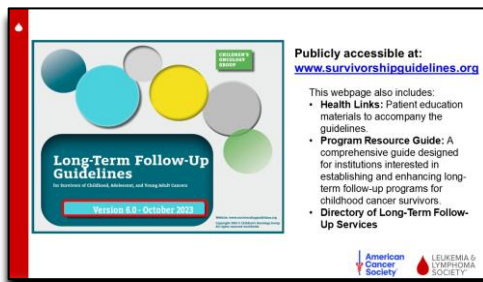
Also AYAs are unique because this phase of survivorship, they're under age 40. They're still hoping that the majority of their life is still in front of them, and they have much longer time to worry about the cancer recurrence, a secondary cancer, and late effects of their treatment in the same body that just went through all this treatment. And many don't find that others understand this experience.



**Slide 20: Accessing Long-term Follow-up Guidelines**

**Michelle Rajotte:** Dr. Friedman, are there guidelines for AYA survivorship care? And if so, how can healthcare professionals access and utilize these guidelines to better support their patients?

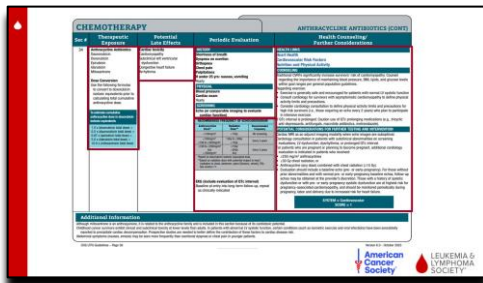
**Danielle Friedman, MD, MS:** Thanks, Michelle. So there are a variety of guidelines available to guide survivorship care.



**Slide 21: Long Term Follow-Up Guidelines**

However, the most common one, and the one that we typically use in our program, are the Long-Term Follow-Up Guidelines, which are put out by the Children's Oncology Group. These are guidelines that are designed for both pediatric cancer survivors and AYA cancer survivors. This is a large multidisciplinary group that works on reviewing the literature and updating these guidelines every five years. So, the most recent update was just

made in October 2023. And importantly, these are publicly accessible at [survivorshipguidelines.org](http://survivorshipguidelines.org). Anyone can access these free of charge.



**Slide 22: Chemotherapy**

These are exposure-based guidelines. So, if you're seeing a patient, perhaps not familiar with the exposures that that patient received, you can literally type into the PDF "control f," which will find the words that you're looking for. So here, just going back to what Dr. Roth mentioned about cardiac dysfunction that is a prevalent and important and serious late effect that is common in many of our AYA survivors. If we are seeing someone

who was exposed to doxorubicin, for instance, you can access the guidelines. Again, it's survivorshipguidelines.org. Type in control f, type in doxorubicin, and a guideline like this will appear. It will show you your therapeutic exposure category, what the potential late effects are, how you should be evaluating this patient in terms of history, physical, and screening.


And then we also have Health Links, which are linked from the guideline, which are patient-facing information that are written for both patients and families about how best to be educated about this particular problem and things that patients can do to ensure that they get the appropriate risk-based screening.

**Significant Gaps in Provider Knowledge of Guidelines**

Hodgkin Lymphoma Survivor Vignette

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

Salik et al. Am J Clin Oncol. Sep 2016;39(9):1041-1048. J Cancer Surv. 2013;23(4):283-291. doi:10.1093/cjco/23.4.283



**Slide 23: Significant Gaps in Provider Knowledge of Guidelines**

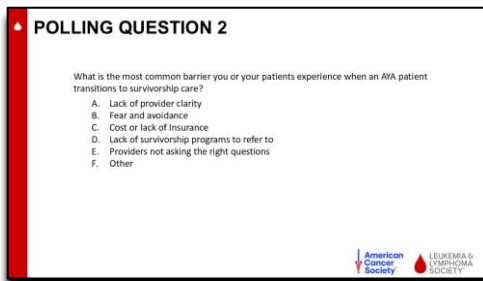
And even though we have these very extensive guidelines available, we know that we continue to face an uphill battle with dissemination of these guidelines and ensuring the providers are familiar with them and with other best screening practices among survivors. So these are different publications that have been published the last decade looking at different types of PCPs along the age

spectrum that is relevant to AYA cancer survivors. So, certainly general internists, family physicians, and pediatric oncologists. And we see that there's really a very low level of familiarity among different providers with these patients. And so, certainly, in both, in all three of these papers, different practitioners were given a vignette about a Hodgkin lymphoma survivor who was treated with chest radiation. The survivor should have been receiving breast cancer screening, thyroid screening, and cardiac screening. And, unfortunately, very few providers were familiar with the guidelines that were recommended for screening in order to enable early detection and intervention of various late effects. And so we know that we need to do better in educating providers outside of the immediate cancer community and both inside the cancer community, and to ensure that we are all taking optimal care of our patients.





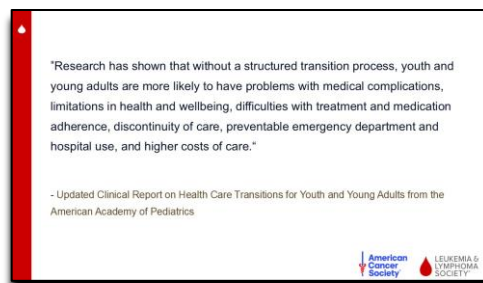
**Slide 24: Transition Challenges**



**Slide 25- Polling 2**

**Michelle Rajotte:** So before we discuss transition challenges, we have another polling question. "What is the most common barrier you or your patients experience when an AYA patient transitions to survivorship care?"

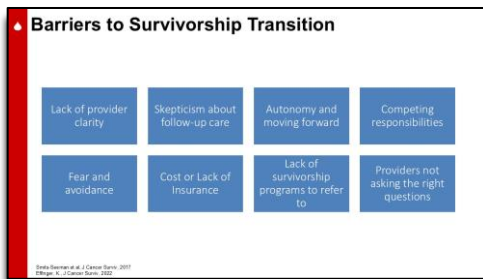
It looks like the obvious one is D, "lack of survivorship program to refer to," and I know we hear that a lot as well at The Leukemia & Lymphoma Society. It also depends on where the AYA lives is a huge issue as well.



**Slide 26-Quote**

**Dr. Yarbrough and Dr. Friedman,** what are the unique needs and barriers for AYA survivors that should be considered in the transition process?

**Dr. Yarbrough:** Of course, 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 well-being, difficulties with treatment and medication adherence, discontinuity of care, preventable emergency department and hospital use, and higher cost of care.



**Slide 27: Barriers to Survivorship Transition**

So as Dr. Friedman said earlier, lack of provider clarity. They don't really know what it is they should be following. Providers may not. Skepticism about follow-up care for the patients. They think once they're done with their treatment that they're done with everything. And so I think it's really important when they're going through their active therapy to make sure that they understand the importance of continued follow-up care.

Autonomy and moving forward, a lot of patients, again, they want to get back to life as normal before cancer treatment, so they just want to put it behind them and go forward. Competing responsibilities. A lot of our young adults are busy raising families or they're in school or they've

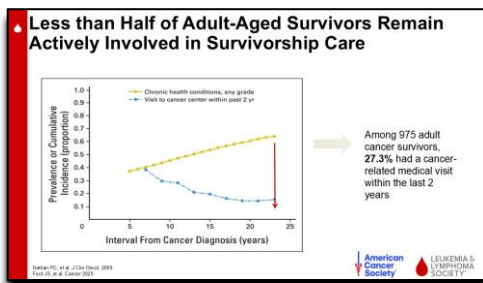
got a career that they're trying to focus on. And so they just don't take the time to set aside time for their doctors' appointments like they should.

Fear and avoidance. I spoke to a patient just this morning when I was in clinic, and she was just in tears. She really gets anxiety every time she comes to the doctor and has a visit. And so trying to get past that, I'm working with them so that they know the importance of it.

Cost or lack of insurance, that is a huge thing. You know, the financial cost of healthcare these days can keep people from seeking it. Lack of insurance as well. So making sure that we can connect them to resources that are available to help with this.

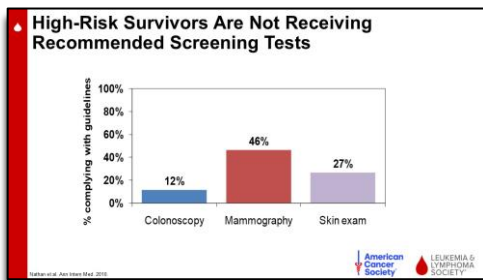
Lack of survivorship programs. I think all of us on this panel are connected to comprehensive cancer centers or large cancer centers where we do have great trends, great survivorship programs; but not everyone in the community has that. So just making sure that we can get patients to where they need to be for the best care or to educate providers out in the community so that they know how to care for these patients.

And then if providers aren't asking the right questions to find out what the needs of the survivorship patient actually are.



**Slide 28: Less than Half of Adult-Aged Survivors Remain Actively Involved in Survivorship Care**

**Dr. Friedman:** And so all of these barriers translate into really important outcomes for our patients. We know that as patients get farther away from their initial cancer diagnosis, as the risk of developing chronic health conditions increases over time, they are less likely to return to the cancer center at which they were treated and also less likely to have a medical visit where cancer-related issues and late effects are addressed.



**Slide 29: High-Risk Survivors Are Not Receiving Recommended Screening Tests**

This, unfortunately, translates into a lack of concordance with guideline-recommended care for our patients. And so particularly among those who are high risk for developing late effects, based on their prior therapies such as developing second solid tumors after radiation therapy. We see that patients are not receiving early screening that is appropriate for the types of treatment

they received.

So here we see, for instance, among patients who were treated with radiation therapy, who should be getting colonoscopies early for colorectal cancer screening, breast cancer screening early after chest radiation, or careful skin exams after radiation to any part of the skin, we see very low compliance rates with guideline concordant care; and this is largely due to the variety of issues that we've already touched on related to problems around transition.

**Michelle Rajotte:** Dr. Roth, in addition to the medical information, what do you think are the most important things that you discuss with your patients before their treatment ends?

**Dr. Roth:** Yeah, that's a great question, Michelle. I try to address the issues that Drs. Yarbrough and Friedman just brought up on their prior slides, all of the challenges that our patients face engaging and staying engaged with medical care post-treatment. We specifically always talk about the need for lifelong survivorship care, meaning the need to have survivorship-focused care based on their treatment exposures. That includes screening often at a younger age for things like cardiovascular disease. It also includes screening for subsequent malignancies based on their exposures.

Many of our patients are at high risk for breast cancer or colorectal cancer, and they require screening at a much earlier age than would be recommended for the general community. The other things I focus on are how do they stay engaged with care? So one is to do their best to always make sure they have insurance coverage. And that means anytime they're thinking about changing jobs, changing careers, they need to focus on what are the benefits like. They specifically need to know will they have coverages for the services that they need?

And the final thing I address with all patients is really to not compare themselves pretreatment to post-treatment and survivorship. Our patients face so many challenges during treatment, and there's often this expectation that they're going to physically and psychosocially get back to where they were from when they started treatment or right before they started treatment.

I want our patients to be kind to themselves. Think about where are they now, and think about the progress that they've made from today moving forward. We focus on exercise and nutrition and those things that they have control over, which can change and positively change the health trajectory that they face moving forward.

So there's a lot to talk about as patients and before patients transition to survivorship, and it's best to do this before patients are about to be transitioned. So we want to set the stage for our patients that survivorship is something to look forward to. It's something to celebrate, and it's also something to prepare for.

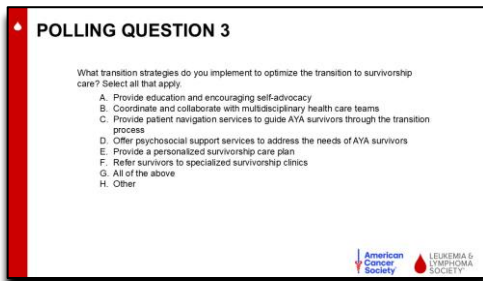
So it's important that we prepare our patients not on the day of transition, but really a year before or two years before to let them know that this is coming, and these are the things that we will do and provide for you to help you transition.

**Michelle Rajotte:** Thank you. That's a huge, huge important thing. Dr. Hall, what is the impact of not preparing patients psychologically for the transition that will occur after their treatment ends?

**Dr. Hall:** Oh, well, I'm sure a lot of people on this call have experienced that directly, that impact. And there's confusion, anger, shock. As I mentioned in that cancer continuum, we know that at the time of diagnosis and right when treatment's going on, the patient is really focused on getting through, getting to the finish line. And so, there's so much information. We know when anxiety is high or there's just a lot of distress or physical pain that patients are focusing on that, and their ability to take in new and additional information is lower.

So, even if this information was presented to them at the start of their treatment, you know long- or late-term effects related to the treatments that they would receive to cure their cancer, they're entering into survivorship; and I can't tell you how many times I see the patient, even when this has been brought to their attention, and they're in my office going, "Nobody told me about that. Nobody said that this is what this was going to look like." And then here they are in survivorship, and they have less care or less access to care, less connection with most of their medical providers than they did before. They're already anxious because they're not receiving the same treatments to actively reduce the likelihood of cancer recurrence, and now they're learning that, wait, there's all these extra effects.

So, there can be a lot of anger and then distrust in the medical providers; and we know that's a really big predictor of whether someone's willing or not to continue engaging in their care, especially for our young people where this is primarily their first encounter with the medical system and then by the time they transition, there's a lot of emotions there. So, there's a high risk that if we don't prepare patients, just as Dr. Roth was mentioning, but they don't understand the impact that this has for them long term. And shifting them from this is a onetime life event, this cancer experience, right, to a mentality of health is now a priority for you, and it's a chronic priority. And that's a really big change for a young person who often has not experienced any medical concerns prior to the onset of cancer.



**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

American Cancer Society | LEUKEMIA & LYMPHOMA SOCIETY

**Slide 30: Polling 3**

**Michelle Rajotte:** Our third polling question, "What transition strategies do you implement to optimize the transition to survivorship care?" It was close, but offering psychosocial support services was what came in the highest, and behind that was providing education and encouraging self-advocacy.

This question is for all of our panelists. What are the strategies that have been proposed or tried in your centers to optimize the transition to survivorship care? And does your center already provide resources to YAs to help with transition to survivorship care?

**Dr. Roth:** I'll start by saying I don't think any center does survivorship transition particularly well. I think we've implemented a lot of changes over the past few years to try to optimize and improve survivorship transitions, specifically making sure that our AYAs are aware of their risks and the need for long-term care focused on their exposures.

Transition Strategies				
<b>Education and Empowerment</b> <ul style="list-style-type: none"><li>Educate AYA cancer survivors about the importance of survivorship care and need for long-term follow-up.</li><li>Empower survivors to advocate for their needs.</li></ul>	<b>Care Coordination</b> <ul style="list-style-type: none"><li>Coordinate care among multidisciplinary health care teams.</li><li>Establish clear communication channels.</li><li>Share treatment summaries and collaborate on care plans.</li></ul>	<b>Patient Navigation</b> <ul style="list-style-type: none"><li>Provide patient navigation services to guide AYA cancer survivors through the transition process.</li><li>Navigators can assist with understanding care plans, scheduling follow-up appointments, accessing services, and navigating the health care system.</li></ul>	<b>Psychosocial Support</b> <ul style="list-style-type: none"><li>Offer psychosocial support services to address the needs of AYA survivors during transition to survivorship care.</li><li>Provide counseling, facilitate support groups, and incorporate psychosocial management into care plans.</li></ul>	<b>Survivorship Care Plans</b> <ul style="list-style-type: none"><li>All survivors should have personalized care plans that outline recommended follow-up care, screening schedules, and strategies for managing late effects.</li><li>Know where specialized survivorship clinics are to refer survivors to.</li></ul>

**Slide 31: Transition Strategies**

So, Dr. Yarbrough and I have embedded within our notes that all patients have access to a survivorship care plan, which includes their exposures and a very, very simple and detailed approach to how do they address and assess for the risk from those exposures, whether it's how frequently they need echocardiograms or the fact that they need thyroid testing or breast cancer surveillance twice a year. So, it's chipping away at the challenges to survivorship

transitions, although I will say that this is a huge challenge across all of our health systems.

**Dr. Friedman:** This is something we are actively working at our center. It's an enormous challenge. We are changing computer systems next year, so this is something we are being very mindful about. Certainly, we know that this is a high priority area, and we're hoping that we can think about technological approaches to make it a little better. We're talking to other centers. And so it's a goal. It's something that we're all working towards, but, certainly, we have a lot of work to do as well.

**Dr. Eary:** I think the transition, the lost to follow-up is a question that everyone is curious about and is it a health system issue that somehow we as the clinicians and the health system team can create better structure infrastructure? You know, what are the missed opportunities? Is it or is it on the patient level where it's something you just can't change like insurance? And so maybe there's a safety net system that you can refer them to. Maybe you can advocate for FQHCs to be able to see those patients, and then you can empower those clinicians to know the guidelines that Dr. Friedman talked about.

There has to be a way. And I think that getting creative because, and everyone has an individualized path, I think, for why that transition isn't happening. And there are some commonalities, but I think that there's space for creativity because it's not just one way to fix it.

**Dr. Yarbrough:** I just want to add I think it's so important to really just educate our patients along the way. I really try to start having some of these conversations when they're in, later years of high school, definitely college about the importance of insurance moving forward and things that they can do in connecting them with services, social services if we have them that are available to help support them as well.

**Michelle Rajotte:** What specialties may be involved in the care of AYA survivors?

**Dr. Roth:** Yeah. I think if we said all, that probably wouldn't be satisfying to many on the call here. So the survivorship is really multidisciplinary in that we need to be holistic and look at what is the patient's needs, the patient who is in front of me. What are their needs? Whether it's physical health needs, whether it's psychosocial health needs, whether it's vocational and educational health needs as well. So, this really is a team effort and a team sport.

And most importantly, we encourage our providers who are seeing our survivors to take a step back and think about the patient, and don't just assume that because the individual is 20 years old or 25 or 30 that they are healthy because the majority of patients this age do not have many health



issues. Many of our patients undergo surgery or receive radiation. They may have orthopedic issues; and many of our patients, as Dr. Hall impressively highlighted, do have mental health needs and ongoing psychosocial health needs. So I will say all of the above is important, and we really need to just make sure that we're looking at the whole patient and addressing any of the needs that come up.

**Dr. Yarbrough:** I always tell our patients as well, it's really in our survivorship clinic, we address the cancer needs; but we really try to encourage our patients to have primary care providers outside of the cancer center so that they have someone that knows them well, can provide that care for other issues that may arise. So that's, and patients are really hesitant to do that because they feel like we should provide all of their care, so that's something we really have to work on to get them established at the primary care physician.

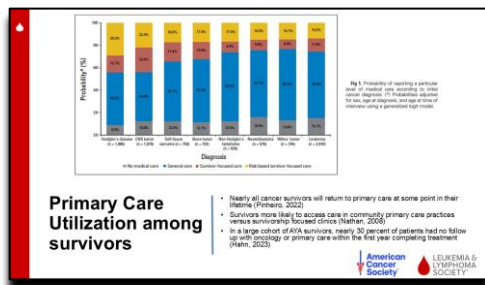
**Dr. Friedman:** I was just going to add that we also, over the past decade or so, have really become mindful of the fact that we need really a larger pool of people involved. So we have people addressing fertility preservation, financial toxicity there are so many needs of this population that really need special attention. And so sort of each day we become more aware of additional resources that are needed as to make up the full complement of the team that's needed to take care of AYA survivors.

**Dr. Hall:** Patients don't always act on a referral right away. We know that our young people, research tells us they require a lot of prompting at different times to follow-up on a referral. And so just because we recommend a follow-up or just because one of the, you know, what are the specialties? Well we can ask them to attend a specialty anytime. That doesn't mean that there's follow-through.

So, I also think whoever is connected with the patient, whoever is kind of maybe the champion or that point person who's helping them transition, it's about repeating those referrals and asking patients about when is a good time that they feel open to connecting with another medical appointment. A lot of times there's medical burnout by that time and when they enter into survivorship.



**Slide 32: Interdisciplinary Care Team Roles**



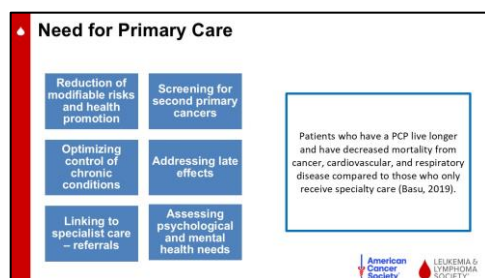
**Slide 33: Primary Care Utilization Among Survivors**  
**Michelle Rajotte:** Thank you. Dr. Eary, I know this got touched on a little bit, but what is the importance of a primary care physician for survivors?

**Dr. Eary:** Great. So, I'll first preface by saying I am a primary care physician; and I'm somebody who practiced in a community setting for a decade before coming to a university setting now where I see cancer survivors only.

And I run the adult long-term follow-up program for childhood and AYA survivors. So, that is the lens that I bring to this conversation here. I think what's important, you know, we're talking about the survivorship stage after treatment has been completed, and all the intricacies, the psychosocial intricacies, the physical manifestations.

But I think the question that's important to kind of land on and let ruminate is where will patients go for care when they're done? And, you know, all of us are from universities where we have long-term follow-up in a tertiary setting in different cities. And that's great, but most survivors in the US will not go to a tertiary long-term follow-up facility for their long-term survivorship care. They're actually going to go to the community.

And this was a large study that was looking at, it's the St. Jude cohort, so it captures some AYAs up until the age of 21. And it showed of the patients who were following with care that the utilization was actually that of a community primary care doctor. So that being said, the conversation can also state that, which has come up on this talk, is while, patients are afraid to do that, maybe because the providers don't feel like they have the confidence or knowledge or skills to address those needs that are unique to those cancer survivors. And so I think hold that thought for a minute, but I think this is important to just let settle in. It's like where will patients go? They're going to go to the community.



**Slide 34: Need for Primary Care**  
 So, I think when you ask the question, you know, what's the importance of primary care? There are so many things that primary care can do for cancer survivors that they already do every single day. But I think if you shift the lens, when you're seeing someone in front of you who's an AYA survivor, thinking about it in terms of this person who's 24 years old had exposure to radiation and chemotherapy.

That means that there are certain organ systems in their bodies that have been affected a bit different than somebody else who's age matched at their same age. So that patient who had chest radiation, not only did that increase their risk of breast cancer, their heart vessels, their heart muscle, that could also be affected. So as they grow and as they age, if they're prediabetic, maybe my conversation with them about reducing modifiable risks, or what can we do for movement or exercise, or what are you doing to nourish your body? that is going to have more of a stick with them because that's something you can control.

So when I think of these things we start with is what does primary care do? And I think this slide on the right is basically saying, if you have a PCP rather than just going to specialists, you're going to live longer. Okay. We all know that.

So, but starting with what can primary care do? Reducing modifiable risks. AYA survivors are more likely to use alcohol than their peers who are non-survivors. That is something that is a conversation that can happen in a primary care office about reducing modifiable risk.

What do they do for movement or exercise? And prefacing that by making you strong, making you flexible, making you able? Can you connect them with community resources, depending on the type of clinic that you're running? What do they do for sleep or stress reduction? That's important. Thinking about the screening for mental health concerns. You know, we do that in primary care routinely for all patients. It's even more applicable here. Are there tools that maybe we could use that are a bit more appropriate for this population? Great. But even screening in general is something that could happen in that space.

I think going down and then thinking about the screening of cancers, really changing that mindset, the average risk screening and the potentially high-risk screening that an AYA may need, right? primary care screens for cancers every day, right? We screen for colon cancer, breast cancer, lung cancer. Those are average risk, age-appropriate screening. So if the patient is 26 years old and had a history of lymphoma with radiation and chemotherapy, that patient needs a Pap smear because she's 26. That's just her average, right? She should have started at 21 every three years. There's, that's just age appropriate. But because of her cancer treatment, she's at increased risk of breast cancer. So her high-risk screening needs means that she needs a mammogram every year and a breast MRI.

And so I'm just going to pause here for a second because I think for practicing clinicians, you're probably also thinking like, "Okay, I know the test to order. I looked at those COG guidelines that Dr. Friedman showed me about, and I can do control f and find it very easily in case I don't remember what this is. But how do I even order this?"

And I think that's a step that is also, can be a barrier. Right? So making sure that you link it to an ICD-10 code that's high risk for breast cancer screening so you appease the insurance gods and it gets covered. say they had radiation to their colon and they needed colon cancer screening earlier, that you link it to the appropriate code.

But the cancer screening section there, that's something that primary care does day in, day out. It's the high-risk screening that's a bit elevated in terms of knowing what you need to do, but we have those guidelines. And so then lastly you think of those other components for primary care, it's the late effects, right? And hopefully, we've talked about those here. Hopefully, that's something that the patient is bringing up of concern. But linking them to specialists and referrals. Some of those patients who do develop cardiomyopathy may need to see a cardiologist for improved management, right? But, maybe there's patients who have a history of brain tumors. You may not be ordering the MRIs of the brain. I don't order the MRIs of the brain for those patients in survivorship. They see neuro-oncology, and they follow with them. But I absolutely am the one putting in the referral and making sure that that gets approved.

So, I think at the end of my soapbox for primary care is that I want to believe that primary care doctors can do some really wonderful things for cancer survivors and that the things that they don't know the intricacies of, that there are these excellent guidelines that you can look at that are very well organized, and you can figure it out. And if you don't have a lot of time in the visit, you can say, "You know what? Let me get back to you to double-check on that" and circle back with the patient. But I'm hopeful for where we can go for the primary care we give to these patients.



**Slide 35: Role of Psychosocial Providers**

**Michelle Rajotte:** Thank you, Dr. Eary. That was really important information as well. Dr. Hall, how can and should psychological services be integrated into AYA cancer survivorship?

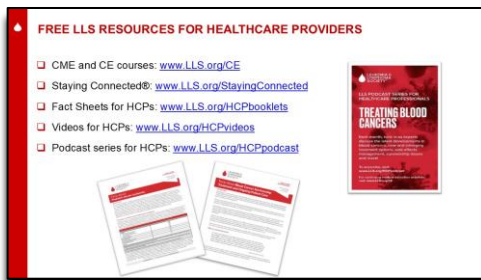
**Dr. Hall:** Flexibly is really the big response. Psychologists and psychology services don't need to function in a box. One of my, I feel like, main roles is

when I see a patient in survivorship is to get them to make sure they have a primary care provider. I am one of the biggest people on the team who makes a lot of referrals, whether it's internal or external, and I don't necessarily just stay behind my door. I do a lot of individual therapy. Now, I do some of that, but flexibly. Use your team, and your resources, however it makes sense for your center.



**Slide 36: Resources**

**Michelle Rajotte:** Thank you. So, now I'm pleased to share some free resources from The Leukemia & Lymphoma Society and the American Cancer Society. Also note that all of these will be in the slides. So, if you miss any of this, you have any other questions, all the details are in there.



**Slide 37: Free LLS Resources for Healthcare Providers**

The Leukemia & Lymphoma Society offers free CE and CME online courses as well as a podcast channel where you can listen to healthcare professionals discuss treatment, side effect management, and strategies to support your patients. New and interesting topics are added every few weeks.

## ***Clinical Strategies and Resources: Caring for AYAs as They Transition to Cancer Survivorship***

**Transcript**

**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.LLSeatinion.org](http://www.LLSeatinion.org)
  - call 877-497-1938
- ❑ **Reach out Monday-Friday, 9 am to 9 pm ET**
  - Phone: (800) 955-4572
  - Live chat: [www.LLS.org/IRC](https://www.LLS.org/IRC)
  - Email: [info@lls.org](mailto:info@lls.org)
  - HCP Patient Referral Form: [www.LLS.org/HCPreferral](http://www.LLS.org/HCPreferral)




### **Slide 38: Free LLS Resources for Patients**

We also have Information Specialists that are highly trained oncology social workers and nurses who can provide accurate and up-to-date blood cancer treatment and support information to your patients. You can either refer them or your patients can contact us directly, and this slide can explain how you can do that.

We also have a nutritionist that does one-on-one nutrition consults through our Nutrition Education Services Center, and consultations are done by phone available for patients of all cancer types, not just blood cancers, and all ages. And it's also available in many languages because we use an interpreter service.

We also have our Clinical Trial Support Center Nurse Navigators who are registered nurses and nurse practitioners who have expertise with blood cancers, and they work one on one with patients via telephone to provide all kinds of information regarding clinical trials, personally assist them through the clinical trial process, and provide information for the patient to bring back to their healthcare provider. And this is a unique service from LLS. So those are all things you can refer your patients to.

**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/Education/videos](http://www.LLS.org/Education/videos)
  - [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




### **Slide 39: Free LLS Resources for Patients and Caregivers**

We also have blood cancer-specific information and support resources that are on our website.

**FREE LLS RESOURCES FOR YOUR PATIENTS**



**BOOKLETS AND FACT SHEETS**

English – [www.LLS.org/Booklets](http://www.LLS.org/Booklets)  
Spanish – [www.LLS.org/Materials](http://www.LLS.org/Materials)




### **Slide 40: Free LLS Resources for Your Patients**

And here's some examples of the booklets and what they look like. And all of our information and support is free.



**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](http://cancer.org) | 1.800.227.2345

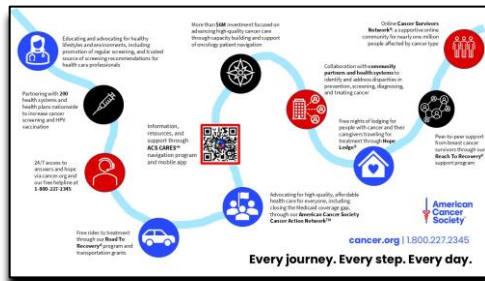
### **Slide 41: American Cancer Society**

The American Cancer Society is on a mission to end cancer as we know it for everyone. ACS improves the lives of patients with cancer and their families through advocacy, research, and patient support to ensure everyone has the opportunity to prevent, detect, treat, and survive cancer.



**Clinical Strategies and Resources: Caring for AYAs as They Transition to Cancer Survivorship**

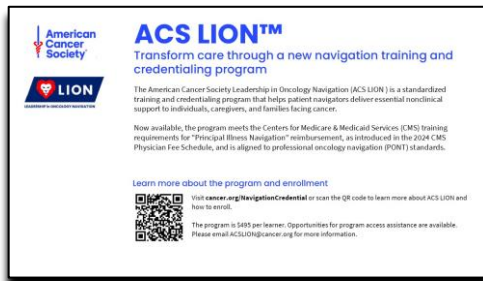
Transcript



**Slide 42: American Cancer Society Resources**

The Society's programs and services help patients and families during and after cancer treatment, including information, education, and resources through cancer.org, free lodging and transportation for patients during treatment, a 24/7 helpline, which connects callers with trained cancer information specialists.

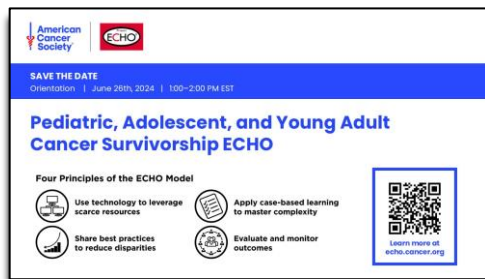
In the middle of the slide is a QR code with the ACS brand so you can get to all the information, and ACS also connects patients and families to tailored resources with one-on-one support.



**Slide 43: ACS Lion™**

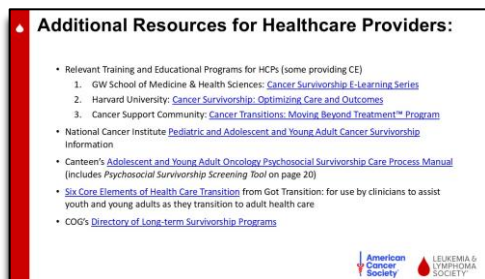
For healthcare professionals on this call, there are two professional education opportunities. In 2023, the American Cancer Society was tapped by the White House to develop a new nonclinical cancer navigation curriculum and credentialing program, and this is called their ACS LION program, which is a standardized training and credentialing program that helps navigators deliver essential support to individuals, caregivers, and families experiencing cancer. And, again, you can learn more

about this program through the QR code.



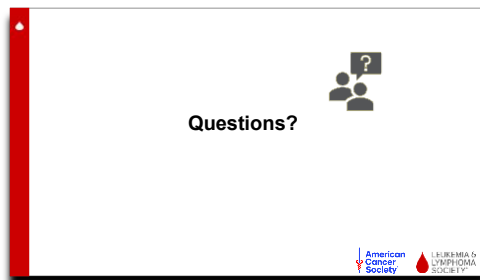
**Slide 44: Pediatric, Adolescent, and Young Adult Cancer Survivorship ECHO**

Upcoming in June, ACS will be launching a 12-month ECHO, all teach, all learn education series on pediatric, adolescent, and young adult cancer survivorship; and each month, it will cover a different topic area related to survivorship and feature experts across the country. The ECHO program is free to participate in, and CMEs will be through the QR code.



**Slide 45: Additional Resources for Healthcare Providers**

There's also additional AYA resources for healthcare professionals.



**Slide 46: Questions**

Now we're going to go onto the question and answer portion of our program. Can you speak to your experience with YAs who were very physically active, ate right, focused a lot on their health, and were diagnosed and now feel it was all worthless thinking they should not have been vulnerable to such health challenge, experiencing a loss of sense of health? Moving forward, do you see these patients going backwards health wise as they are no

longer as focused on their health having gone through what they did?

**Dr. Roth:** We tell every patient that there's nothing they did to cause their cancer. There's nothing they could have done to prevent it. And living a healthy lifestyle is only going to be beneficial for them during and long after treatment.

really the few things that folks can do to improve their health trajectory are, one, focus on their fitness, their health, their movement, their nutrition, and also get, appropriate healthcare for screening and treatment of any chronic health conditions.

So we always try to motivate our patients to be more active and also not compare themselves to pretreatment. So, if they were a marathon runner pretreatment, that's okay. During treatment, many patients are a little bit more sedentary. Think about where you are today. Think about what you can do tomorrow, and just be proud of yourself for the progress that you're making.

**Michelle Rajotte:** Thank you. So our next question is what age do COG or COG survivor guidelines go to? Do they cover AYA cancer diagnosis such as CRC, thyroid, breast that fall in the adult realm which most AYAs are treated?

**Dr. Friedman:** the guidelines are intended for children, adolescents, or young adults, so anyone diagnosed under the age of 39. They are exposure driven. So everything in the guidelines is based on what type of chemotherapy you received, what field of radiation you were exposed to. they are disease-agnostic. So they really apply to any survivor of any type of cancer who was diagnosed and treated during this age range.

And importantly, we don't have data yet on late effects after various novel therapies. We do have a novel therapies task force that is monitoring the literature. as we learn about these new late effects, we will make those available too. But, certainly, they are relevant to any disease group within this age group.

**Michelle Rajotte:** Thank you. Another great question is how do you help or support AYAs treated under the pediatric protocol setting and the transition to adult oncology care?

**Dr. Eary:** I think that depends on location and accessibility regarding insurance. Hopefully wherever the pediatric treating hospital is has connections either in the community or within their own, you know, university setting for that. But I think that's kind of the issue we brought up before that there can be some hurdles and barriers and the need for creativity and how you can deliver that care.

**Michelle Rajotte:** Thank you. The next question is what strategies and interventions have been shown to be effective addressing language and cultural barriers with AYA survivors with limited English proficiency?

**Dr. Roth:** This is a challenging one that I don't think that there have been evidence-based effective interventions to really address many of the needs of our underrepresented and underserved populations. That's definitely an area where we need to focus more. There are definitely studies that show there are disparities in long-term health outcomes based on sociodemographic backgrounds. So, patients with fewer resources are at higher risk for having poorer long-term health issues, similar to disparities we see in the general population, which to the individual who put this question in the Q&A, to your point, we need to focus more on this population and target interventions specifically to address the health needs of our underrepresented and underserved populations, including those who English is not their primary language. Thank you for the question.

**Michelle Rajotte:** Great, thank you. The next would be, what would be the recommendation if an AYA needs a survivorship clinic? Is there a list of these clinics? What would be the recommendation for referral if it is through a PCP or a direct patient referral?

**Dr. Eary:** So on the COG website, there is a link for long-term survivorship clinics, and it's done by location and state. I will say that connecting with a PCP, that comes down to the logistics of, unfortunately, insurance. You know? Is the clinic taking new patients? Right? That's barrier number one. you find a PCP. You Google a PCP. You think they're going to be the right fit. You call and then you find out they're not taking any new patients. And I think the strongest recommendation I would make is talking with the treating facility or the treating university or unit. Where are they sending their patients to find out their suggestions?

**Michelle Rajotte:** Thank you. And going back to our last question about the language barrier, I know and I believe ACS does as well. We have a lot of our information in Spanish and in English, so that might be a good resource to help as well.

**Dr. Eary:** I will add something too if there's a patient at your system. We had this come up recently. And, even though the patient is in the survivorship phase, we elevated this to the social worker and the cancer center, and there are Spanish-speaking nurse navigators who are going to help. It was a patient who was having trouble scheduling visits.

I think there's another element here too, the younger AYA patient who may have had their parent or a family member helping them. I think that can also compound some of how scheduling, who's making those appointments, but maybe looking even internally in those services that are sometimes only offered to active patients for help.

**Michelle Rajotte:** Thank you. Could you address the impact you see from the lack of social and societal understanding and not knowing how to communicate with and act around AYAs, often leading to imposing social isolation.

**Dr. Hall:** I can talk about it from a mental health perspective, and I think there's a lot of direct coaching that we can do with our patients. Now does that fix things from a societal, a larger level?

I think spreading awareness that we see into the community that cancer is not, again, coming back to this idea, a one and done thing that once treatment is over that everyone can expect this person to return back to normal. There should probably be an adjustment of expectations than knowing that forever this life has been changed.

And I think if we can spread awareness, however that looks, whether it's social media platforms or however to get the word out. But I think with our patients, it's direct coaching with them on how to orient their caregivers, their family members. And, there's a really great research study Dr. Andrea Betts is conducting to, and it's for friends of young adults to receive coaching themselves on how to interact with their friend who's an AYA. And the more research we have in this lane that can be spread more broadly can only be helpful to the patient in a very positive way.

**Michelle Rajotte:** Thank you. That sounds like an interesting study because I know a lot of AYAs feel very lonely, and I think it's because people don't how to address or interact with them after treatment is over. Okay, next question. Does your healthcare system programs have psychosocial oncology social workers for transition?

**Dr. Roth:** So at MD Anderson, we have social workers embedded specifically within our AYA survivorship program. We also have psychosocial health counselors to assist as well. The role of our social workers isn't specifically to only focus on transition that is part of their role. Really, what we've tried to do is to centralize AYA resources within our center to make sure that no matter where patients are treated, who their primary oncologist is, all AYAs, all survivors get access to the same resources, which hopefully helps with transition. Although, many of our patients do stay within our system for their long-term survivorship care.

**Michelle Rajotte:** Thank you. Do you use Passport for Care or other similar programs to help patients track and communicate their past treatment when they're moving from pediatric care into adult, young adult survivorship?

**Dr. Eary:** So I've been on the receiving end of that because I'm a primary care doctor who sees cancer patients. And I will say, one of the clinics we're at if they weren't treated at our university, it's finding the records before they get to the visit because that's going to help you with understanding the exposure. And it is very helpful when , they can pull it up on their phone and I can see the medicines. Okay, let me see. When were you treated? Did you have radiation? And then it can help me focus my visit.

So, whether it's Passport to Care, whether it's a screenshot that they took of a summary that Dr. Roth did, I just want to see what the exposure was. That's very, very helpful to the visit.

**Michelle Rajotte:** Thank you.

Are PCPs getting some training about how to address AYA needs? And, also, do you have any tips for finding PCPs who are comfortable caring for cancer survivors?

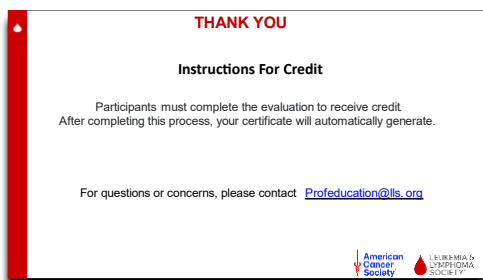
**Dr. Eary:** I think that I speak for a lot of primary care doctors who are in the space in survivorship, who care about the education of PCPs with survivorship care is that we're trying on multiple levels. Right, we're trying on the medical student level. We're trying in the residency level, getting exposure to learning and education on an earlier front. There are ECHO programs that are

available. The George Washington CME is free, which you had a link to, that survivorship for all types of cancers. There's the COG link, which is also free. And I think that, you know, it's going to take a community to kind of help elevate this knowledge. And it's going to take time, but I do think people are in place to help the education of PCPs.

How do you find a PCP who feels comfortable? It's a really good question. If you're talking on the patient level, you want someone who's going to be able to feel comfortable if you have chronic conditions or things that you're concerned with that can first, that your insurance accepts, and so it's not going to be financially toxic for you to go to the university hospital and then get, an added copay because they're out of network. So finding some place that you can actually go and receive care that won't be financially toxic for you.

But I think there's probably a dance here that needs to occur - Having your history yourself with you at all times no matter who you access for healthcare is my biggest piece of advice for someone. And when you meet that first PCP, they may not know all the intricacies of survivorship. But if you came to them with, like, this is my survivorship summary, which probably also links the COG guidelines, you're going to have a much better conversation. I think empowering on a patient level, this is just my advice, that you have your information and that then that's a conversation between the two of you, I think, will lend better for what that relationship could be.

**Michelle Rajotte:** So, thank you to the audience for all your questions. To receive credit for this program, please complete the evaluation form. Again, thank you, Dr. Eary, Dr. Friedman, Dr. Hall, Dr. Roth, and Dr. Yarbrough for your continued education to patients and fellow healthcare professionals.



**Slide 47: Instructions for Credit**

This concludes our program.

Thank you all for participating, and we hope the information presented will be useful in your work with your patients and families. We look forward to your participation in future LLS programs.