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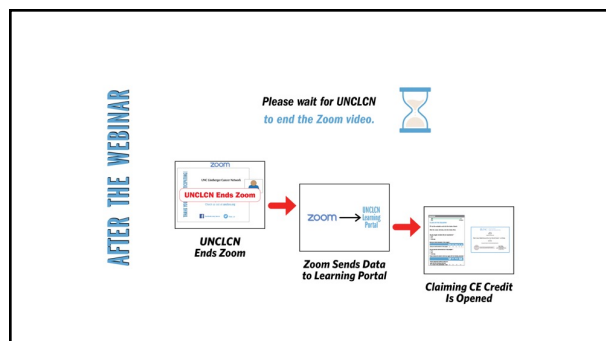
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UNC | Lundberg Cancer Network

**PATIENT CENTERED CARE**  
Live Webinar

Lauren Liu, MSW

Meissa Watson, MSW, NCPD/CNE

Catherine Swift, MSW, LCSW

**Improving the Lives of Adolescents and Young Adults with Cancer**

September 13

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OUR PRESENTER



Lauren Lux, MSW

Lauren Lux (she/her), LCSW, directs the AYA Oncology Program at UNC. Her work as Program Director focuses on patient care, psychosocial research, programming, provider education, quality improvement, and advocacy. Along with her fabulous partners, she leads efforts to improve care for AYAs around the state of North Carolina and is involved in the advancement of the AYA oncology field in the United States. She has worked as a clinical social worker in the field of oncology throughout her career and her clinical practice and program work is inspired and informed by the incredible young people she meets every day.

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OUR PRESENTER

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OUR PRESENTER

3. Lauren Lux, MSW has worked in oncology social work for 17 years

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OUR PRESENTER

3. Lauren Lux, MSW has worked in oncology social work for 17 years

2. She is a Tarheel for work but a Blue Devil in her heart

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OUR PRESENTER

3. Lauren Lux, MSW has worked in oncology social work for 17 years

2. She is a Tarheel for work but a Blue Devil in her heart

1. She works with the best people who take incredible care of the young people treated at UNC

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OUR PRESENTER



**Melissa Matson,**  
MSN, RN, AGPCNP-BC

Melissa Matson, MSN, RN, AGPCNP-BC, AOCNP is a nurse practitioner with the UNC Adolescent and Young Adult Cancer Program. Prior to joining the UNC AYA team in 2020, Melissa served as an adult leukemia NP both in the inpatient and outpatient setting. During that time, she loved precepting student NPs and continues as an adjunct instructor in the UNC School of Nursing. Today, Melissa completed her graduate education at the University of North Carolina at Chapel Hill, with a focus on adult/gerontology primary care and specialization in oncology. She holds two bachelor's degrees, one in nursing and one in communication and English.

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OUR PRESENTER

3.

Melissa Matson, MSN, RN, AGPCNP-BC launched a national collaborative of advanced practice providers caring for young adults with cancer

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3.

Melissa Matson, MSN, RN, AGPCNP-BC launched a national collaborative of advanced practice providers caring for young adults with cancer

2.

Currently leading an interdisciplinary working group of UNC cancer and affiliated professionals developing guidance on engaging in sexual activity during cancer treatment

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1.

2.

Melissa Matson, MSN, RN, AGPCNP-BC launched a national collaborative of advanced practice providers caring for young adults with cancer

Currently leading an interdisciplinary working group of UNC cancer and affiliated professionals developing guidance on engaging in sexual activity during cancer treatment

Has been published on the topic of supporting cancer caregivers

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OUR PRESENTER



Catharine Swift,  
MSN, LCSW

Catherine Swift (she/her), LCSW, provides direct patient care for the AVA population, acting as a counselor, advocate, and support services coordinator for teens and young adults. With a background in narrative medicine, religious studies, and palliative care, she is passionate about helping AVAs navigate the complex roles and identities they inhabit as young people, cancer patients, and so much more.

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OUR PRESENTER

3.

Catharine Swift, MSW, LCSW co-lead our AVA sarcoma palliative care collaborative with Dr. Jacob Stein and Dr. Julie Childers.

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OUR PRESENTER

3.

Catharine Swift, MSW, LCSW co-lead our AVA sarcoma palliative care collaborative with Dr. Jacob Stein and Dr. Julie Childers.

2.

Her clinical training was at the Duke Hospice IPU and here with the AVA team and CCSP.

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OUR PRESENTER

3.

Catharine Swift, MSW, LCSW co-lead our AVA sarcoma palliative care collaborative with Dr. Jacob Stein and Dr. Julie Childers.

2.

Her clinical training was at the Duke Hospice IPU and here with the AVA team and CCSP.

1.

She's contributed to research around parenting with cancer with Dr. Leeza Park as a study interventionist.

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Join by Web [PollEv.com/uncncln](https://polltv.com/uncncln) Join by Text Send uncncln to 22333

AYA is an abbreviation for Adolescents and Young Adult.

(A) True 0%

(B) False 0%

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AYA is an abbreviation for Adolescents and Young Adult.

True 0%

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## Improving the Lives of Adolescents and Young Adults with Cancer

LAUREN LUX, LCSW  
CATHERINE SWIFT, LCSW  
MELISSA MATSON, NP

SEPTEMBER 13, 2023

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### Objectives

- Identify the unique and unmet needs of adolescents and young adults diagnosed with cancer.
- Describe tools that health care professionals can use to provide developmentally and age appropriate care to AYAs.
- Recognize strategies that health care professionals and healthcare systems can deploy to create a better treatment environment for AYAs.

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## The ABC's of Adolescents and Young Adults:

Age Appropriate Information  
No BS  
Care for the Whole Person



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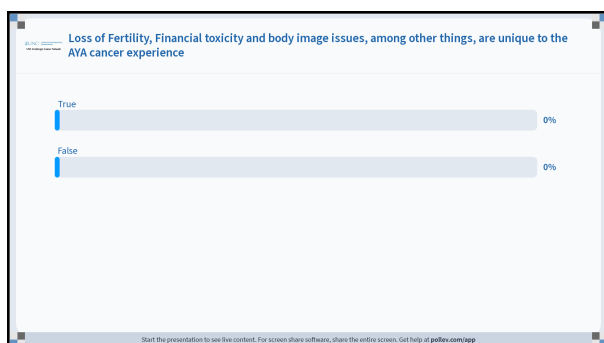
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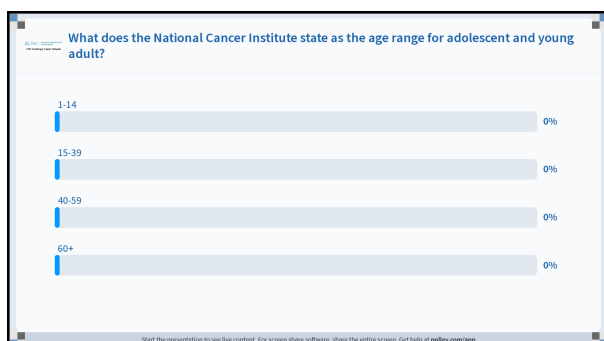
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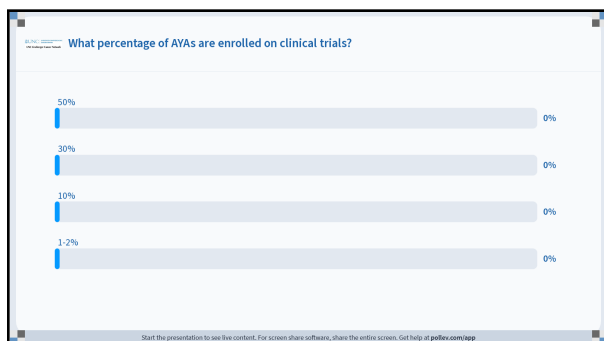
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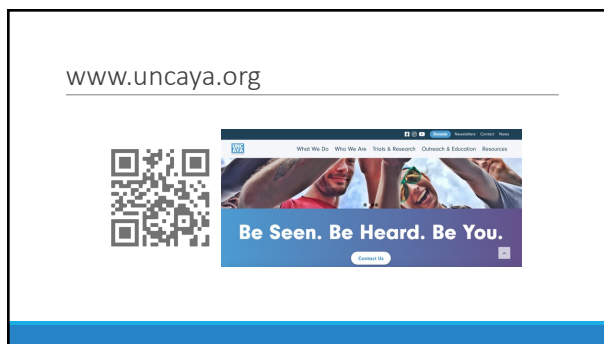
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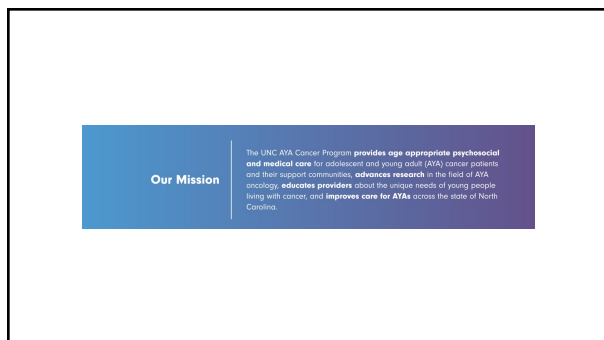
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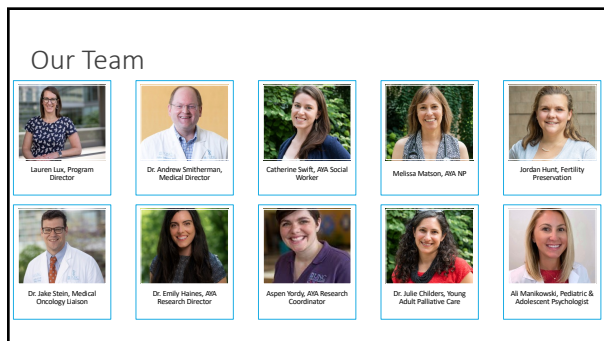
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## Scope of Work



Clinical Care	Research	Education / Advocacy
<ul style="list-style-type: none"> <li>NP &amp; SW Consult at Diagnosis (13-39y)</li> <li>Triage (18-22y)</li> <li>YA Survivorship Clinic (Hillsborough)</li> <li>Sarcoma Palliative Care Collaborative</li> <li>Sexual Health Working Group</li> <li>Fertility Preservation Support</li> </ul>	<ul style="list-style-type: none"> <li>Clinical Trials (connection between peds and adult cooperative groups)</li> <li>AYA Research Working Group (Nichols)</li> <li>AYA Cancer Registry</li> <li>AYA P01: Kaiser California, Utah, UNC (Nichols, Baggett) – AYA survivorship outcomes</li> <li>Co-Is on multiple studies conducted by colleagues in Public Health, Nursing, Social Work, and Journalism</li> </ul>	<ul style="list-style-type: none"> <li>Mentoring learners (SW, Onc Fellows, Pall Care Fellows, Residents, Medical Students, and soon NPs)</li> <li>Annual NC AYA Cancer Symposium – October 20 in Winston-Salem (QR Code)</li> <li>Consult support for program development at other institutions</li> </ul>

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## What you don't have to be...

1. Cool
2. Up to date on recent slang terms
3. A snap chat user
4. Young
5. Cool

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## What you do have to be...

1. Authentic
2. Flexible
3. Compassionate
4. Honest
5. Willing to get to know the PERSON not just the PATIENT

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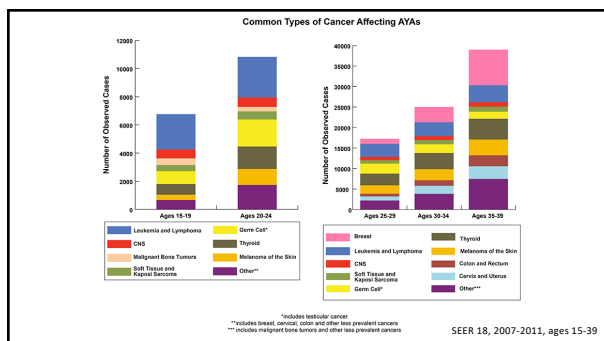
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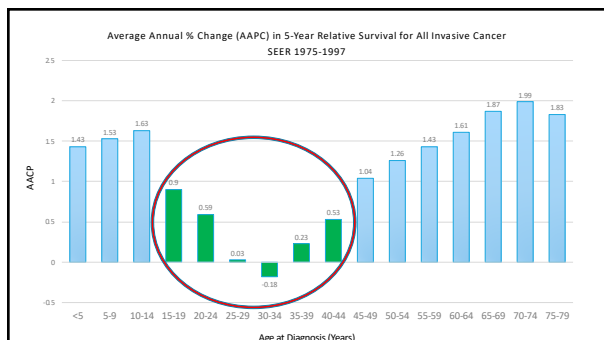
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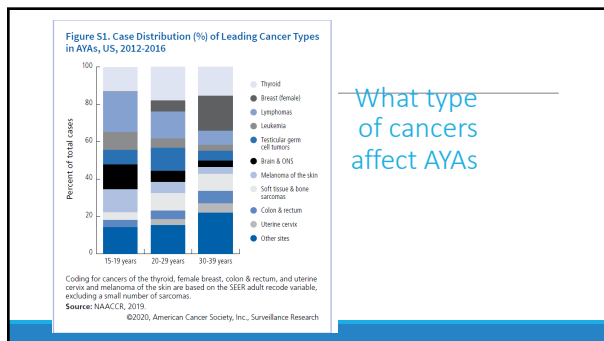
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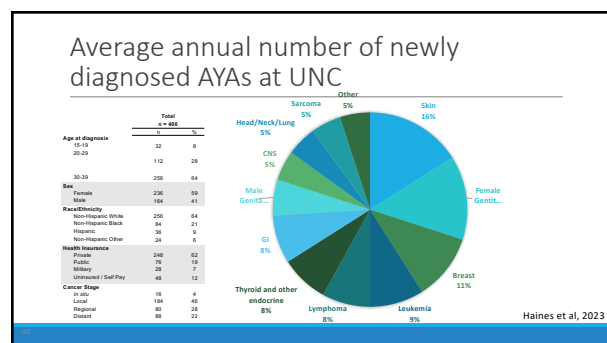
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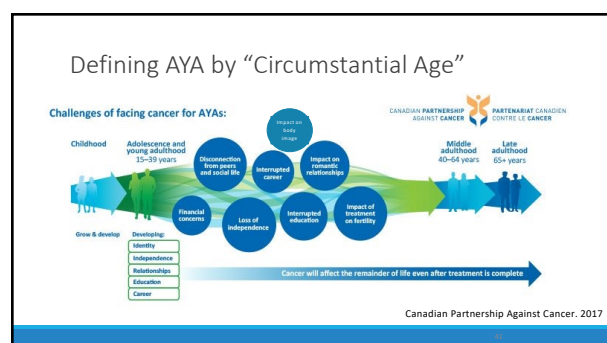
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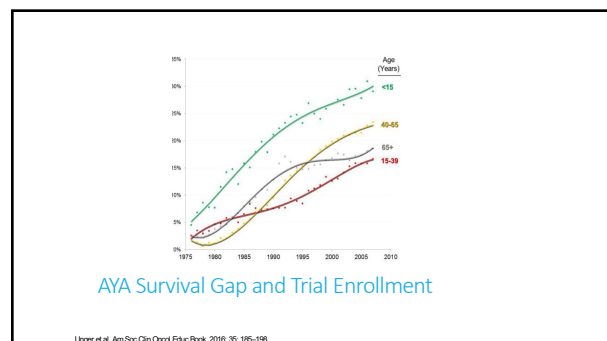
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### Why poor outcomes?

- Tumor biology
- Delay in diagnosis
- Adherence to therapy
- Underinsured/not insured
- Psychosocial issues
- Financial issues
- Low clinical trial enrollment rate (1-2% vs. 60-70% in peds)
- Treatment protocols used vary

Barr, D. et al, 2016

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### AYA developmental tasks

- Establishing autonomy from parents
- A personal set of values and identity
- Strong peer relationships, including intimate and sexual relationships
- Obtaining adequate preparation to join the workforce
- Financial independence

\*\*A note about frontal lobes



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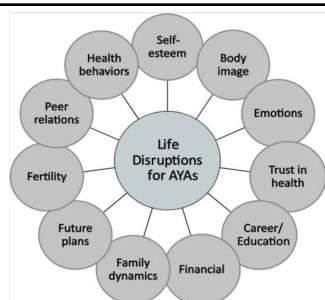


Figure: Possible life disruptions for AYA cancer survivors.  
Source: Institute of Medicine Identifying and Addressing the Needs of AYAs with Cancer Workshop (2013). Abbreviation: AYAs, adolescents and young adults

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## No BS

AKA How do we effectively communicate with AYAs

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"The simplest advice I can give to facilitate conversations with adolescents and young adults is this: be respectful, and genuine. We are forced to confront our mortality at a time in our lives when society tells us we are invincible, fearless, limitless. When this construct crashes down around us and shatters, we can feel vulnerable..."

-23 year old with relapsed lymphoma and has dreams of drinking espresso at every coffee shop in the triangle

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## Communication

- Honesty is key
- Direct
- Non-judgmental
- Avoid controlling/punitive language
- Help AYA understand how they best receive information
- Repeat, repeat, repeat
- Text vs. Phone vs. Email
- **Discuss things other than cancer**

Zebrack, B. 2008

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## Control- how do we give more?

Often want very much control over day-to-day issues

Where can we give young adults control

- Food
- Schedule
- Rooms
- "Opt in" activities
- Decision making
- Peers at the bedside
- Admission dates
- Physical activity

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## Age Appropriate Information

What are AYA specific information needs?

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“Can you come talk to me bout  
that sperm thing?”

-19 year old with ALL and biggest Steelers fan in NC

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## Fertility Preservation

- Major barriers:
  - urgency to initiate treatment
  - inadequate information
  - clinic time constraints
  - cost
  - relationship status
  - sociodemographic status
  - **HOSPITAL PROCESS**
- Currently no tracking systems or evidence based guidelines regarding these topics
- Get educated- ECHO & ENRICH

Fink, Sheeder, Kondapalli- 2015

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“What’s the deal with having sex IN the  
hospital?”

-25 year old going through BMT who loves to hike

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## S-E-X

- Why is this so important to discuss with patients?
  - Reproductive health ranks as one of the most important issues cited by AYAs
  - Risk-taking behaviors of AYAs + Not having SEX talks = health risks (esp. if fertility status is ?)
- Who is having these conversations?
- Include partners
- BETTER Model: Bring up the topic, Explain that sex is an important part of life, Tell patients that resources will be found to address their concerns, Timing of intervention, Education re: sexual side effects of tx, Record

Murphy, Klosky, Termuhlen, Sawczyn, Quinn, 2013  
Katz, Anne, 2005

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“What if I just eat the pot instead of smoke it?”

-20 year old with AML who is a self described “hater of vegetables”

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## Drug and Alcohol Use

- Very little data about substance use and AYA
- Some indication that substances are used to cope with stressors
- Open, honest conversations
- Inform of risks
- Provide better options
- Sticky situations– Providers lack of consensus

Deniel, C. et al. 2015

57

"What if I stand outside the 3 point line and only shoot during the game? No one will touch me, I swear!"

-25 year old with AML and a beautiful 1 year old daughter

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### Physical Activity

- AYAs cite physical activity as a major unmet need during treatment
- Has been shown to reduce treatment symptoms and increase mood
- Must adjust exercise to meet the needs of younger patients
  - Pokemon Go
  - Laps around football field
  - Over the door basketball hoop
  - Softball player

Galvao, DA. 2005

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"Please don't tell my mom \_\_\_\_\_!"

-All of the patients

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"I never imagined my days and nights would be filled with insulin shots, IV ports, steroids, and lots of fatigue. There are new things to be learned every day. Am I up for the challenge? Will I do a good job? Can I handle the pressure?"

-26 year old wife who hates running but has to do it every morning in the military

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### Caregivers, Partners & Confidentiality

- Consent, confidentiality, and decision making capacity
- Legal obligations
- Ethical considerations
- Establish expectations from the beginning
- How do we support them?

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### Care for the Whole Person

Who are you before, during, and after treatment?

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## Transitions – survivorship, end of life and palliative care

- AYAs experience “transitions within transitions”
- End of treatment to survivorship can be a particularly difficult time
  - What life does an AYA “return” to and what does “normal” look like?
- Living with metastatic disease as young person – symptom management and goals of care/priorities
- End of life and care utilization may look very different for AYAs

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## Resources

### General

- Stupid Cancer
- Critical Mass
- NCCN Guidelines “Caring for Adolescent and Young Adult Patients”
- Teen Cancer America

### Fertility Preservation

- Livestrong
- Save My Fertility (also an App)
- Fertile Action
- MyOncofertility.org
- NCI

### Financial

- SamFund
- Hope for Young Adults with Cancer
- The Ullman Cancer Fund for Young Adults
- Patient Advocate Foundation
- Cancer Care

### Parenting with Cancer

- Single Father’s Due to Cancer
- NCI
- Cancer.gov
- Cancer.org
- Mightspace.org (Parenting at a challenging time)
- American Cancer Society

### Cancer Peer Connections

- Instapeer
- Stupid Cancer Meet Ups
- Innerman Angels
- Young Survival Coalition
- Cancer Support Community

### Career & Legal

- Cancer and Careers
- National Cancer Legal Services Network

### Adventure Programs

- First Descents
- Epic Experience
- True North Treks

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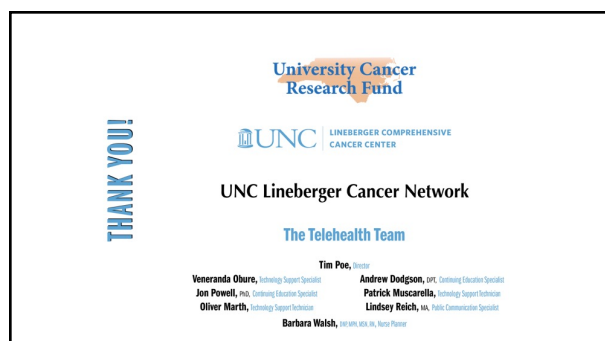
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SELF-PACED, ONLINE COURSES



**ADVANCED PRACTICE PROVIDER**  
Parenting with Cancer  
Justin Yopp, PhD



**RESEARCH TO PRACTICE**  
Radiation Oncology Management of Lung Cancer in NC: Update on Small-Cell Lung Cancer  
Ashley Weiner, MD, PhD



**PATIENT CENTERED CARE**  
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Joseph Polich, MSW, LCSW-A, JD

Complete details on our Self-Paced, Online Courses:  
[learn.uncmc.org/spoc](http://learn.uncmc.org/spoc)

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