

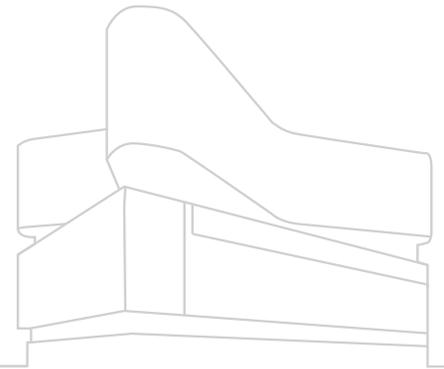
None of this is “normal”: Psychological and behavioral challenges faced by adolescents/young adults in palliative care

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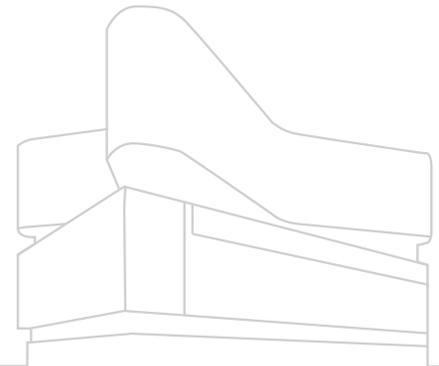
Disclosures

- I have no financial relationships to disclose



Overview

- Demographics of AYAs in US
- Life threatening illness and death in AYAs
- Developmental goals of AYAs
- Case examples and tips for providers
- Discussion



Defining adolescents/young adults (AYAs)

- What defines an AYA?
 - No clear consensus
- For the purposes of this talk, we will be focusing on patients ranging in age from about 12-29
- Discussing in the context of US culture

Term	Age range
Adolescence- WHO, 2016	12-20 years old
Emerging adulthood- Arnett, 2000	18-25 years old
Young adult- Adolescent and Young Adult Oncology Progress Review Group, 2008	15-39 years old

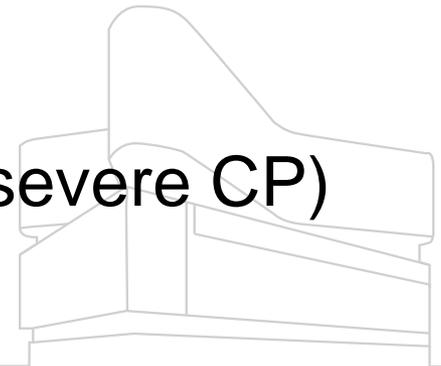
AYAs in the US

- According to the 2012 US census, there were:
 - 41,844,000 youth between the ages of 10 and 19
 - 42,771,000 youth between the ages of 20 and 29
 - **Nearly 85 million AYAs in the US**
- In total, AYAs comprise almost **30%** of the US population



Life threatening illness and death in AYAs

- Approximately 500,000 children and adolescents in the US are living with a life-threatening condition
- Common life-threatening conditions seen in AYAs in palliative care/hospice
 - Malignancies
 - Neuromuscular disorders (DMD, SMA, etc.)
 - Cystic fibrosis
 - Renal failure
 - Other neurological conditions (e.g. severe CP)



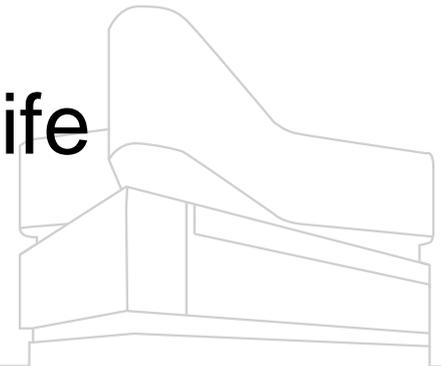
Life threatening illness and death in AYAs

- In 2013, **52,455** children, adolescents, and young adults between the ages of 10 and 29 died of any cause
- Death during AYA is relatively rare in our society

Age range	Top 3 causes of death
10-14 years of age (both sexes, all races)	<ol style="list-style-type: none">1. Accident2. Cancer3. Suicide
15-34 years of age (both sexes, all races)	<ol style="list-style-type: none">1. Accident2. Suicide3. Homicide

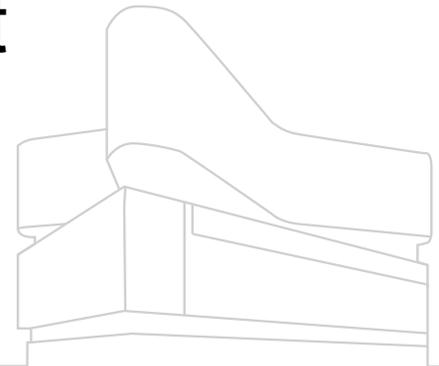
Life threatening illness and death in AYAs

- In percentages, that means...
 - 0.6% of AYAs in the US are living with a life-threatening illness
 - 0.06% of AYAs in the US die of *any* cause annually
- Although chronic illness is relatively common, life threatening illness and death is *rare*
- Typically the healthiest time of life



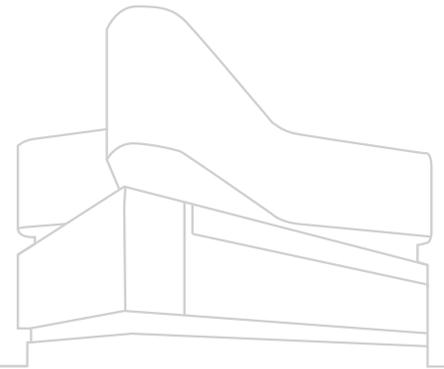
Adolescence

- From Latin *adolescere*- “to grow up”
- The transitional developmental period marked by the onset of puberty and ending with the “achievement” of adulthood
- Cognitively similar to adults, but emotionally and socially distinct
 - Problems with judgement



Young Adulthood

- Typically starts at the end of adolescence and can range anywhere from the ages of 18 to 40
- Usually characterized by achievements of various developmental milestones
 - Marriage/partnering
 - Career establishment
 - Having children



Developmental goals of AYAs

- Erik Erikson
 - Identity vs. Role confusion (adolescence)
 - Fidelity
 - Separation from family
 - Intimacy vs. Isolation (young adulthood)
 - Love
 - Exploration of relationships and sexuality



Realities for AYAs with life-threatening conditions

Developmental Goal	Interruption by life-threatening illness
Creating unique identity	<ul style="list-style-type: none">• Interruption of “normal” daily functioning and activities• Inability to engage in activities associated with self-concept and identity (e.g. sports, hobbies)• Changes in appearance, resulting in lower-self esteem



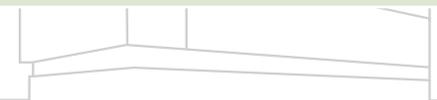
Realities for AYAs with life-threatening conditions

Developmental Goal	Interruption by life-threatening illness
Increasing autonomy	<ul style="list-style-type: none">• Increased, rather than decreased reliance on parents/family for practical and emotional support• Inability to move out, become independent



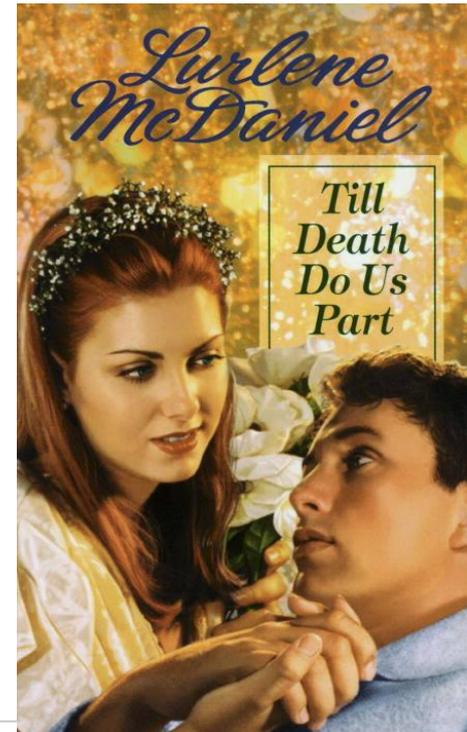
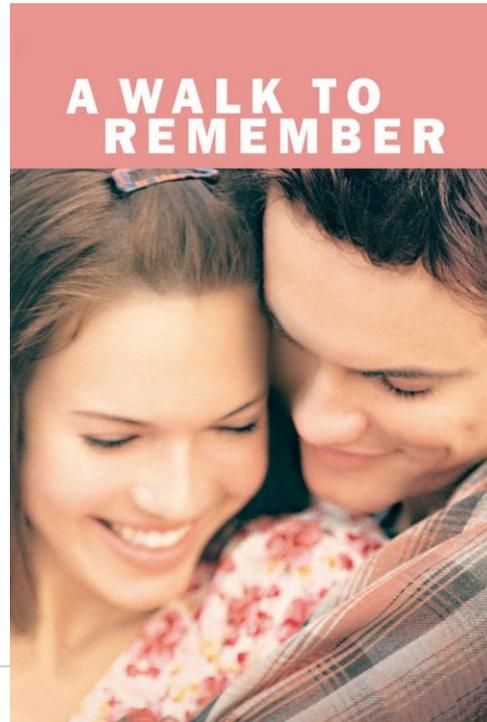
Realities for AYAs with life-threatening conditions

Developmental Goal	Interruption by life-threatening illness
Establishing intimate relationships	<ul style="list-style-type: none">• Unable to keep up with “typical” social activities• Difficult to relate to peers who are “starting” their lives while yours is potentially ending• Strain on existing romantic relationships, hard to establish new ones



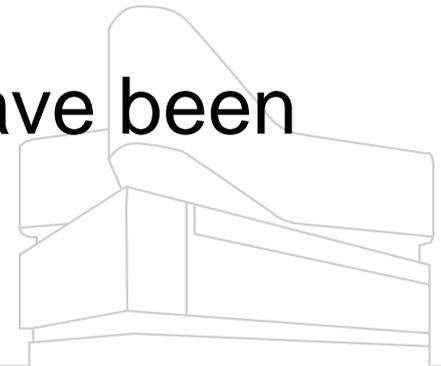
Cultural implications

- What are the representations of palliation/death for AYAs in our culture?



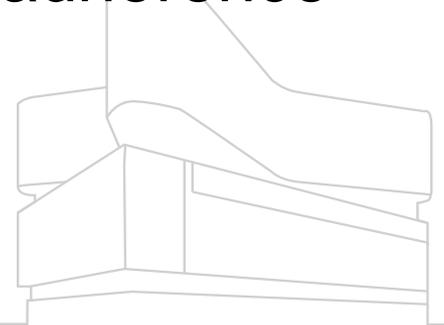
Psychological/Behavioral challenges faced by AYAs with life-threatening illness

- Three case examples highlighting common psychological/behavioral challenges
- Tips for how to address AYAs in these situations
- Tips for when to refer to a mental health professional
- Note: names and some details have been changed to protect privacy



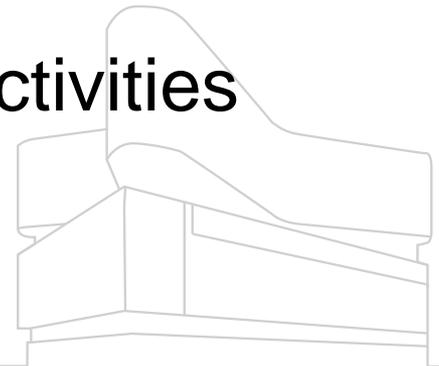
Case example 1: Non-adherence

- Scott, 23-year-old male with end-stage CF
 - Multiple pulmonary and endocrine complications
 - Conflicted relationship with family and CF team
 - Over the course of several years, refusing to engage in treatments or meaningful conversation with CF team
 - Psychology consulted while Scott was inpatient to assess possible causes for his non-adherence



Case example 1: Non-adherence

- Scott was demonstrating symptoms of severe depression
 - Withdrawal
 - Excessive sleeping (in excess of what would be medically expected)
 - Not eating (in excess of what would be medically expected)
 - Not engaging in basic self-care activities



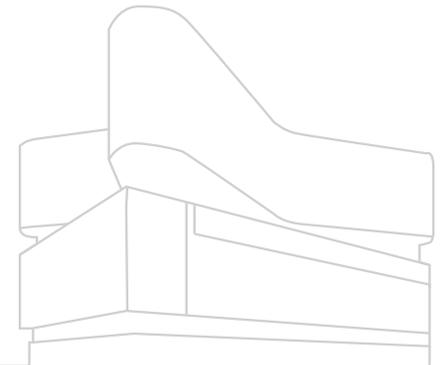
Case example 1: Non-adherence

- Scott was helped to identify his values, including spending more time with his sister and friends
- Eventually this provider was able to challenge Scott's behavior in the context of his values
- Scott's adherence improved, and he received a lung transplant
- However, his current adherence is unclear



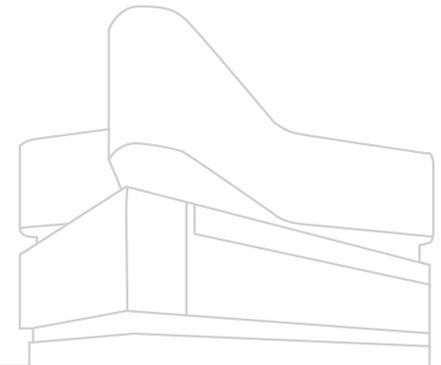
Non-adherence

- Extremely common in AYAs with chronic illness
- Can be particularly confusing for palliative care providers when non-adherent to treatments that alleviate symptoms (e.g. pain medication)



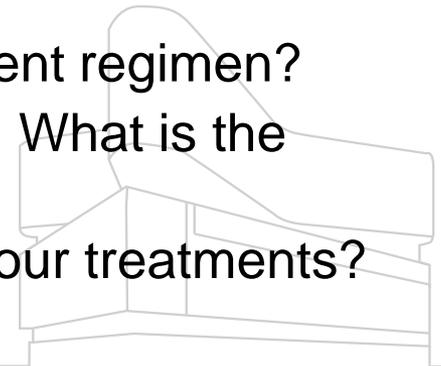
Non-adherence

- Multifactorial in nature
 - Cognitive factors
 - Understanding of disease/treatment, ability to adhere
 - Developmental factors
 - Harder time imagining future implications for their decisions
 - Psychological factors
 - Mental health, motivation
 - Treatment factors
 - Side effects
 - Family/Environment factors
 - Access to care, support network



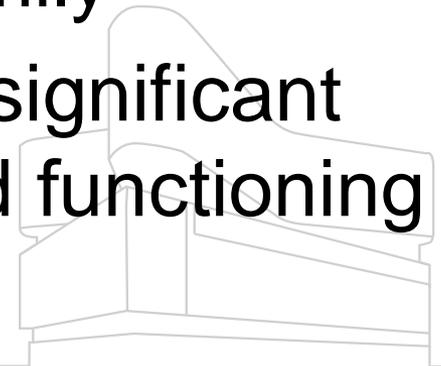
Non-adherence: Provider tips

- Be as non-judgmental as possible
- Try to take the patient's perspective
- Express your concern in an open, honest way
- Helpful questions to understand the patient's perspective:
 - What is most important to you in your life right now?
 - How do your treatments fit into your day?
 - What parts of treatment are helpful? What aspects are less helpful?
 - What would you change about your treatment regimen?
 - What is the easiest treatment to get done? What is the hardest?
 - How can we help you get the most out of your treatments?



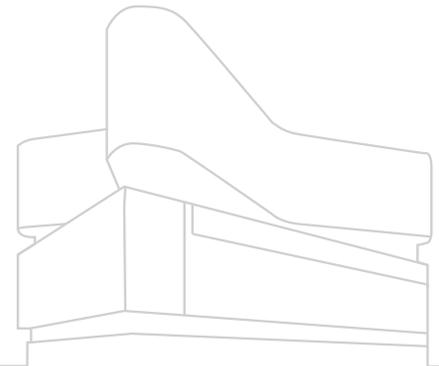
Non-adherence: When to refer

- If you suspect the non-adherence is related to a mental health problem, including depression or anxiety
- If you suspect the non-adherence may be related to a desire to hasten death
- If the non-adherence is becoming a source of distress for the patient or their family
- If the non-adherence is having a significant impact on the patient's health and functioning



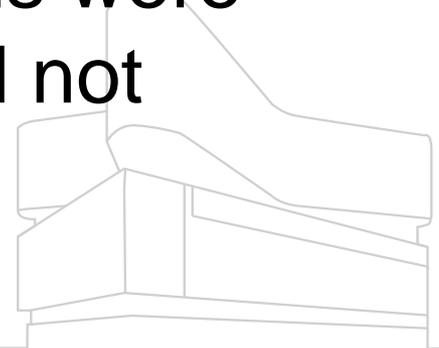
Case example 2: Social withdrawal

- Matt, 18-year-old male with metastatic osteosarcoma
 - Advanced disease in his lungs
 - Still undergoing intensive treatment in an attempt to slow disease progression
 - Difficult family situation



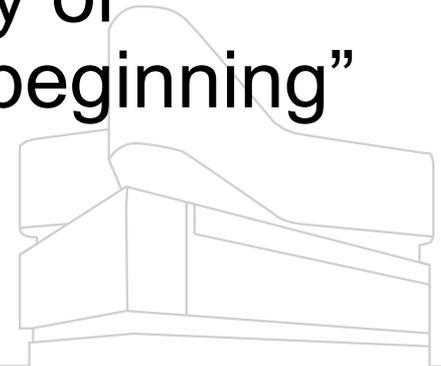
Case example 2: Social withdrawal

- Matt became more withdrawn from friends as his disease progressed
- Eventually told one best friend that his treatments weren't working
- His team became very concerned about Matt's disengagement from "typical" activities
- At the time of his death, his friends were reportedly very surprised and had not realized the severity of his illness



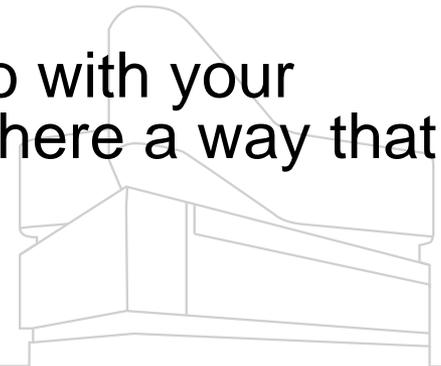
Social withdrawal

- Some level of social withdrawal is common and expected in AYAs in palliative care, especially in AYAs approaching death
 - Difficulty relating to peers
 - Desire to protect peers
 - Dissolution of relationships in advance of death
- Life-threatening illness is in direct contrast to the more typical adolescent reality of preparing for adult life (e.g. the “beginning” of “real life”)



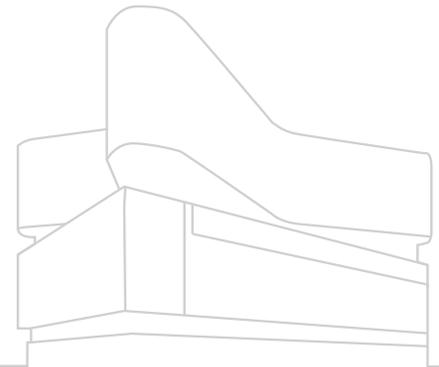
Social withdrawal: Tips for providers

- Get to know the patient as an individual
- Talk to the patient about their support network
- Normalize social challenges for the patient
- Helpful questions for talking to patients about social withdrawal:
 - Tell me about your friends. Do you have a best friend?
 - Who is in your support network?
 - Do you feel comfortable talking about your condition with any friends?
 - Tell me about what you would like to do with your friends, if you were feeling up to it. Is there a way that we can help you do these things?



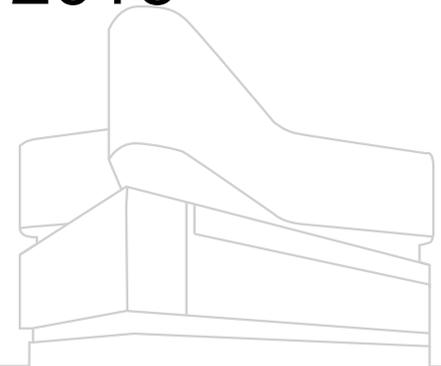
Social withdrawal: When to refer

- If you suspect social withdrawal is a symptom of more significant depression
- If the patient lacks other sources of support (e.g. lack of family support)
- If the patient or family seems distressed by the social withdrawal



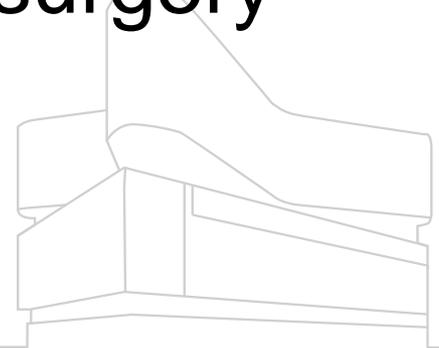
Case example 3: Risk-taking behavior

- Cathy, 19-year-old female with metastatic osteosarcoma
 - Long, complex psychological/psychiatric history
 - Completed initial treatment for osteosarcoma in June 2015
 - Had a relapse to her lung in April 2016
 - Elected to not receive additional chemotherapy



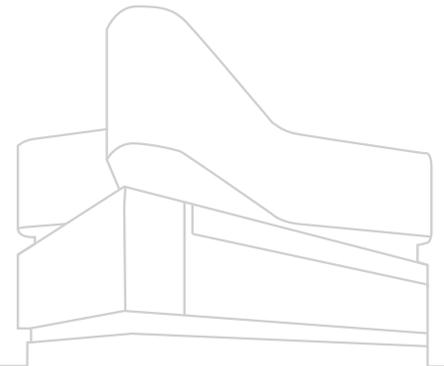
Case example 3: Risk-taking behavior

- Leading up to her relapse, Cathy was engaging in a number of risk-taking behaviors, including multi-substance use and unsafe sexual encounters
- This provider followed Cathy through her initial treatment course and reconnected with her following her first lung surgery



Case example 3: Risk-taking behavior

- Cathy required intensive therapy (at least weekly) and medication management to help her improve her behavior
- A partial hospitalization program was recommended
- Cathy remains in intensive psychological treatment



Risk-taking behavior

- Could include:
 - Unsafe sexual encounters
 - Drug use (including inappropriate use of prescribed drugs)
 - High-risk novel situations
- Limited research exists on risk-taking behavior in this population
- Risk-taking behavior is somewhat more common in AYAs with chronic illness



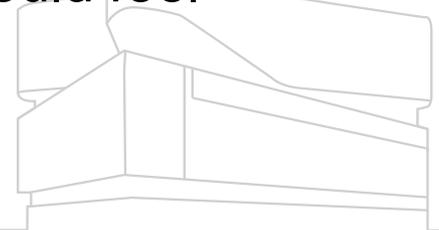
Risk-taking behavior

- Developmentally, AYAs may not be able to process the possible negative outcomes of their behavior
 - “Adolescent egocentrism”
 - Boundary testing and risk-taking part of adolescent development
- The addition of a life-threatening illness may heighten this sense of invulnerability, or a “whatever” attitude about risky behaviors
- Highly correlated with depression



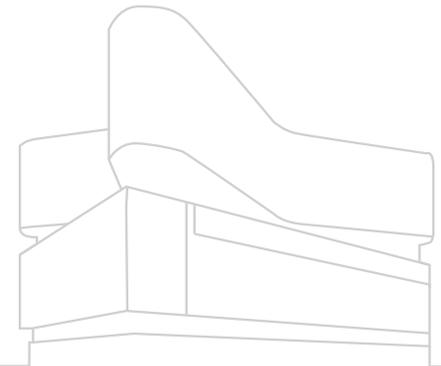
Risk-taking behavior: Tips for providers

- Having a well-established relationship with the patient is extremely helpful
- Be as non-judgmental as possible
- Express your concern in an authentic way
- Helpful questions:
 - Are you using drugs or alcohol right now? How about in the past? What types?
 - When are you likely to use drugs or alcohol?
 - Are you having any sexual relationships right now (hooking up/talking to people)?
 - Would you feel comfortable talking about [alternatives to drug use, drug treatment, safe sex practices] with me? If not, is there someone else on our team who you would feel comfortable talking to?



Risk-taking behavior: When to refer

- In general, err on the side of referring out
- Consider referrals to the appropriate mental health specialist
 - Substance abuse expert
 - Therapist with adolescent experience
 - Therapist with experience in chronic illness/palliative care



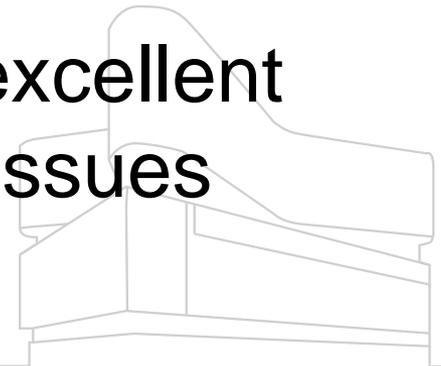
Take home points

- Life threatening illness/death is not “normal” for AYAs in the US
- All aspects of typical AYA development are interrupted by a life-threatening illness



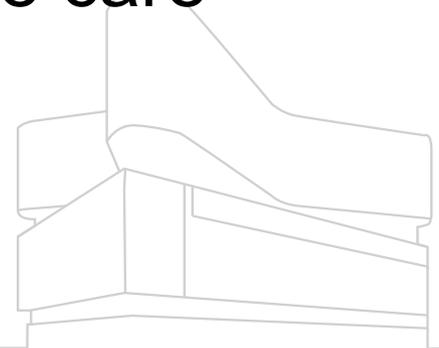
Take home points

- Having an open, authentic, and non-judgmental relationship with the AYA patient is crucial in trying to manage psychological challenges
- Common psychological and behavioral problems can include non-adherence, social withdrawal, and risk-taking behaviors
- Mental healthcare providers are excellent resources to help manage these issues



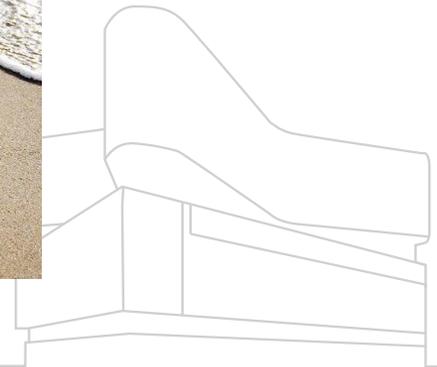
Resources

- Reflection for providers
- To find mental health providers:
 - www.psychologytoday.com – Use the “Find a Therapist” tool
 - Contact the patient’s insurance provider
 - Discuss resources available through the patient’s treating hospital/palliative care program



Questions and Discussion

- My contact information:
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 - Phone: 312-942-8597



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