

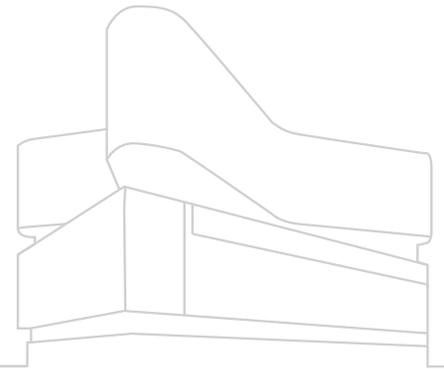
# **None of this is “normal”: Psychological and behavioral challenges faced by adolescents/young adults in palliative care**

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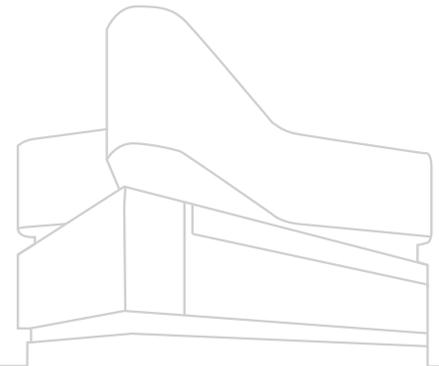
# Disclosures

- 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

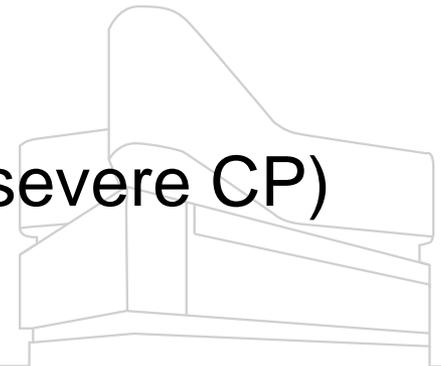
# AYAs in the US

- 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)



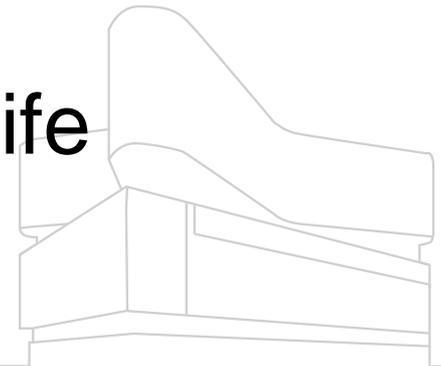
# Life threatening illness and death in AYAs

- 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"><li>1. Accident</li><li>2. Cancer</li><li>3. Suicide</li></ol>
15-34 years of age (both sexes, all races)	<ol style="list-style-type: none"><li>1. Accident</li><li>2. Suicide</li><li>3. Homicide</li></ol>

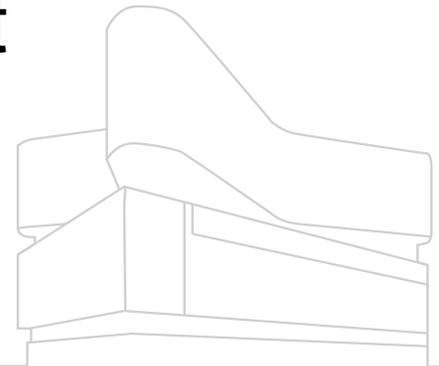
# Life threatening illness and death in AYAs

- 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



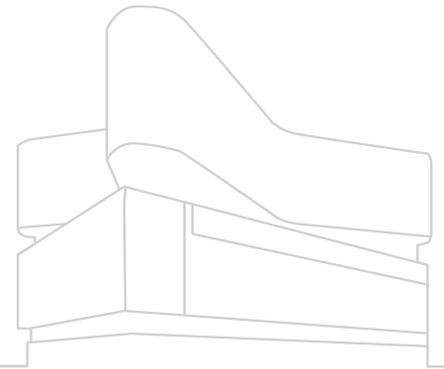
# Adolescence

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



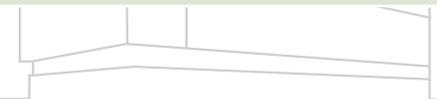
# Realities for AYAs with life-threatening conditions

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



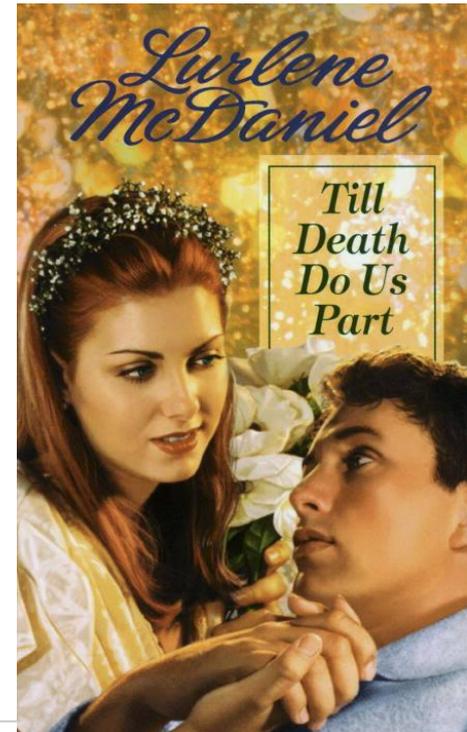
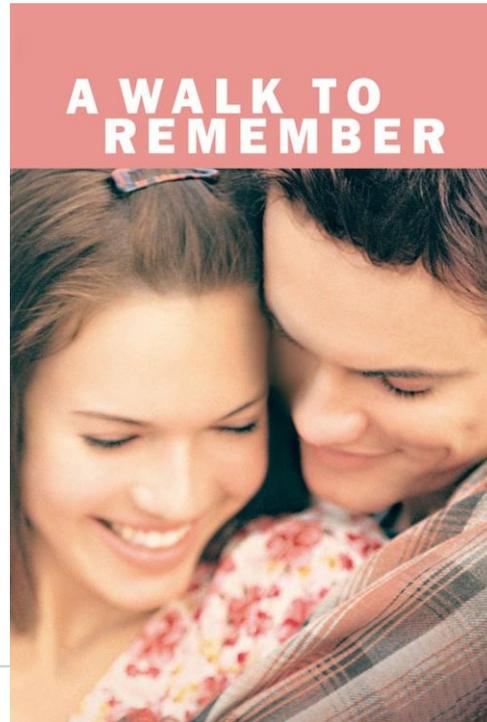
# Realities for AYAs with life-threatening conditions

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



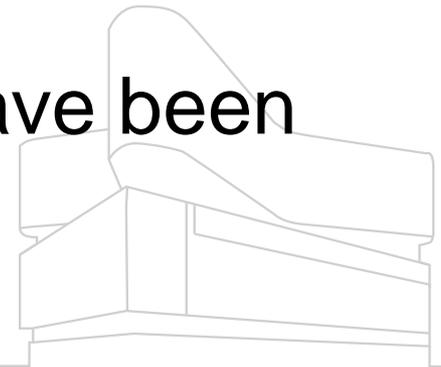
# Cultural implications

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



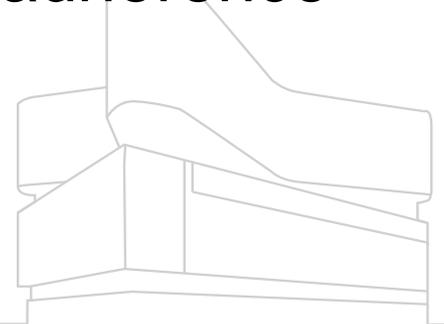
# Psychological/Behavioral challenges faced by AYAs with life-threatening illness

- 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



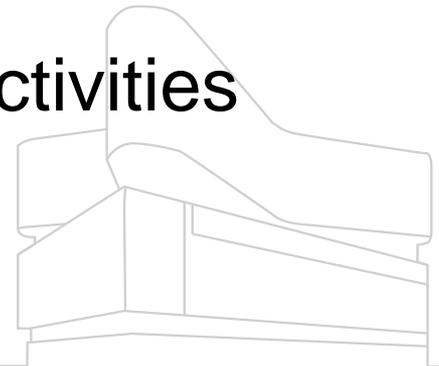
# Case example 1: Non-adherence

- 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



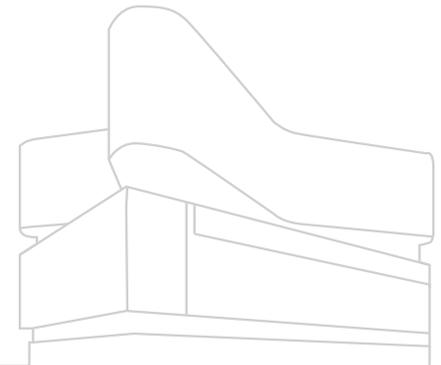
# Case example 1: Non-adherence

- 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



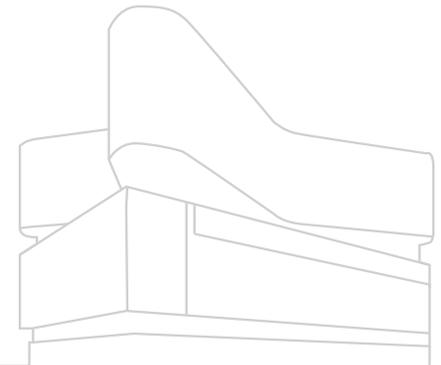
# Non-adherence

- 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)



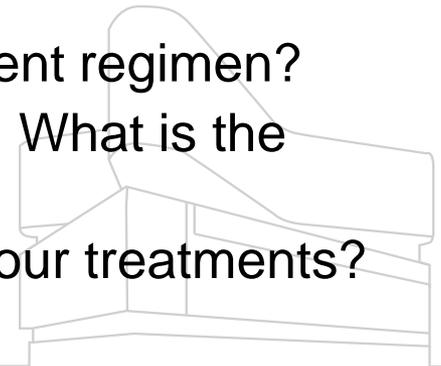
# Non-adherence

- 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



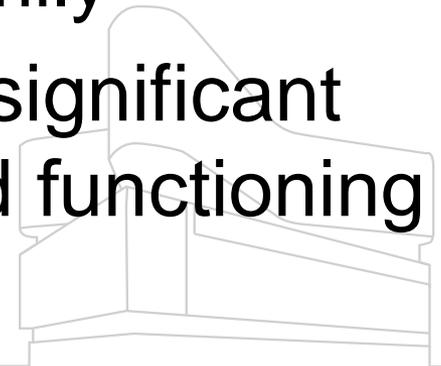
# Non-adherence: Provider tips

- 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?



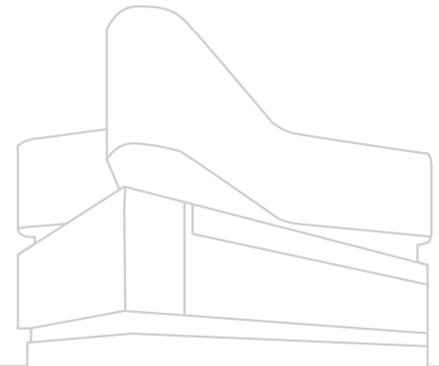
# Non-adherence: When to refer

- 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



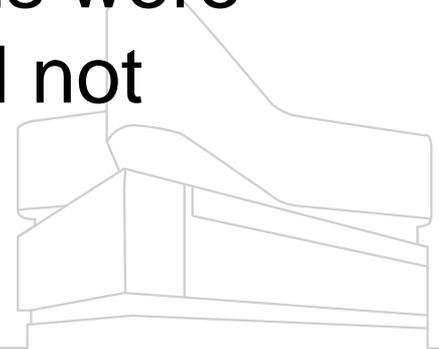
# Case example 2: Social withdrawal

- 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



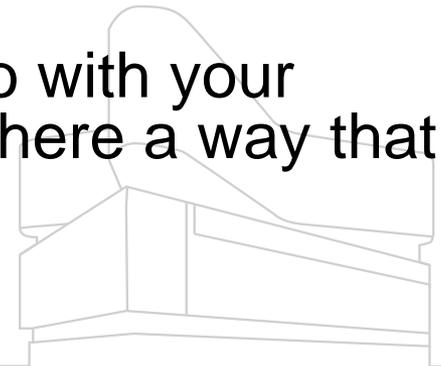
# Social withdrawal

- 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”)



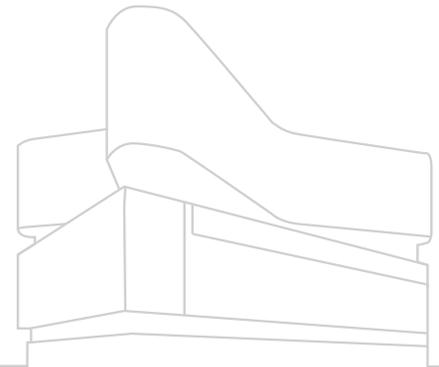
# Social withdrawal: Tips for providers

- 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?



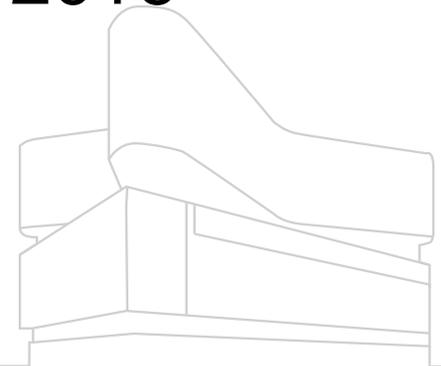
# Social withdrawal: When to refer

- 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



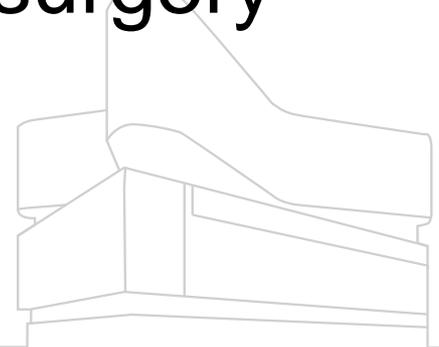
# Case example 3: Risk-taking behavior

- 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



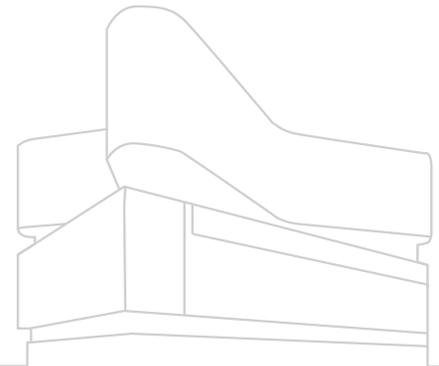
# Case example 3: Risk-taking behavior

- 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



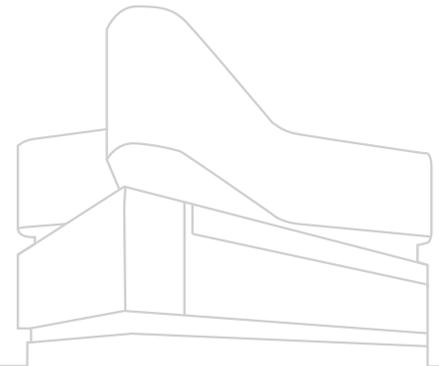
# Risk-taking behavior: Tips for providers

- 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



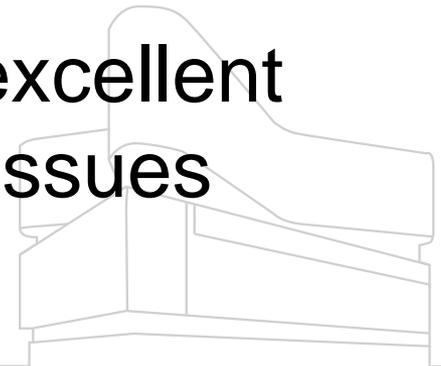
# Take home points

- 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



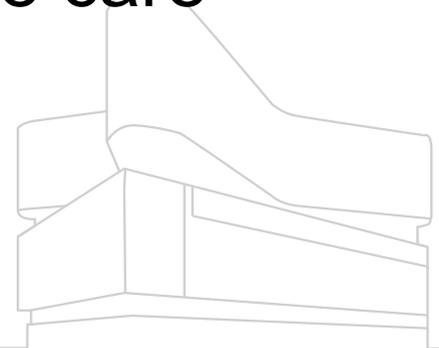
# Take home points

- 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



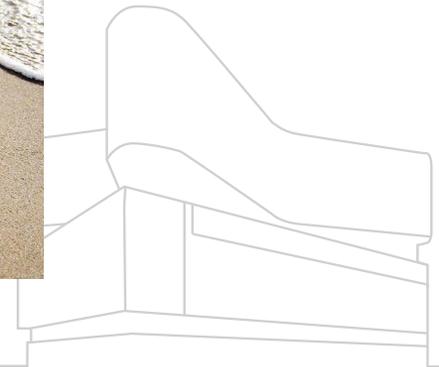
# Resources

- Reflection for providers
- To find mental health providers:
  - [www.psychologytoday.com](http://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

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  - Phone: 312-942-8597



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