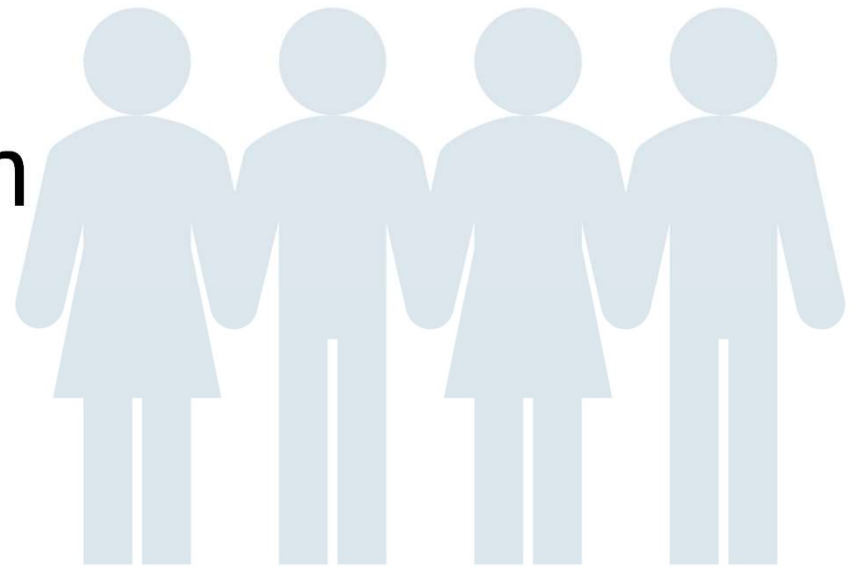




Adolescents and Young Adults with Cancer

Thriving and surviving before and
after treatment



Objectives

- Review the definition and epidemiology of Adolescent and Young Adult Cancer.
- Define the specific issues faced by Adolescents and Young Adults both during and after treatment.
- Review strategies to ease the burden of disease for this population.

Case Presentation

- Steve is a 23 year old male with relapsed metastatic neuroblastoma.
- He first presented at 20 years of age with back pain.
- His initial therapy included traditional chemotherapy and a novel immunotherapy.
- After his first treatment he was in remission for 11 months.



*Disclaimer: Names and likeness have been changed to conform to HIPAA

Case Presentation



- At the time of his original presentation he was enrolled in a local college, studying computer science and living in a dorm.
 - He also had a part time job at a local retailer.
- He is in a long term monogamous relationship with his significant other.

Case Presentation

- Between the time of his original diagnosis and his relapse, he paused his college career due to complications of therapy.
- He was released from his job due to sick days and his part time status.
- He moved back home with his parents.
- His relationship with his significant other remains strong.



Case Presentation

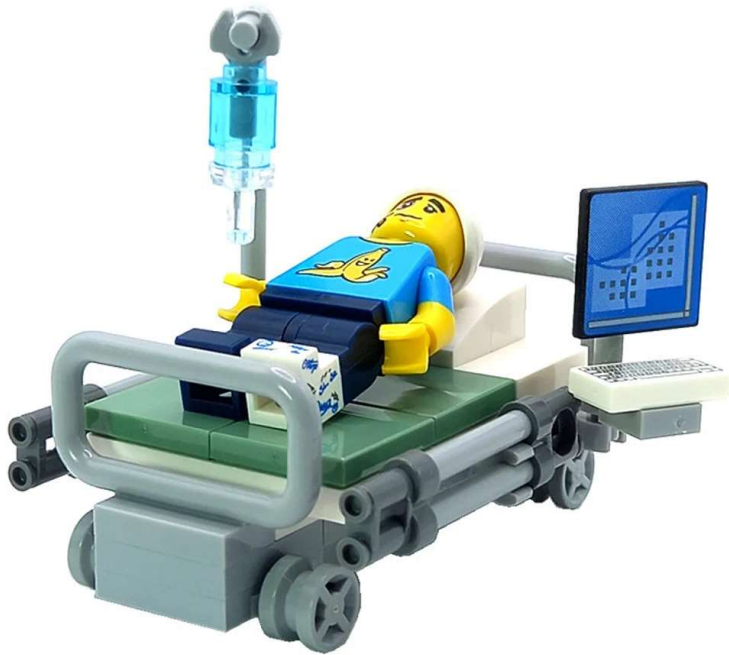
- Steve's relapse was diagnosed while he and Shelly were making plans for their wedding.
- He also had planned a number of trips with friends from college.

Case Presentation

- Tyler is a 15 year old male who originally presented in 2018 with widely metastatic Ewing Sarcoma.
- At the time of his initial diagnosis he was a sophomore in High School and active in sports.
- His future goals included attending college and studying biochemistry.



Case Presentation



- Tyler's initial therapy involved multiple hospitalizations for intense chemotherapy and immunotherapy, with unscheduled hospitalizations for complications.
- Attendance at school was impacted, as were his grades and ability to socialize with friends.

Case Presentation

- Tyler had multiple relapses during his cancer journey, but was able to graduate on time.
- He was unable to attend college.
- He stayed in his parent's home and worked at a local convenience store.

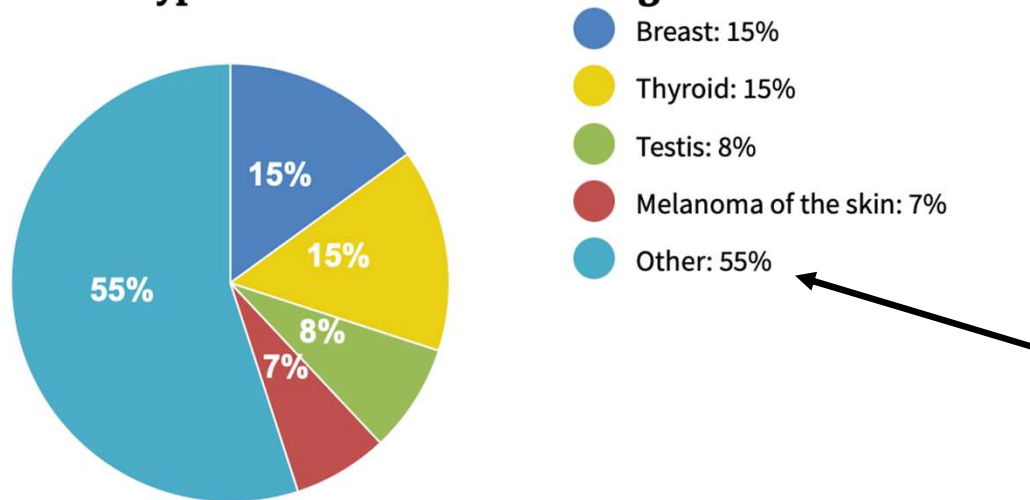


Adolescent and Young Adult (AYA) Group Definition

- Individuals diagnosed with cancer at ages 15 through 39
 - Ages can be different in other countries
 - Europe and Australia: 15 – 24
 - Canadian Cancer Society: 15 – 29
- In 2024 it was estimated that over 84,000 AYA will be diagnosed with cancer
 - This is an increase from 68,000 in 2002
- The overall 5 year survival rate of AYA cancer is 85.9 %

Common types of cancer in AYA age group

Common Types of New Cancers Among AYAs



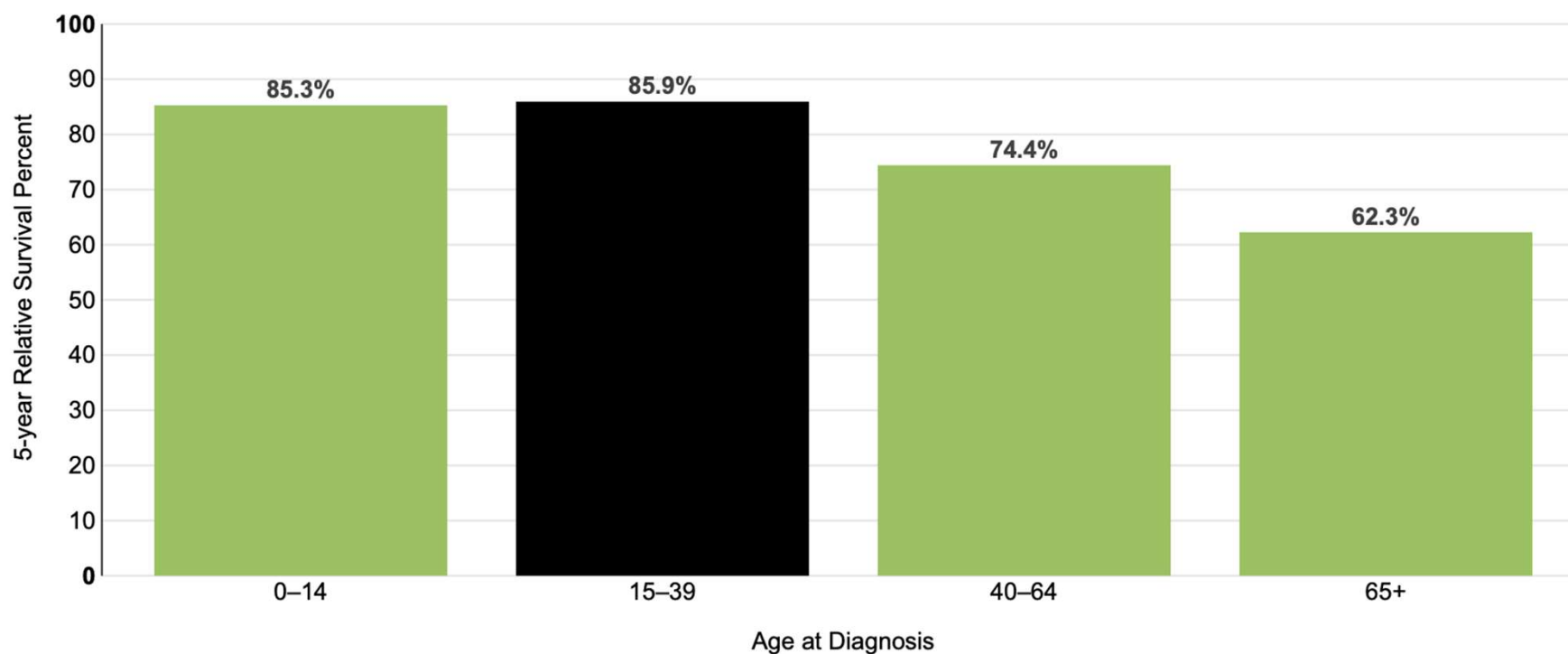
- Leukemia, NHL, Bone Tumors, Brain Tumors
- Patients may do better with pediatric therapy if they can tolerate it.

Distribution based on age-adjusted rates of new cases.
SEER 22, 2017–2021.

Impact of ACA and Medicaid Expansion on AYA care

ACA Provision	Year ^a
Patients can file appeals if an insurer denies coverage for a medical service	2011
No annual or lifetime limits on health insurance coverage limits	2011
Insurance companies cannot deny insurance coverage due to preexisting health conditions	2011
Dependents can stay on their parents' private health insurance through age 26 years	2011
Coverage of preventive care (eg, cancer screenings) meeting US Preventive Services Task Force grades of A or B with no co-pays	2011
Expanded insurance options through state/federal health insurance marketplace and Medicaid expansion in 38 states and Washington, DC	2014
Clinical trials—coverage of routine patient costs	2014

Cancer survival by age group



SEER 22 (Excluding IL/MA) 2014-2020

Medical Barriers to AYA Care

Late Diagnosis

Disease Management Philosophy

Uninsured or Underinsured

Location of Care

Fertility Preservation

Sexual Health

Late Diagnosis

- Necessary events for diagnosis:
 1. Symptom recognition
 2. Presentation to Health Care Professional
 3. Diagnosis
 4. Treatment initiation
- In a study from 2006 – 2015 average interval was 27 days
- Limited Knowledge
- Missed Appointments
- Fear

Disease Management Philosophy

- Hodgkins Lymphoma as an example:

Pediatric

Risk Stratified

Response Adapted

Combined Therapy

Addition of Radiation
for Unfavorable Disease

Adult

Risk Stratified

Response Adapted

Chemotherapy alone

Higher chemo doses

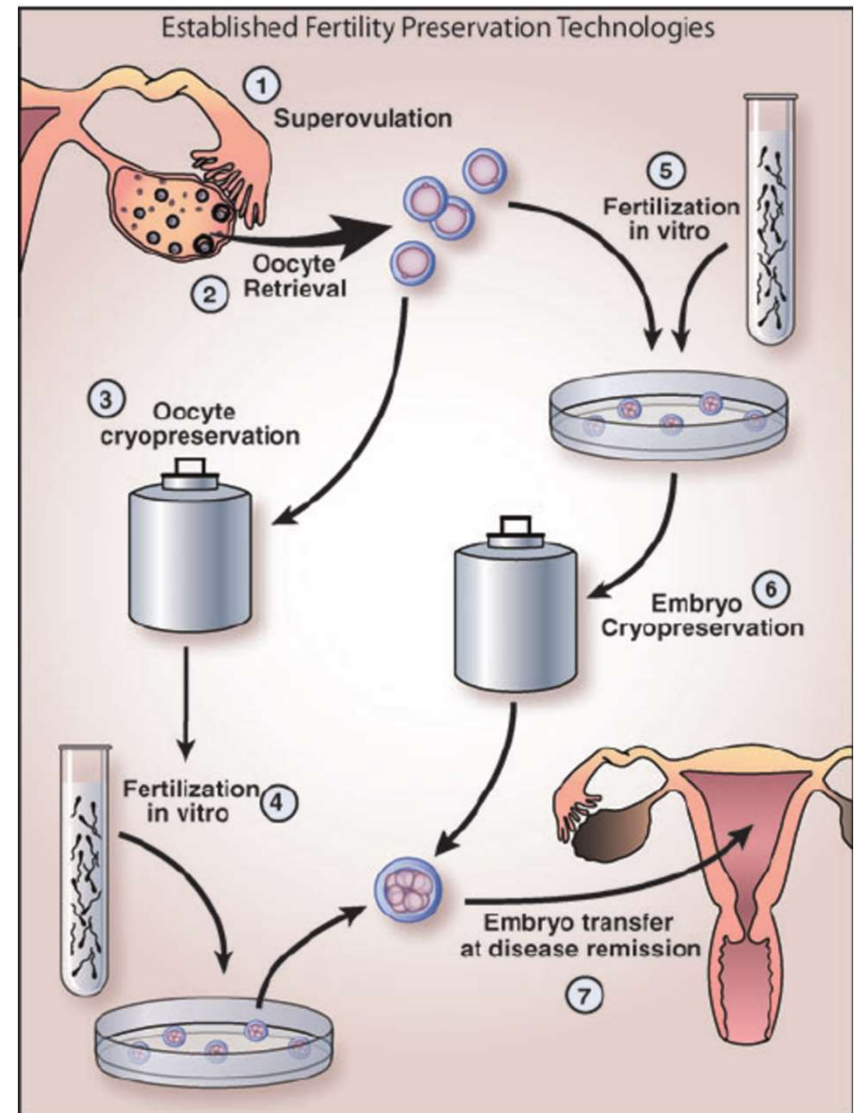
Radiation for refractory or
relapsed disease

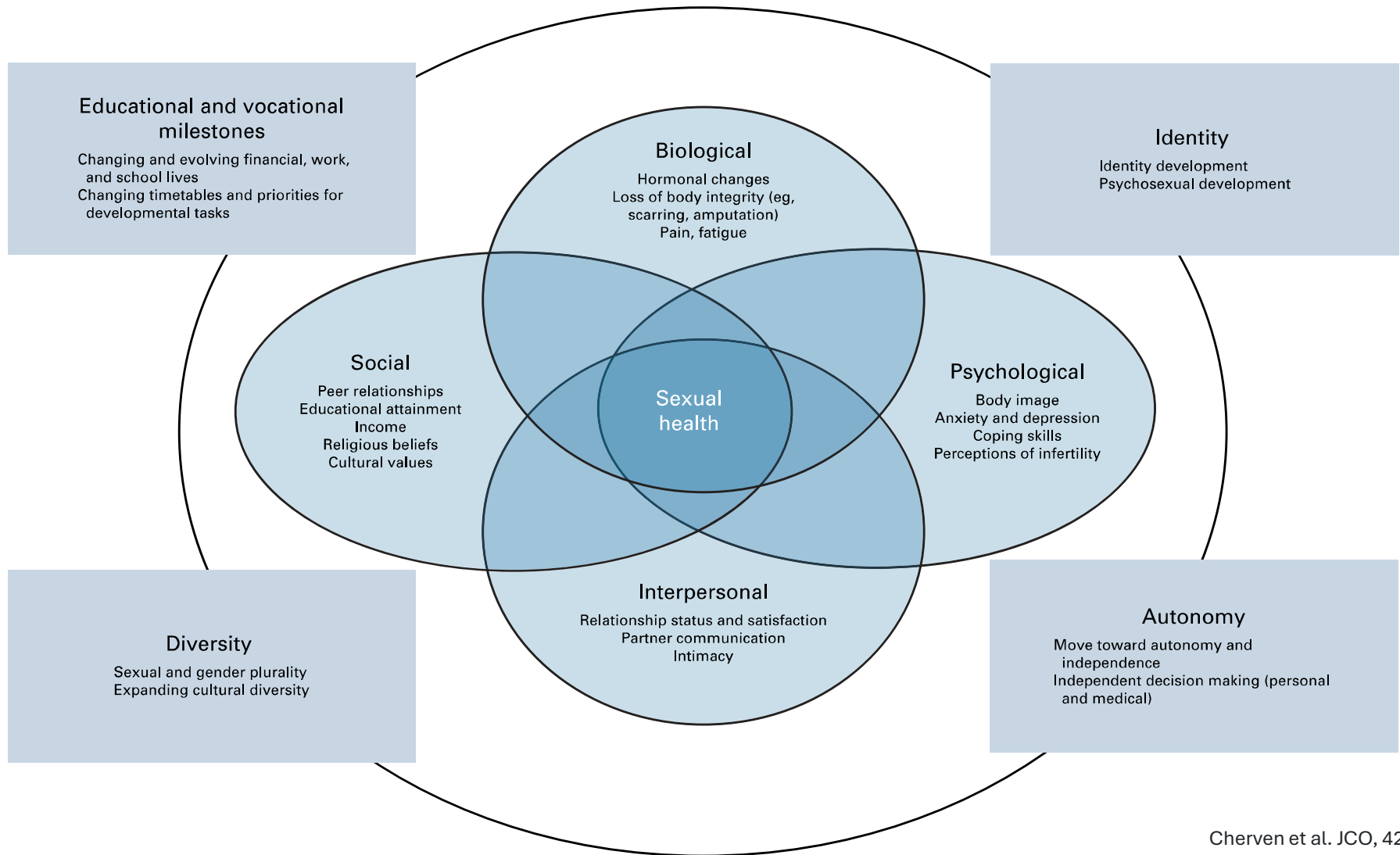
AYA Clinical Trial Participation

- In 2022, 14 % of AYA patients participated in some type of Clinical Trial.
 - Increase from 4.5 % in 2006
 - As a comparison, participation on pediatric trials is approximately 65 %
- Barriers to participation include awareness of trial availability and location of treatment.
 - Only 8 % of AYA patients are treated at academic institutions

Fertility Preservation

- Knowledge gap for providers and patients.
- Concern regarding delay in starting therapy.



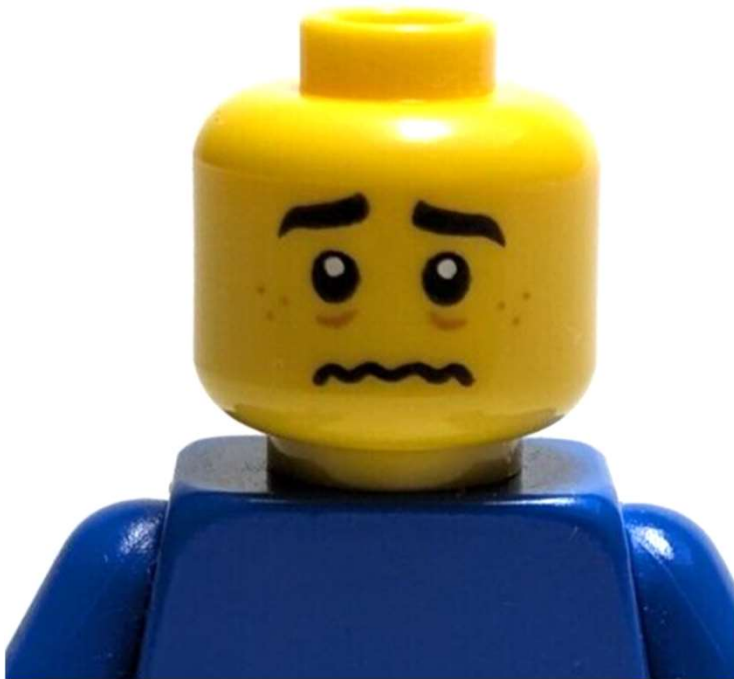


Social Barriers to AYA care

- Comparisons to other age groups
 - In many cases they are not children but not yet independent adults.
- No standard international definition of AYA
 - Decreases ability to conduct international trials.
- Times of transition
 - School, job, family
- Insensitivity from friends and family
- Financial Concerns



How is Steve handling these barriers ?



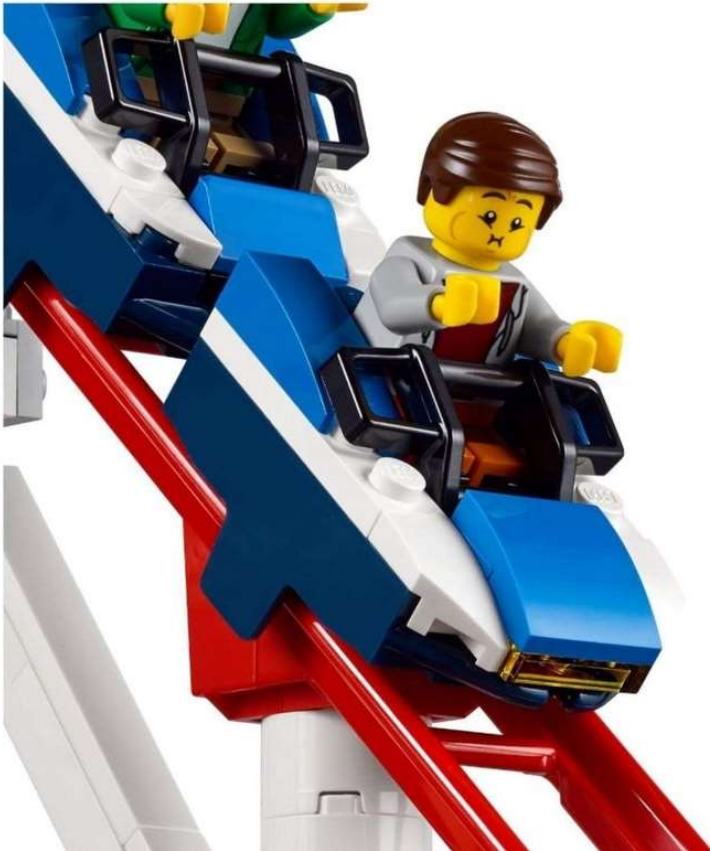
- Steve is living at home now.
- His Mother provides most of his care.
- He is not working.
- Steve is trying to balance hospital admissions and complications of therapy with wedding planning and travel goals.

Barriers to AYA Survivorship Care

- Quality of Life
- Fear of recurrence
- Education and Career Disruptions
- Social Isolation
- Stunted development



How did Tyler handle these barriers ?



- Relapse was a constant concern and experience.
- Tyler had open communication with his family and medical team regarding his goals.
 - Prioritize time with family
 - Stay out of the hospital
- Tyler was able to achieve his goals.

Solutions

- A growing number of academic institutions are developing specific AYA programs.
 - These multidisciplinary teams include members of both pediatric and adult services
- Oncofertility counseling prior to treatment is becoming the standard, and fertility preservation for females is more accessible.
- Survivorship care has taken great strides over the last decade.

Conclusions

- Gains have been made in survival rates and participation on clinical trials for AYA patients.
- The complexity of the interaction of medical and social needs are especially critical for this age group.
- Providers and patients need to maintain open communication to voice goals.
- Medical systems should continue to develop multi-disciplinary clinics that can help these patients navigate the health care system.