



# Transitions: From Cancer Kid to Adulting

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June 10, 2023

# Transitions

- Definition
- Why is it important?
- What can we do to help?
- What are the transitions in our patients?

# Transitions: A definition

- a change from one state or condition to another
  - Merriam-Webster Dictionary

# Why are transitions important?



- *“There is nothing permanent except change.”*
  - **Heraclitus**, Ancient Greek Philosopher (540 BC - 480 BC)
- *“If you always do what you've always done  
You'll always be where you are right now.”*
  - **Unknown**

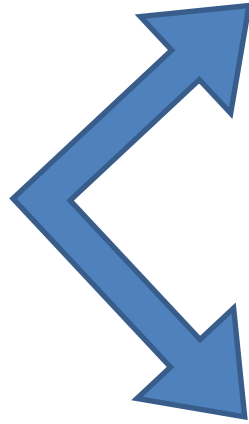
# Why are transitions important?



gg66185406  
images.search.yahoo.com

- In other words,
- No matter what you do or how hard you try, **your kids are going to grow up.**

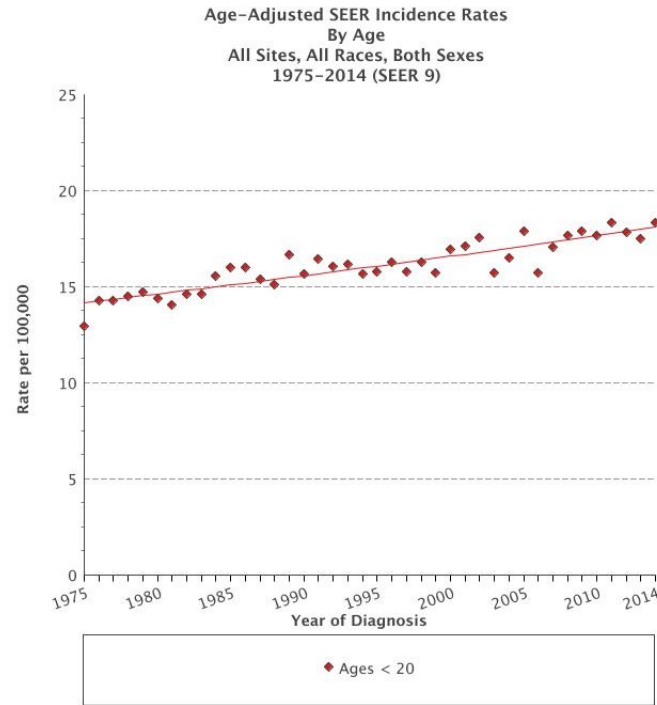
# Transitions





- *“When I grow up I want to be a little boy.”*  
– Joseph Heller

# Pediatric Cancer Background



Cancer sites include invasive cases only unless otherwise noted.

- The incidence of pediatric cancer is approximately 18 cases/100,000
- It is a relatively rare disorder



# Pediatric Cancer Background

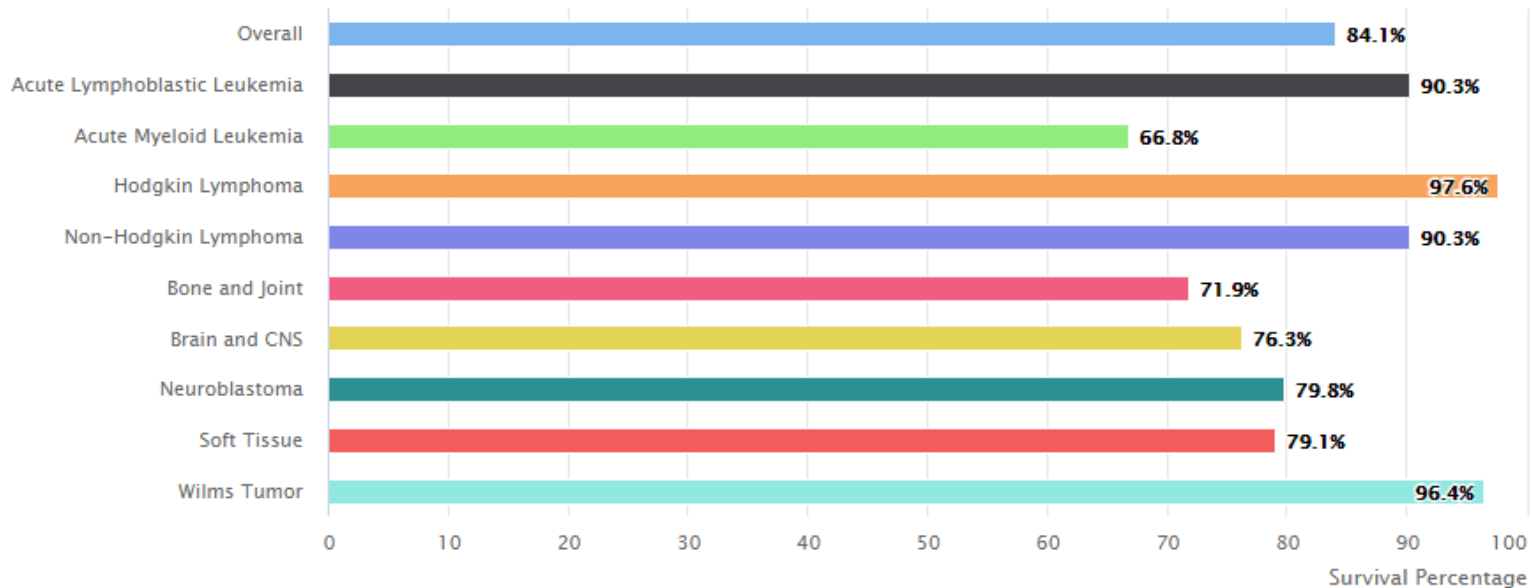
Table 6. Ten Leading Causes of Death by Age and Sex, United States, 2014

	ALL AGES		AGES 1 to 19		AGES 20 to 39	
	MALE All Causes 1,328,241	FEMALE All Causes 1,298,177	MALE All Causes 12,128	FEMALE All Causes 6,538	MALE All Causes 65,486	FEMALE All Causes 30,221
1	Heart diseases 325,077	Heart diseases 289,271	Accidents (unintentional injuries) 4,409	Accidents (unintentional injuries) 2,023	Accidents (unintentional injuries) 24,467	Accidents (unintentional injuries) 8,850
2	Cancer 311,296	Cancer 280,403	Intentional self-harm (suicide) 1,681	Cancer 757	Intentional self-harm (suicide) 10,353	Cancer 4,440
3	Accidents (unintentional injuries) 85,448	Chronic lower respiratory diseases 77,645	Assault (homicide) 1,563	Intentional self-harm (suicide) 581	Assault (homicide) 7,040	Intentional self-harm (suicide) 2,649
4	Chronic lower respiratory diseases 69,456	Cerebro-vascular disease 77,632	Cancer 1,028	Assault (homicide) 477	Heart diseases 5,077	Heart diseases 2,459
5	Cerebro-vascular disease 55,471	Alzheimer disease 65,179	Congenital anomalies 498	Congenital anomalies 428	Cancer 4,020	Assault (homicide) 1,287
6	Diabetes mellitus 41,111	Accidents (unintentional injuries) 50,605	Heart diseases 373	Heart diseases 266	Chronic liver disease & cirrhosis 971	Pregnancy, childbirth & puerperium 748
7	Intentional self-harm (suicide) 33,113	Diabetes mellitus 35,377	Chronic lower respiratory diseases 158	Influenza & pneumonia 126	Diabetes mellitus 970	Chronic liver disease & cirrhosis 628

- Cancer is the 2<sup>nd</sup>-Leading cause of death in children, only behind accidents and injuries

# Pediatric Cancer Background

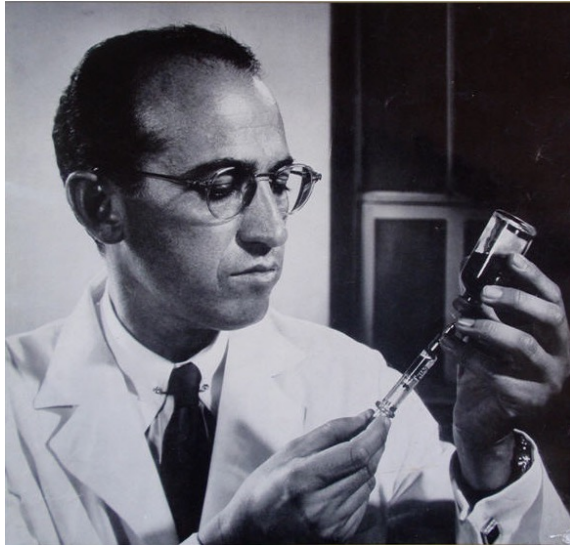
5-Year Survival Rate, Age 0-19



Source: Surveillance, Epidemiology, and End Results (SEER) Program ([seer.cancer.gov](http://seer.cancer.gov))  
SEER 9 areas based on follow up of patients into 2015

- Survival for all pediatric cancers has been steadily improving.
- In 2017, 85% of children diagnosed with cancer are expected to survive

# **THE MEDICAL TRANSITION**



- *"Good parents give their children Roots and Wings. Roots to know where home is, wings to fly away and exercise what's been taught them."*
  - Dr. Jonas Salk, Discoverer of the Polio Vaccine

# 2018 AAP Report on Transitions

Youth with medical complexity represent approximately 1% of all US children.

..programs have been established to provide outpatient and inpatient coordination and management for youth and young adults with medical complexity, recognizing their needs for more individualized planning and collaborative care partnerships between pediatric and adult clinicians or practices.

...Special populations may not represent the majority of youth transitioning to adulthood, but in the aggregate, they include those most vulnerable to poor outcomes and higher health care costs.

**-Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home.** *Pediatrics* (2018) 142 (5): e20182587.

# Survivorship

- Late Effects
  - Surgery: Local effects (Neurologic development, orthopedic function, scarring, cosmetic appearances)
  - Radiation: Local effects (Neurologic development, growth, secondary malignancy, organ and endocrine dysfunction)
  - Chemotherapy: Systemic effects (cardiomyopathy, pulmonary fibrosis, growth, neurologic development, xerostomia, secondary leukemia)

What can we do to help



[www.gottransition.org](http://www.gottransition.org)

## SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE







- *“You have to do your own growing no matter how tall your grandfather was.”*  
– Abraham Lincoln

# Transition Readiness Assessments

- University of Florida's Electronic Pediatric Transition Assessment Tool
- Transition Readiness Assessments are completed in all General Pediatric and certain Pediatric Subspecialty Clinics including Hematology and Oncology
- EMR allows for patient access and communication

# Transition Readiness Assessments

**Patient Core** ↑ ↓

Responsible + Create Note ☑ Show All Choices

### Patient Core Questions

I can explain my health needs to others

No  I want to learn  Yes ▼ □

I know how to ask questions when I do not understand what my doctor says.

No  I want to learn  Yes ▼ □

I know my allergies to medicines.

No  I want to learn  Yes ▼ □

I know my family medical history.

No  I want to learn  Yes ▼ □

I talk to the doctor instead of my parent/caregiver talking for me.

No  I want to learn  Yes ▼ □

I see the doctor on my own during an appointment.

No  I want to learn  Yes ▼ □

I know when and how to get emergency care.

No  I want to learn  Yes ▼ □

I know where to get medical care when the doctor's office is closed.

No  I want to learn  Yes ▼ □

I carry important health information with me every day (e.g. insurance card, emergency contact information).

No  I want to learn  Yes ▼ □

I know that when I turn 18, I have full privacy in my health care.

No  I want to learn  Yes ▼ □

I know at least one other person who will support me with my health needs.

No  I want to learn  Yes ▼ □

I know how to make and cancel my own doctor's appointments.

No  I want to learn  Yes ▼ □

I have a way to get to my doctor's office.

No  I want to learn  Yes ▼ □

I know how to get a summary of my medical information (e.g. online portal).

No  I want to learn  Yes ▼ □

I know how to fill out medical forms.

No  I want to learn  Yes ▼ □

I know how to get a referral if I need it.

No  I want to learn  Yes ▼ □

I know what health insurance I have.

No  I want to learn  Yes ▼ □

I know what I need to do to keep my health insurance.

No  I want to learn  Yes ▼ □

I talk with my parent/caregiver about the health care transition process.

No  I want to learn  Yes ▼ □

I know my own medicines.

No  I want to learn  Yes ▼ □

I know when I need to take my medicines without someone telling me.

No  I want to learn  Yes ▼ □

I know how to refill my medicine if and when I need to.

No  I want to learn  Yes ▼ □

Patient Core - Action ▼ □

# Transition Readiness Assessments

**Specialties** ↑ ↓

👤 Responsible 📝 Create Note  Show Last Filed Value  Show All Choices 🔗

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**Pediatric Specialties** ⤴

**Pediatric Specialties**

Primary Care  Adolescent Medicine  Allergy/Immunology  Cardiology  Craniofacial 🔍 ⌵ 🗑

CT Surgery  Developmental/Behavior  Diabetes  Endocrine  Gastroenterology

Infectious Disease  Hematology/Oncology  Nephrology  Neurology  Neuromuscular

Neurosurgery  Ophthalmology  Otolaryngology  Orthopedics  Surgery  Psychiatry

Pulmonary  Rheumatology  Sleep  Urology  Other

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**HemOnc sub-specialty:**

Hematology  Oncology  Sickle Cell ⌵ 🗑

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How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

0 (not)  1  2  3  4  5  6  7  8  9  10 (very) ⌵ 🗑

---

The transfer to adult health care usually takes place between the ages of 18 and 22. How important is it to you to move to a doctor who cares for adults before age 22?

0 (not)  1  2  3  4  5  6  7  8  9  10 (very) ⌵ 🗑

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What is most important to you when you transition to an adult doctor?

⌵ 🗑

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**Specialty Summary - Action**

⌵ 🗑

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Has the patient received and reviewed the UF Health Transition Policy?

Yes  No  Not sure ⌵ 🗑

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Has the parent/caretaker received and reviewed the UF Health Transition Policy?

Yes  No  Not sure ⌵ 🗑

# Transition Education

- Education and Documentation Tool

Transition Education provided:

Topic	Date	Educator Initials
Age 12-14		
<input type="checkbox"/> Transition Policy Provided		
<input checked="" type="checkbox"/> Diagnosis	1/3/23	DMR
<input type="checkbox"/> Medications and their purpose		
<input type="checkbox"/> Keeping track of your medications		
<input checked="" type="checkbox"/> Disease Treatment Plan	1/3/23	DMR
Age 15-16		
<input type="checkbox"/> Clinic visit preparation		
<input type="checkbox"/> Communicating with your care provider		
<input checked="" type="checkbox"/> Following up with tests and labs	1/3/23	DMR
<input type="checkbox"/> Contacting your care provider		
<input type="checkbox"/> Keeping track of your appointments		
Age 17-Adults		
<input type="checkbox"/> Managing your money and budgeting		
<input type="checkbox"/> Eating right and managing meals		
<input type="checkbox"/> Refilling Medications		
<input type="checkbox"/> Insurance		

## SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE



# Planning the Transfer

- Set a time of the transfer
- Identify barriers
- **Identify an Adult Physician**
- Outline the process
- Complete Medical Summary
- What happens after the transfer?

# Planning the Transfer - Barriers

- Developmental Disability
- Financial Dependency
- Continuing Education – College or Trade School
- Relocation
- Intimate Relationships
- Transportation
- Successful Adult Role Models



# Planning the Transfer - Adult Physician

- Relates to overcoming the barriers
  - Relocation
  - Insurance
- Dedicated Survivorship Clinic
- Another Adult Oncologist
- An Adult Oncologist “practicing” Pediatrics
- Academic Center or Private Practice
- Primary Care Physician
- Offer to contact the new physician

# Why are transitions important?



- *“Parents can only give good advice or put them on the right paths, but the final forming of a person's character lies in their own hands.”*
  - Anne Frank
- If change is inevitable, it is important that we give our patients the right tools to take care of themselves and lead successful lives

# Cancer Treatment Summary

- Basic Demographics
- Diagnosis information
- Treatments Used
  - Chemotherapy
  - Surgery,
  - Radiation
- Complications experienced

**CHILDREN'S  
ONCOLOGY  
GROUP**

The world's childhood  
cancer experts

# Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent,  
and Young Adult Cancers



**Version 5.0 - October 2018**



Website: [www-survivorshipguidelines.org](http://www-survivorshipguidelines.org)

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# Survivorship Care Plan

- Known or expected effects resulting from the treatments
- Degree of risks to health of these effects
- A monitoring and treatment plan for health maintenance

# Passport for Care



**7 years old Male**

DOB: [REDACTED]  
Record Number: [REDACTED]  
Email: [REDACTED]

**Demographic Information** Edit Demographics Delete Patient Survivor Account

Name: [REDACTED]  
Medical Record Number: [REDACTED]  
Sex: Male  
Email Address: [REDACTED]

Date of Birth: [REDACTED]  
Race/Ethnicity: White  
Address: Unknown US

**Primary Diagnosis** Edit Primary Diagnosis

**Diagnosis:** Leukemia: Acute lymphoblastic leukemia  
**Date of Diagnosis:** October 03, 2018  
**Date Therapy Completed:** December 26, 2020

**Age at Diagnosis:** 3 years, 3 months  
**Primary Site:** Bone Marrow

**Relapses** Add Relapse

No relapses entered.

**SMNs** Add SMNs

No SMNS entered.

**Treatment Center** Add Treatment Center

**Primary Diagnosis:** Leukemia: Acute lymphoblastic leukemia

University of Florida Delete

Discoill Children's Hospital Delete

**Protocol** Add Protocol

**Primary Diagnosis:** Leukemia: Acute lymphoblastic leukemia

Standard Risk ALL - AALL0932 Delete

- Manage Patient Record
- Cumulative Summary
- Abbreviated Summary
- Additional Information
- Follow-Up Guidelines
- Evaluations
- PLE Patient Output
- PLE Patient Output (Spanish)
- Survivorship Care Plan
- Health Links
- Printable Guidelines for This Patient
- All Printable Guidelines
- Cancer Screening Guidelines
- Evidence-Based Scoring
- Survivor Account
- Revision History

# Cancer Treatment Summary

Abbreviated

## Chemotherapy

[Add Chemotherapy](#)

**Primary Diagnosis: Leukemia: Acute lymphoblastic leukemia**

Methotrexate PO		<a href="#">Delete</a>
Thioguanine (6TG)		<a href="#">Delete</a>
Cyclophosphamide	1000 mg/m2	<a href="#">Delete</a>
Doxorubicin	75 mg/m2	<a href="#">Delete</a>
Methotrexate (low dose IV)		<a href="#">Delete</a>
Mercaptopurine (6MP)		<a href="#">Delete</a>
Methotrexate IT		<a href="#">Delete</a>
Cytarabine IT		<a href="#">Delete</a>
Asparaginase		<a href="#">Delete</a>
Dexamethasone		<a href="#">Delete</a>
Vincristine		<a href="#">Delete</a>

## Surgery

[Add Surgery](#)

No surgeries entered.

## Radiation

[Add Radiation](#)

No radiations entered.

## Hematopoietic Cell Transplant

[Add Hematopoietic Cell Transplant](#)

No hematopoietic cell transplants entered.

## Other Therapeutic Modality

[Add Other Therapeutic Modality](#)

No other therapeutic modalities entered.

## Complications/Late Effects

[Add Complication/Late Effect](#)

No complication/late effects entered.

## Adverse Drug Reaction

[Add Adverse Drug Reaction](#)

# Survivorship Care Plan

## Recommended Testing

All sections include History and Physical screenings

System	Late Effect	Exposure	Screening	Frequency																				
Cardiovascular	Cardiac toxicity	<b>Chemotherapy</b> <b>Anthracycline antibiotic</b> Doxorubicin  To gauge the frequency of screening, use the following formulas to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracycline dose. <b>Doxorubicin:</b> Multiply total dose x 1 <b>Daunorubicin:</b> Multiply total dose x 0.5 <b>Epirubicin:</b> Multiply total dose x 0.67 <b>Idarubicin:</b> Multiply total dose x 5 <b>Mitoxantrone:</b> Multiply total dose x 4	<b>Screening</b> ECHO (or comparable imaging to evaluate cardiac function) EKG (include evaluation of QTc interval)	Baseline at entry into long-term follow-up, repeat as clinically indicated																				
	<table border="1"> <thead> <tr> <th colspan="3">Recommended Frequency of Echocardiogram</th> </tr> <tr> <th>Anthracycline Dose*</th> <th>Radiation Dose**</th> <th>Recommended Frequency</th> </tr> </thead> <tbody> <tr> <td rowspan="3">None</td> <td>&lt; 15 Gy or none</td> <td>No screening</td> </tr> <tr> <td>≥ 15 - &lt; 35 Gy</td> <td>Every 5 years</td> </tr> <tr> <td>≥ 35 Gy</td> <td>Every 2 years</td> </tr> <tr> <td rowspan="2">&lt; 250 mg/m<sup>2</sup></td> <td>&lt; 15 Gy or none</td> <td>Every 5 years</td> </tr> <tr> <td>≥ 15 Gy</td> <td>Every 2 years</td> </tr> <tr> <td>≥ 250 mg/m<sup>2</sup></td> <td>Any or none</td> <td>Every 2 years</td> </tr> </tbody> </table> <p>*Based on doxorubicin isotoxic equivalent dose. See dose conversion instructions in section 33.                      **Based on radiation dose with potential impact to heart (radiation to chest, abdomen, spine [theracic, whole], TBI). See section 76.</p> <p>Based on our calculations you should receive a periodic screening every 5 years.</p>		Recommended Frequency of Echocardiogram			Anthracycline Dose*	Radiation Dose**	Recommended Frequency	None	< 15 Gy or none	No screening	≥ 15 - < 35 Gy	Every 5 years	≥ 35 Gy	Every 2 years	< 250 mg/m <sup>2</sup>	< 15 Gy or none	Every 5 years	≥ 15 Gy	Every 2 years	≥ 250 mg/m <sup>2</sup>	Any or none	Every 2 years	
Recommended Frequency of Echocardiogram																								
Anthracycline Dose*	Radiation Dose**	Recommended Frequency																						
None	< 15 Gy or none	No screening																						
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	≥ 35 Gy	Every 2 years																						
< 250 mg/m <sup>2</sup>	< 15 Gy or none	Every 5 years																						
	≥ 15 Gy	Every 2 years																						
≥ 250 mg/m <sup>2</sup>	Any or none	Every 2 years																						
CNS	Clinical leukoencephalopathy	<b>Chemotherapy</b> <b>Antimetabolite</b> Methotrexate IT																						
	Neurocognitive deficits	<b>Chemotherapy</b> <b>Antimetabolite</b> Methotrexate IT	<b>Screening</b> Referral for formal neuropsychological evaluation	Baseline at entry into long-term follow-up, then periodically as clinically indicated for patients with evidence of impaired educational or vocational progress																				
Dental	Dental abnormalities	<b>Chemotherapy</b> Any Chemotherapy	<b>Screening</b> Dental exam and cleaning	Every 6 months																				
GI/Hepatic	Hepatic dysfunction; Sinusoidal obstruction syndrome (SOS) [previously known as veno-occlusive disease (VOD)]	<b>Chemotherapy</b> <b>Antimetabolite</b> Mercaptopurine (6MP) Thioguanine (6TG)	<b>Screening</b> ALT AST Bilirubin	Baseline at entry into long-term follow-up, repeat as clinically indicated.																				



# Why use Passport for Care

- Quick and Easy to Use
- Linked to the Children's Oncology Group's Long-Term Survivorship Guidelines
  - Recommendations are up to date
- Accessible electronically from any computer

## SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE



# The Transfer

- Stick to the Plan
- Support the new team
  - Provide them with information
  - +/- Peds team at first clinic visit
  - Emphasize the adult team's leadership
- Support the patient and the family
  - Reassurance

## SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE



# Transition Completion

- Be available for questions
- Opportunity to get feedback on the process
- Quality Measures of the Transition Process
  - # visits/year to adult hematologist
  - # visits/year to Emergency Room
  - # prescription refills for hydroxyurea
- It is not closing the door
  - It is a child leaving his family to go to college
  - The pediatric team is still there to support them
  - Still like to know how patients are doing and where they are in life

Not just the medical transition

# **THE LIFE TRANSITIONS**

# What does adulting mean?

- Where in the world am I
- Your on your own
- College and Trade school
- Independence
- It's my decision
- My significant other
- Do I make enough money
- What is my health insurance plan





- *“Too many people grow up. That's the real trouble with the world-- too many people grow up. They forget. They don't remember what it's like to be 12 years old.”*  
– Walt Disney



# Introduction of the Panel

- In their own words....