



UNIFORMED SERVICES UNIVERSITY  
*of the Health Sciences*



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# Pediatric Oncology Long Term Effects Clinic Transition Initiative

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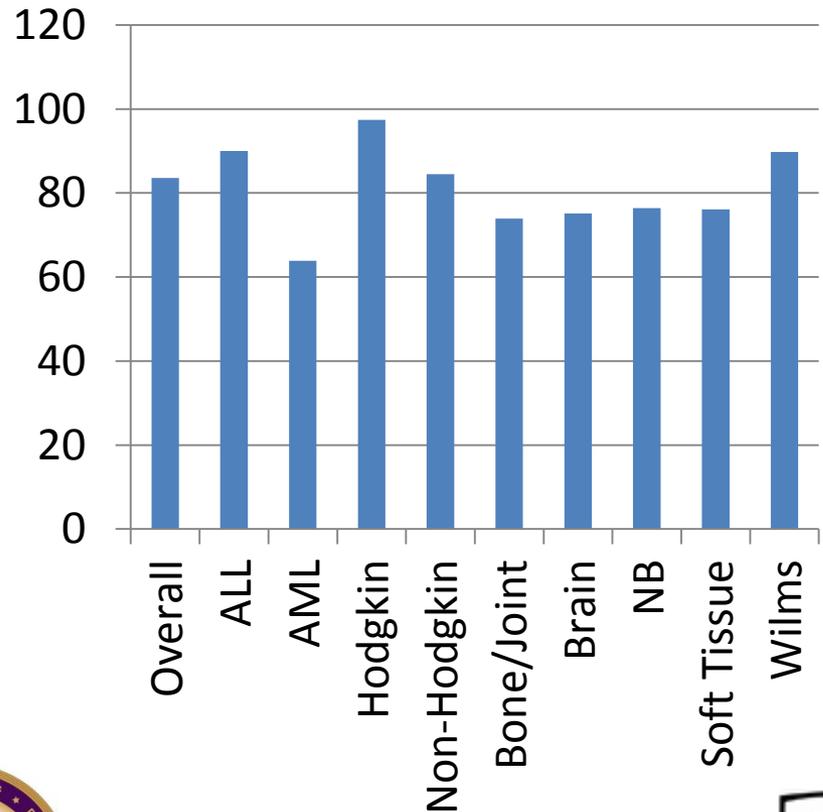
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# Background - Survivorship

- 84% of children who are diagnosed with cancer survive
- 60% of children who survive have significant long term health effects
- 375,000 adult survivors of childhood cancer in the US

5-Year Survival Rate



Today one in every **680** U.S. adults is a **childhood cancer survivor**

# Background – Late Effects

- Avascular Necrosis
- Bone Health
- Cardiovascular Illness
- Chronic Pain
- Educational Issues
- Emotional Health
- Hormones & Reproduction
- Neuropathy & Neuromuscular Disorders
- Pulmonary Disease
- Renal Disease
- Secondary Cancers
- Sensory (Vision/Hearing) Problems



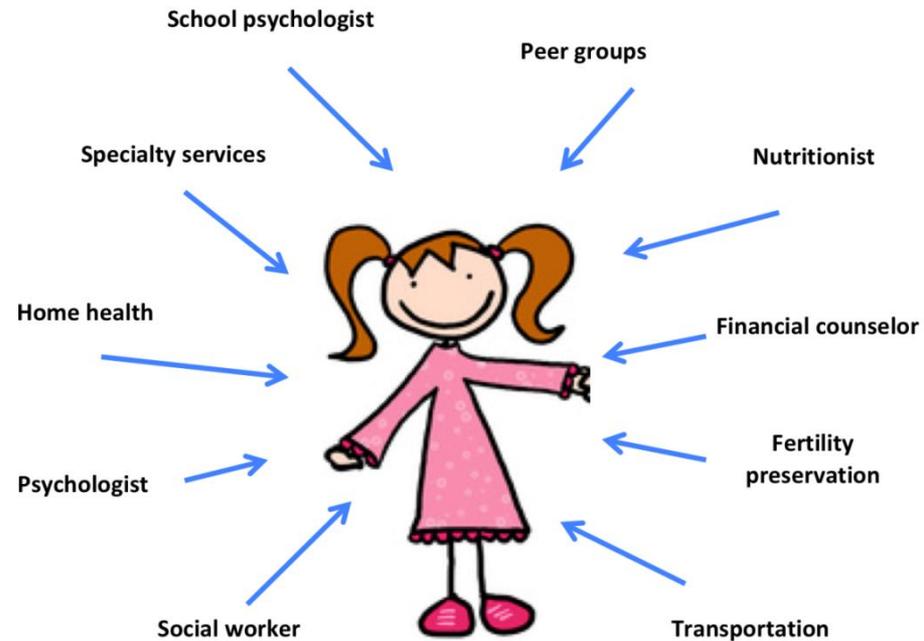
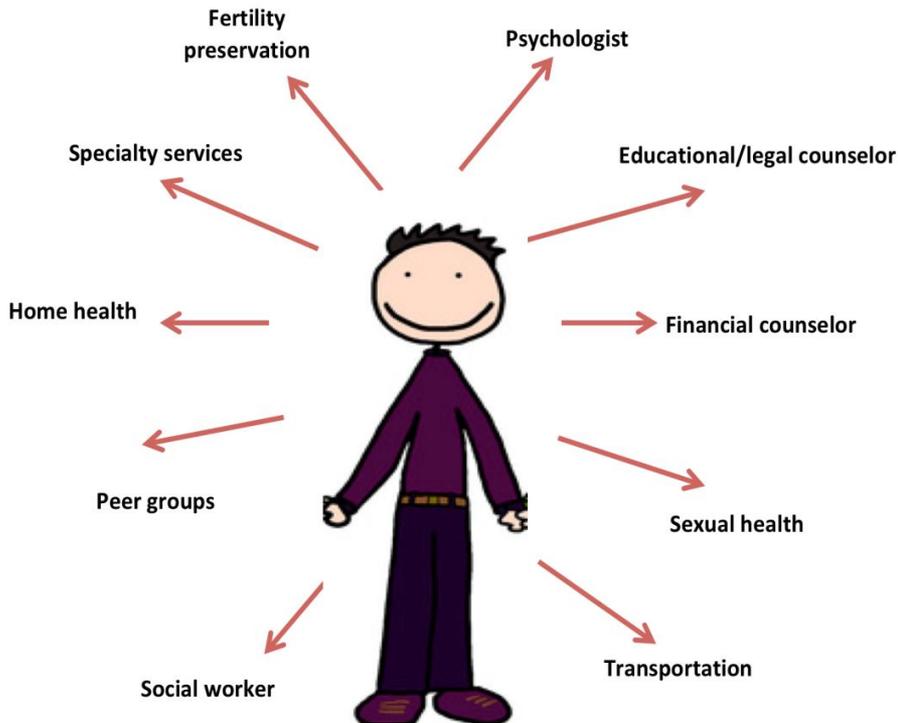
# Healthcare Transition

- Youth & families are not adequately prepared for adult-focused health care
- Few currently receive transition assistance from health care providers
- Youth who have undergone treatment for cancer are disproportionately represented
- Patients face the potential for life-long side effects



# Adult vs Pediatric Practice Model

courtesy of AYA Oncology Program at USC, S. Siegel



# Six Core Elements of Health Care Transition (HCT)

Center for Health Care Transition Improvement

## **Pediatric Health Care Setting**

- Transition Policy
- Transitioning Youth Registry
- Transition Preparation
- Transition Planning
- Transition and Transfer of Care
- Transition Completion

## **Adult Health Care Setting**

- Young Adult Privacy and Consent Policy
- Young Adult Patient Registry
- Transition Preparation
- Transition Planning
- Transition and Transfer of Care
- Transition Completion



# Challenges for Transition of Care for DoD dependents

- Transition time will not be at a specific time or age but based on individual circumstances
- Transition is unlikely to be to an adult provider in the MTF
- Transition will be to a variety of civilian providers often geographically distance from WRNMMC



# Center for Health Care Transition Improvement

- Have designed a tool kit and processes to implement care transition practice into pediatric practice
- Tool kit has not been used in a military health care setting
- Tool kit was not designed with the special health care needs for survivors of pediatric cancer





## Health Care Transition Transfer of Care Checklist (Pediatric)

<Patient Name> <Date of Birth>	Date
<input type="checkbox"/> Transfer of care policy discussed with youth and family	
<input type="checkbox"/> Transfer of care options discussed with youth and family	
o Timing of transfer of primary care discussed with youth and family	
o Option of using the family's existing adult primary care provider(s)	
o Review of the practice's list of available adult primary care providers	
o Options and timing for transfer of specialty care discussed	
<input type="checkbox"/> Pediatric primary care practice confirms transfer with adult primary care practice	
o For youth with special health care needs, personal communication between pediatric and adult primary care providers	
o Date of transfer of care determined with mutual agreement	
<input type="checkbox"/> Final youth readiness assessment completed	
<input type="checkbox"/> Transfer of care package prepared or updated	
o For all youth, include the following:	
▪ Cover or referral letter	
▪ Current portable medical summary	
▪ Most recent readiness assessment with action plan status	
▪ Final transition plan including	
• Name and contact information for pediatric primary care provider	
• Name and contact information for new adult primary care provider	
• Effective date for transfer	
o For youth with special health care needs, include the following:	
▪ Cover or referral letter	
▪ Current portable medical summary	
▪ Condition-specific "fact sheet"	
▪ Current HCT action plan of pending and upcoming activities needing attention	
▪ Emergency care plan – what's an emergency, what to do	

<ul style="list-style-type: none"> <li>▪ Most recent readiness assessment</li> <li>▪ Relevant information, if appropriate, regarding guardianship, custodial arrangements, and powers of attorney</li> <li>▪ Final transition plan including <ul style="list-style-type: none"> <li>• Name and contact information for pediatric primary care provider</li> <li>• Name and contact information for new adult primary care provider</li> <li>• Effective date for transfer</li> <li>• Preferred means of interim communication and consultation between pediatric primary care team and adult primary care team identified and documented</li> </ul> </li> </ul>	
<input type="checkbox"/> Transfer of care package communicated to adult primary care provider via best available means (mail, fax, email, electronic health information transfer)	
<input type="checkbox"/> Initial visit with new adult primary care provider scheduled	
<input type="checkbox"/> Follow-up communication with emerging adult (and family as appropriate) by pediatric primary care team regarding completion of transfer of care and level of satisfaction with result	
<input type="checkbox"/> Follow-up communication with new adult primary care team by pediatric primary care team regarding completion of transfer of care and level of satisfaction with results; identify any future plans/needs for on-going communication or consultation	



# Pediatric Oncology Long Term Effects Clinic Transition Initiative

- Adapt the current transition tool kit to meet the anticipated needs for transition for survivors of pediatric cancer
- Focus on patient education & transition summaries as receiving provider will be variable
- In addition implement the Passport for Care: on line tool to track the special health care needs of pediatric cancer survivors



# Pediatric Oncology Long Term Effects Clinic Transition Initiative

- Patients 14-18 with history of cancer or current under therapy will be recruited
- Informed consent from parents and assent from participating adolescents will be obtained
- Transition assessment surveys will be done periodically throughout the study period
- A post-transition survey will be completed by the receiving adult provider 3 to 6 months after transition



# Pediatric Oncology Long Term Effects Clinic Transition Initiative

## Study Time Line

<b>Assessment</b>			
Study Day / Period	At Study Entry	At Follow- up Clinic Visits	3-6 months after Transfer of Care to Adult Care Provider
Screening	X		
Informed Consent, discuss Plan, etc.	X		
Transition Education	X	X	
Passport for Care Enrollment	X		
Passport for Care Updates		X	
Transition Assessment Survey	X	X	
Post-Transition Assessment Survey			X



# Pediatric Oncology Long Term Effects Clinic Transition Initiative

- Study goal – prove that using the adapted transition tools and passport to care are the best practice for transition for pediatric cancer survivors
- Study goal II – improve the health and functional status of adolescents and young adults during the transition process to adult care



# Pediatric Oncology Long Term Effects Clinic Transition Initiative

- Future plans:
- Adapt tools to meet the needs of other pediatric populations with special health care needs
- Sickle Cell Disease, Hemophilia, Chronic Anemias



# Pediatric Oncology Long Term Effects Clinic Transition Initiative

Questions?

