

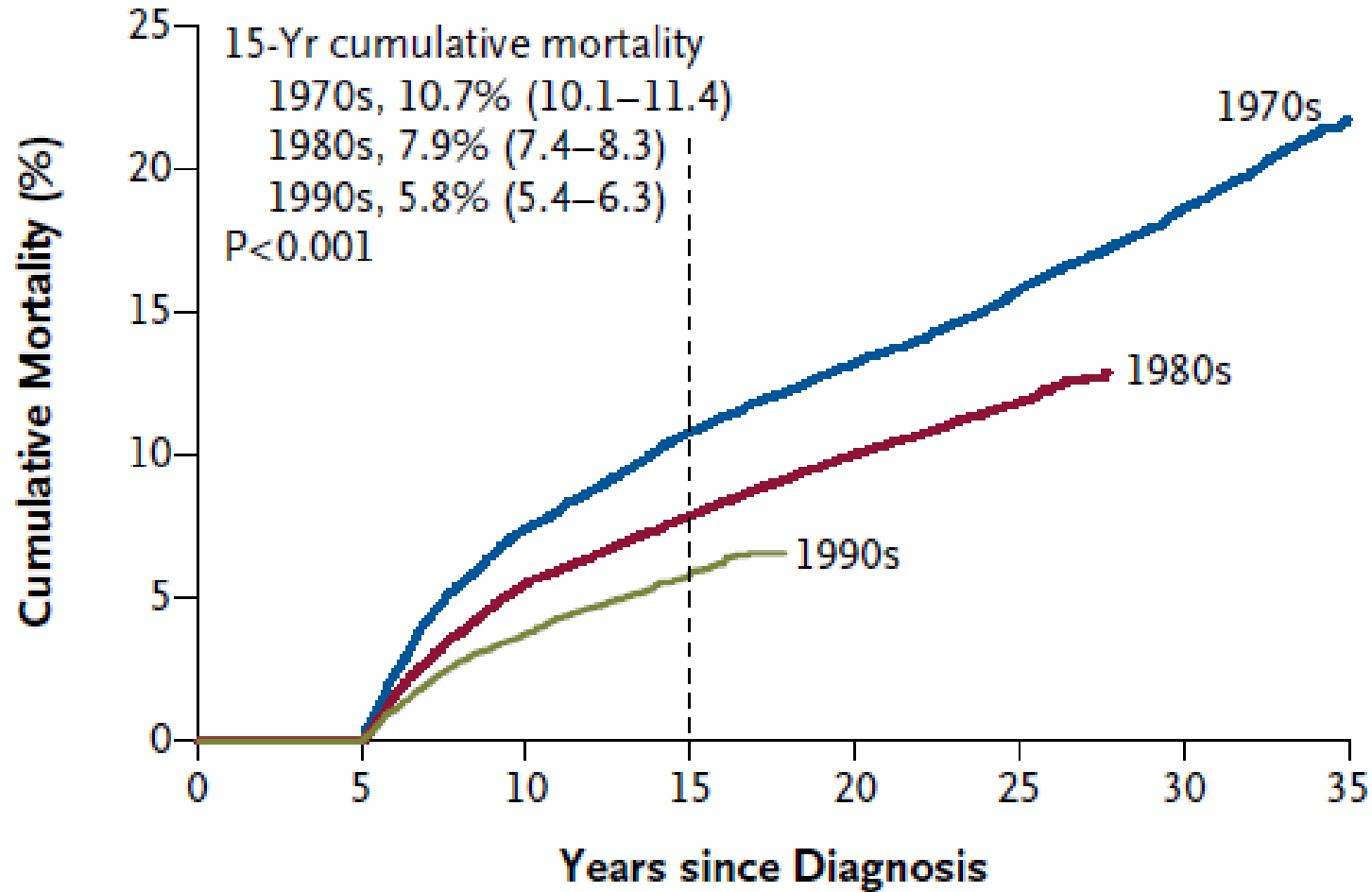
# *Moving Beyond Cancer To Wellness 2019*

**Eric Chow, MD, MPH**  
**Seattle Children's Hospital**  
**University of Washington**



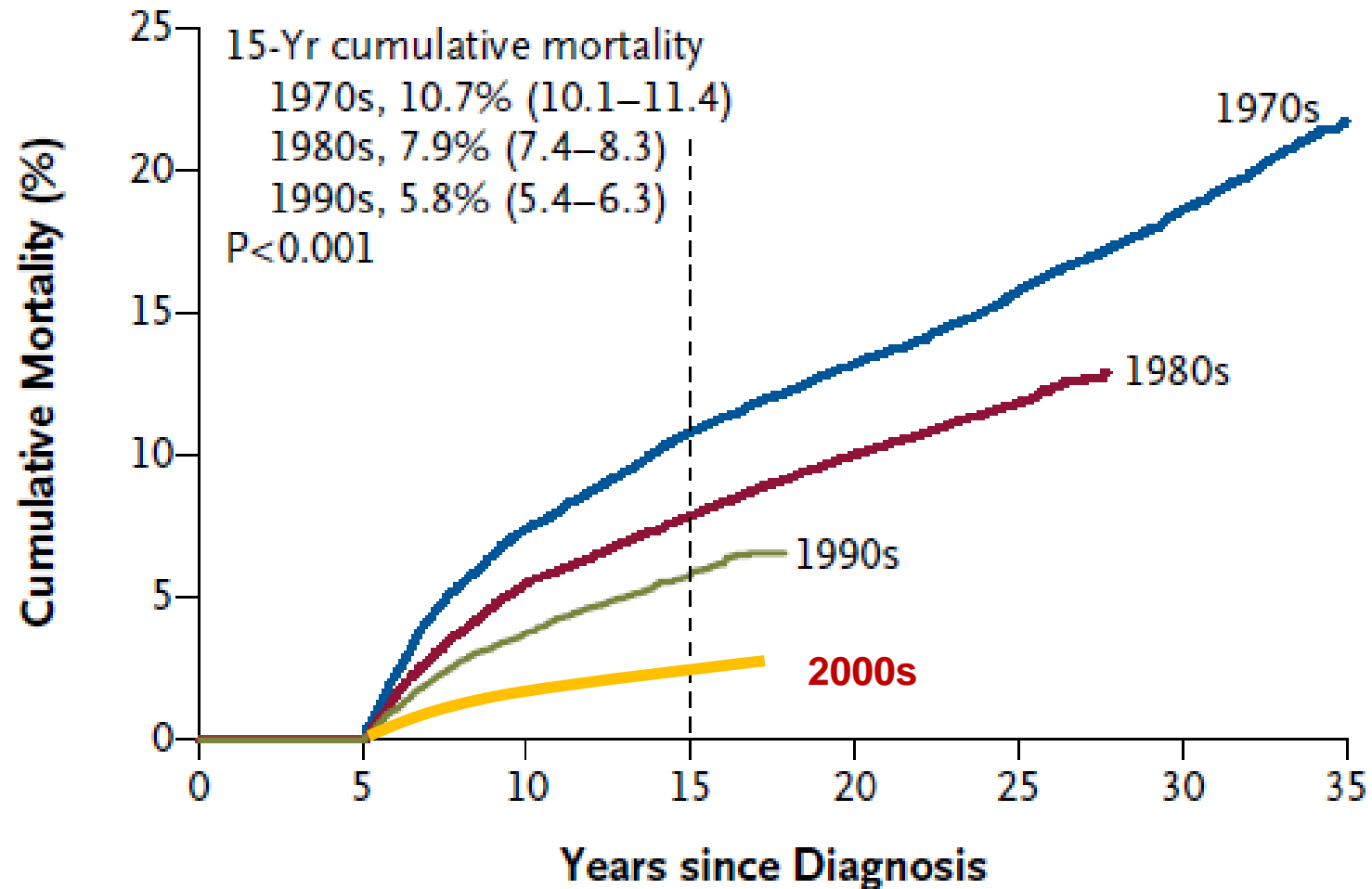
**FRED HUTCH**  
CURES START HERE®

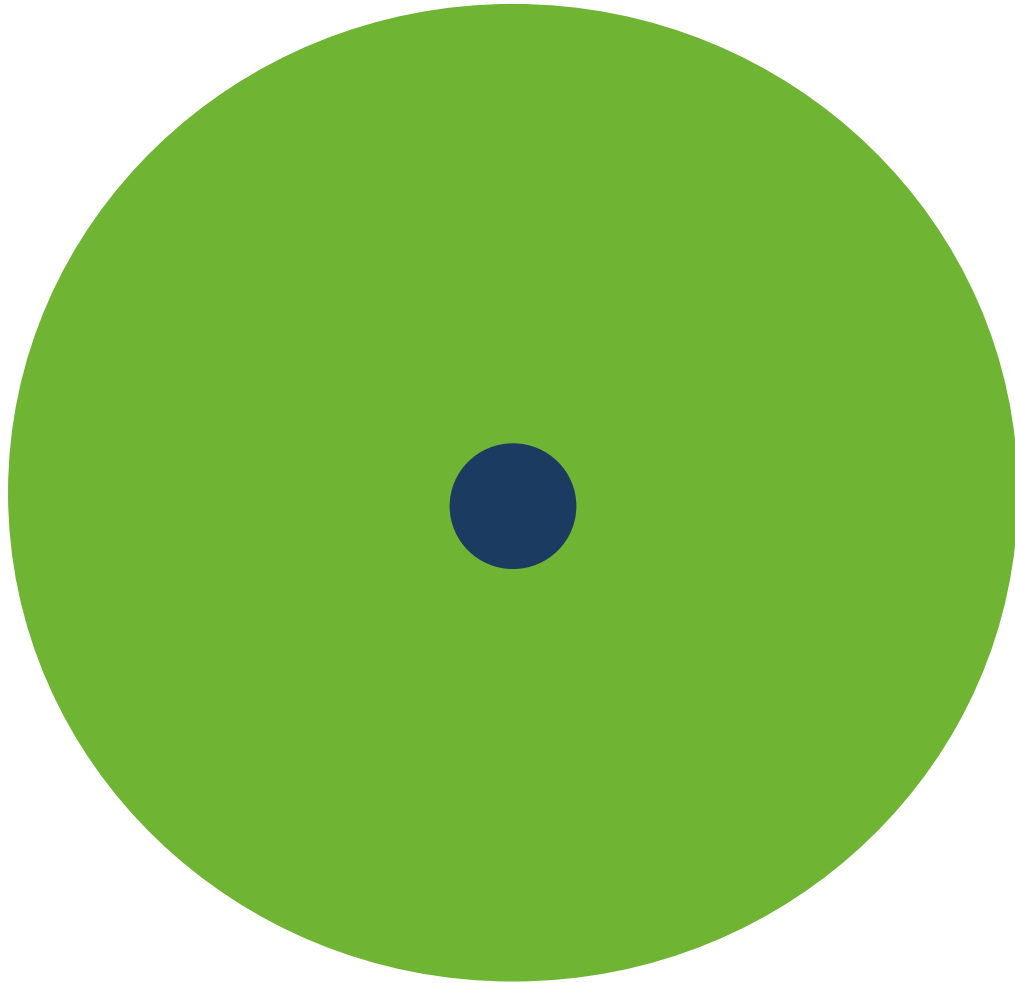
# Long-term survival has improved over time



# Hope that Future Generations of Children will do even better

## Death from Any Cause





**US cancer survivors,  
17 million**

*(>75% diagnosis:  
age 55 years)*

**Survivors of  
childhood cancer,  
~500,000**

*(BUT anticipated future years of life:  
>55 years)*

# Effects of treatment on growing bodies

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phillipmartin.com

- **Brain:** intrathecal chemotherapy, surgery, tumor
- **Hearing:** platinum-agents like cisplatin
- **Heart:** anthracyclines like doxorubicin
- **Lungs:** bleomycin, busulfan
- **Fertility:** alkylating agents like cyclophosphamide
- **Bones:** steroids, high-dose methotrexate

***Radiation – effects on all of these!***

# Effects of treatment on growing bodies

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*No one gets all these problems*  
*No one is completely unaffected*  
*Most survivors lead healthy lives*

- **Radiation & second cancers:**
  - **Brain:** annual history and exam
  - **Thyroid:** annual exam to feel for nodules
  - **Breast:** after puberty, annual exam for lumps; consider breast imaging (mammography, MRI) starting age 25
  - **Colorectal:** consider screening starting age 30
  - **Skin:** annual exam for moles

***Consider visit with genetic counselor even if no family history***

# Moving from Cancer Patient to Survivor

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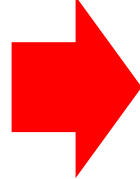
Many families identify end of treatment as a time of new uncertainty, frustration and stress

*“ We lived with these people (staff) for 8 months, and then they say ‘ OK, you’re done, see you. We will see you in 3 months. Bye.’ .....hey, wait a minute. This is really not over for us.”*

# Moving from Cancer Patient to Survivor

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## *Transitions*

- End of treatment
  - Oncology team
  - Pediatric care
- 
- Return to “normal”
  - Primary care & survivor program
  - Adult care

## *Things to learn about*

- Cancer treatment summary & late effects
- Follow-up schedule



# Survivor Knowledge of Past Cancer History often Limited

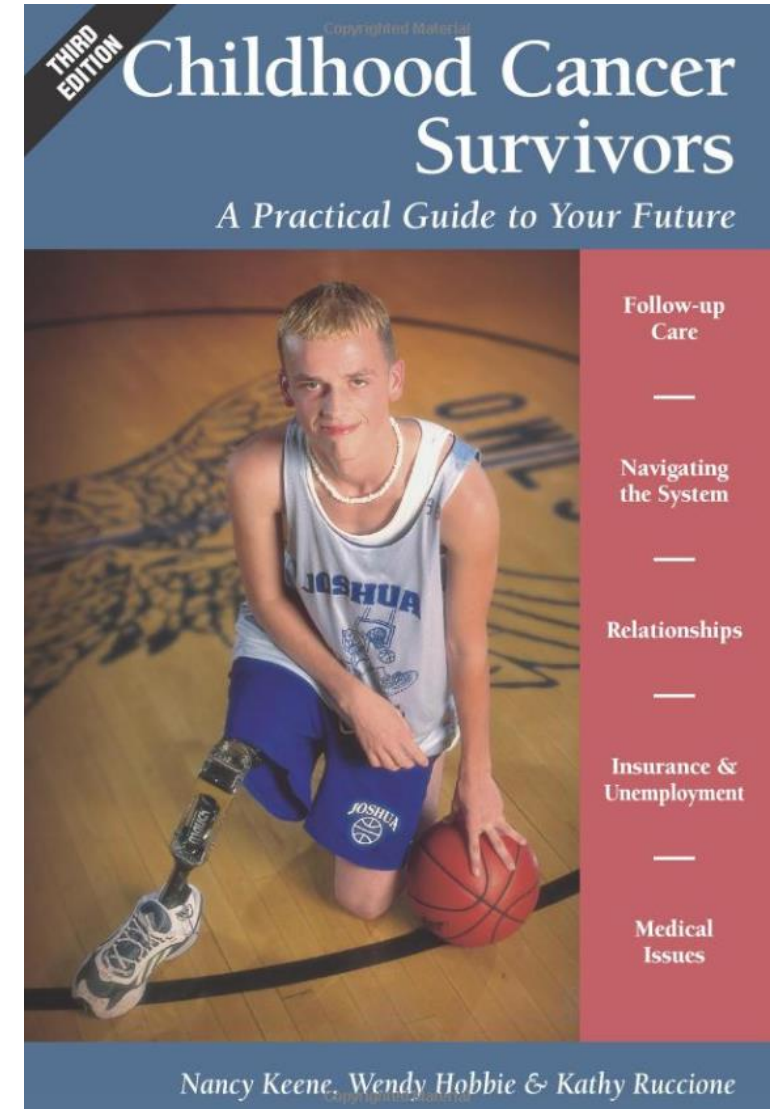
## Diagnosis

- 91% knew (72% detailed knowledge)
- 2% cancer
- 7% unaware

## Treatment exposures

- Radiation ~90% aware (only 70% knew site)
- Anthracycline chemotherapy <50% aware
- Splenectomy (surgery) ~2/3 aware

*Kadan-Lottick, Journal of the American Medical Association 2002*



# Survivorship Care Plan

- Tool to improve knowledge, awareness

- For patients & other providers

Seattle Children's Hospital Cancer Treatment Summary and Survivorship Care Plan Date of Service: 9/6/2017				
<b>Dx</b> <b>Cancer Diagnosis</b> <i>Values with * are estimated</i>				
1	<b>Other Female Genital: Sacral malignant germ cell tumor</b>		Date of Diagnosis	
<b>Subtype/Staging</b>				
	<i>Histopathologic Subtype</i>	No data reported		
	<i>Stage</i>	IV		
	<i>Size</i>	No data reported		
	<i>Histologic Grade</i>	No data reported		
	<i>Regional Lymph Nodes</i>	No data reported		
	<i>Metastases</i>	M1 Distant metastasis present [Lung, Lymph Nodes]		
	<i>Staging or Other Comments</i>	lung, axillary, and inguinal lymph node metastases		
<b>Receptor Status</b>				
	<i>Other</i>	No data reported		
<b>Genetic/Molecular Markers</b>				
	<i>Other</i>	No data reported		
<b>Tumor Biomarkers</b>				
	<i>Other</i>	alpha fetoprotein		
<b>Significant Past Medical History:</b>				
<b>Cancer Treatment</b>				
<b>Treatment Facility:</b> Seattle Children's Hospital				
<b>Surgery</b>				
<b>Dx</b>	<b>Procedure</b>	<b>Site</b>	<b>Date</b>	
1	Total surgical removal of primary site	Sacralcoccygeal germ cell tumor		
1	Local tumor excision	Sacrococcygeal tumor re-excision		
1	Local tumor excision	Sacrococcygeal tumor re-excision		
<b>Complications:</b> Initial sacrococcygeal tumor resection with positive microscopic margins; 2 re-excisions for concern for progressive tumor, but in both instances, only mature teratoma identified.				
<b>Systemic Therapy</b>				
Central Line: 1 - Yes				
<b>Dx</b>	<b>Agent</b>	<b>Dose</b>	<b>Start</b>	<b>Stop</b>
1	Bleomycin (Blenoxane)	60.00 mg/m2 [Total] - IV		
1	Etoposide (Etopophos, Toposar, VePesid, VP-16, VP-213)			
1	Cisplatin (Platinol, Platinol AQ)	400.00 mg/m2 [Total] - IV		
1	Paclitaxel (Abraxane, Taxol)			
1	Ifosfamide (Ifex)	22.50 g/m2 [Total] - IV		
1	Cisplatin (Platinol, Platinol AQ)	375.00 mg/m2 [Total] - IV		

Complications: TIP for relapse. First course of TIP dose reduced by 75% because of prior toxicity.				
Providers				
General Medical Care		Oncology Care		
No data reported		Seattle Children's Hospital		
Long Term Effects and Follow Up Care		Recommendation		
Oncology Care	The Cancer Survivor Program will determine how often and for how long you should be seen based on your specific needs. Most children diagnosed with cancer continue to be followed for at least 5 - 10 years after completion of therapy.			
Hearing	Treatment with certain chemotherapy agents (cisplatin, carboplatin) and high doses of head/neck radiation may affect your hearing and/or balance. Evaluation by an Audiologist is recommended if you are noticing these changes.			
Oral/Dental	Chemotherapy and/or radiation may increase the risk for cavities, abnormally shaped or missing teeth, and oral cancer. Recommend twice yearly dental exams and cleanings.			
Lung/Respiratory	Chemotherapy (bleomycin, busulfan, carmustine, lomustine) and radiation may impact lung function. Your lungs should be examined by a health care provider annually and pulmonary function tests may be recommended as needed.			
Gastrointestinal	Surgery and abdominal radiation can lead to scarring of your gastrointestinal tract and changes in bowel motility and nutrient absorption. Recommend high fiber diet and gastroenterology consultation/follow up as indicated.			
Kidney - general	There is a risk of kidney problems from radiation to kidneys or chemotherapy (cisplatin, carboplatin, ifosfamide). Recommend monitoring blood pressure annually. Kidney function and urine may be periodically checked.			
Fertility	Chemotherapy (cyclophosphamide, ifosfamide, busulfan, lomustine, melphalan, procarbazine, thiotepa) and radiation can affect your fertility. Recommend close monitoring of menses for females. Men may consider sperm testing once age-appropriate. A referral to a fertility specialist can be made. Visit <a href="http://www.asrm.org">www.asrm.org</a> or <a href="http://www.fertilehope.org">www.fertilehope.org</a> for information on fertility preservation.			
Hormonal changes	Treatment of your cancer may cause changes to your sex hormones. Recommend close monitoring of puberty and baseline sex hormone labs around age 13.			
Mental Health	Survivors and their families can sometimes experience emotional problems and/or difficulty or delay in returning to normal home and school life. This could occur soon after treatment or could even be delayed many years after treatment. If any of these changes are noted, we recommend an evaluation by a psychologist trained in this area for assistance. Interaction with peers and family should be encouraged in school, home and social settings.			
Secondary Cancers	Avoid smoking, tobacco products, or drinking too much alcohol when age appropriate, use sun protection and have a healthy diet. Any new, unusual and/or persistent symptoms should be brought to medical attention.			
Secondary Cancers - Topoisomerase inhibitors/Alkylators	Some chemotherapy drugs can increase the risk of new cancers, including new leukemias (typically within the first 5-10 years) - monitor clinically.			
Wellness Topic		Recommendation		
Coordination of Care/Health Maintenance	It is important to have a primary care provider to coordinate and manage your general health care. They will help you stay current on wellness visits, immunizations, tests, and coordination with specialists.			
Exercise/Physical Activity	Recommend regular exercise (children: average 60 minutes per day; adults 30-60 minutes at least 5 days each week).			
Substance Use	As people grow into their adult years, avoid smoking and tobacco products, avoid drinking too much alcohol or any drugs, and always use safe sex practices.			
Oncology Follow-up				
<i>Based on your oncologist recommendations, personal diagnosis, treatment exposures, and/or risk factors.</i>				
Specialist or Test	Last Done	Frequency	Provider to Contact	Next Due

- Recommended follow-up and identify who is responsible

Oncology Follow-up	9/6/2017	AFP and exam yearly through 5-years off-therapy	Seattle Children's	Summer/Fall 2018
Survivorship	9/6/2017	Yearly with labs as indicated	Seattle Children's	Summer/Fall 2018
Pulmonary Function (PFT)	Never	Baseline requested for 2018	Seattle Children's	Summer/Fall 2018
Immunizations:		All routine vaccines are ok	Primary care provider	Anytime
Audiology/Hearing	2013	Repeat at 5-years off-therapy	Seattle Children's	Summer/Fall 2018
<b>Wellness Screening</b>				
<i>Based on National Cancer Institute, U.S. Preventive Task Force, and National Institutes of Health recommendations.</i>				
<b>Test or Exam</b>	<b>Frequency</b>		<b>Provider to Contact</b>	
Well Physical Skin, eyes, mouth, thyroid, carotids, heart, lungs, breast, abdomen, lymphatics, blood pressure, immunization status	Yearly		Primary Care	
Dental and Oral	Twice a year or as indicated		Dentist	
<b>Contact/Resources</b>				
<p><b>Seattle Children's Hospital Cancer Survivor Program</b>            4800 Sand Point Way NE, MB.8.501, Seattle WA 98105            Phone: 206-987-2106 Fax: 206-987-3946  <a href="http://www.seattlechildrens.org/cancersurvivorprogram">www.seattlechildrens.org/cancersurvivorprogram</a></p> <p><i>For more detailed information on many of these topics, please see Health Links at <a href="http://www.survivorshipguidelines.org">www.survivorshipguidelines.org</a></i></p>				

Prepared: 9/25/2017  
Prepared By: Eric Chow

# Development of Evidence-based Guidelines

- Children's Oncology Group (COG)



- Clinical trials network uniting >200 pediatric centers across North America, Australia, New Zealand, Europe, Middle East.
- Supported by federal dollars (National Institutes of Health) and private philanthropy
- Test new therapies in large clinical trials
- Develop evidence-based supportive care guidelines

**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**

Updated every 5  
years by pediatric  
survivorship  
experts in COG

Basis of most  
North American  
survivorship care



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

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# RADIATION

# POTENTIAL IMPACT TO HEART

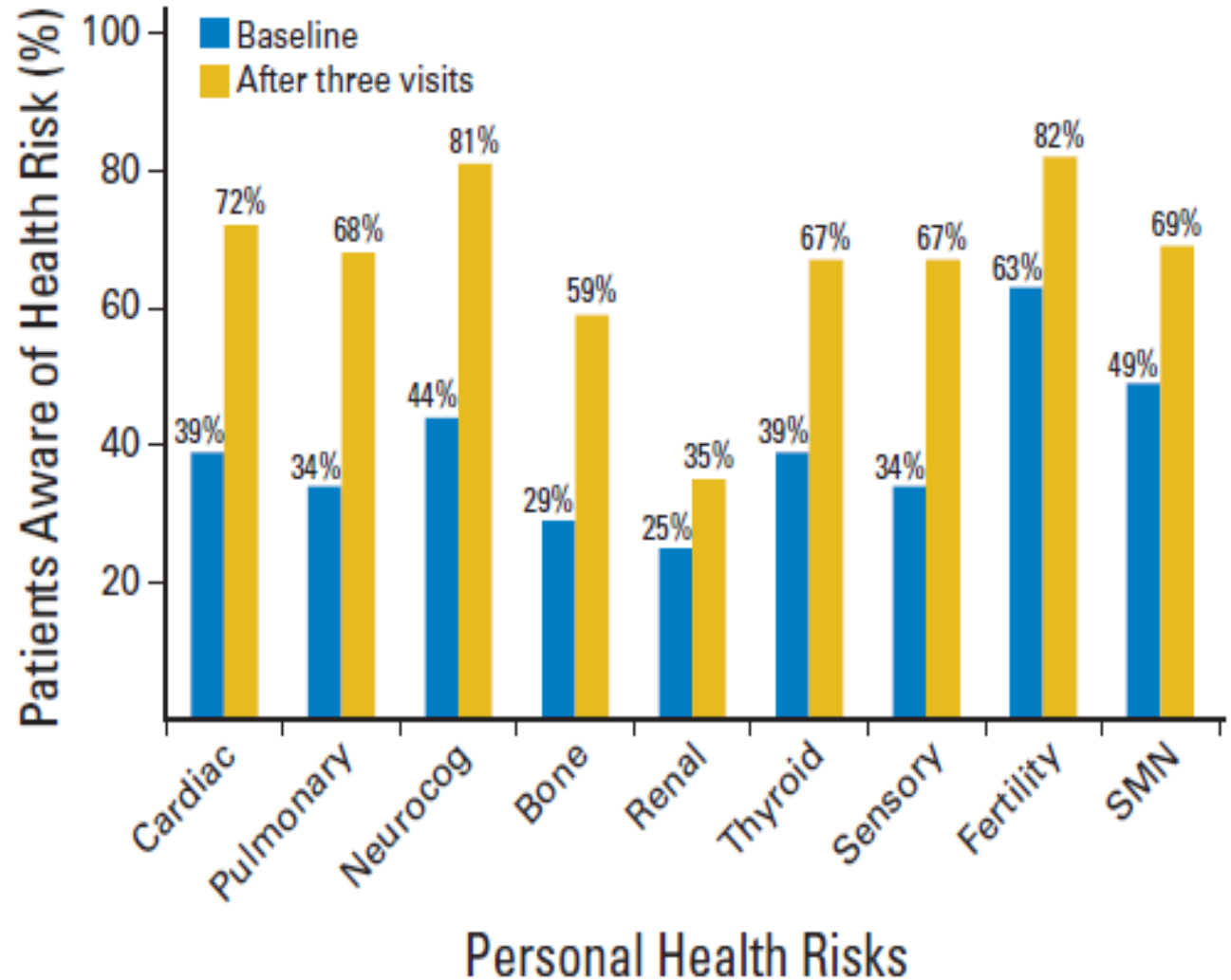
Sec #	Therapeutic Exposure	Potential Late Effects	Periodic Evaluation	Health Counseling/ Further Considerations																					
76	<b>Chest</b> <b>Abdomen</b> <b>Spine (thoracic, whole)</b> <b>TBI</b> (TBI is included for cumulative dose calculation purposes only; this section is not applicable to patients who received TBI alone.)	<b>Cardiac toxicity</b> Cardiomyopathy Subclinical left ventricular dysfunction Congestive heart failure Pericarditis Pericardial fibrosis Valvular disease Atherosclerotic heart disease Myocardial infarction Arrhythmia	<b>HISTORY</b> If dose $\geq 15$ Gy: Shortness of breath Dyspnea on exertion Orthopnea Chest pain Palpitations If under 25 yrs: abdominal symptoms (nausea, vomiting) Yearly  <b>PHYSICAL</b> If dose $\geq 15$ Gy: Blood pressure Cardiac exam Yearly  <b>SCREENING</b> ECHO (or comparable imaging to evaluate cardiac anatomy and function)  <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><math>\geq 15</math> - &lt; 35 Gy</td> <td>Every 5 years</td> </tr> <tr> <td><math>\geq 35</math> 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><math>\geq 15</math> Gy</td> <td>Every 2 years</td> </tr> <tr> <td><math>\geq 250</math> 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 [thoracic, whole], TBI). See section 76.</p> If dose $\geq 15$ Gy: EKG (include evaluation of QTc interval) Baseline at entry into long-term follow-up, repeat as clinically indicated	Recommended Frequency of Echocardiogram			Anthracycline Dose*	Radiation Dose**	Recommended Frequency	None	< 15 Gy or none	No screening	$\geq 15$ - < 35 Gy	Every 5 years	$\geq 35$ Gy	Every 2 years	< 250 mg/m <sup>2</sup>	< 15 Gy or none	Every 5 years	$\geq 15$ Gy	Every 2 years	$\geq 250$ mg/m <sup>2</sup>	Any or none	Every 2 years	<b>HEALTH LINKS</b> Heart Health Cardiovascular Risk Factors Diet and Physical Activity Dental Health  <b>COUNSELING</b> Maintain appropriate weight, blood pressure and heart-healthy diet. Regarding exercise: - Regular exercise is generally safe and should be encouraged for patients who have normal LV systolic function. - Survivors with asymptomatic cardiomyopathy should consult cardiology to define limits and precautions for physical activity. - Cardiology consultation may be reasonable to define limits and precautions for physical activity for high risk survivors (i.e., those requiring an ECHO every 2 years) who plan to participate in intensive exercise. If QTc interval is prolonged: Caution regarding use of medications that may further prolong the QTc interval (e.g., tricyclic anti-depressants, antifungals, macrolide antibiotics, metronidazole).  <b>POTENTIAL CONSIDERATIONS FOR FURTHER TESTING AND INTERVENTION</b> Optimize cardiovascular risk factors, including blood pressure, lipid profile, and blood glucose. Cardiac MRI as an adjunct imaging modality when echocardiographic images are suboptimal. Cardiology consultation in patients with subclinical abnormalities on screening evaluations, left ventricular dysfunction, dysrhythmia, or prolonged QTc interval. Cardiology consultation (5 to 10 years after radiation) may be reasonable to evaluate risk for coronary artery disease in survivors who received $\geq 35$ Gy chest radiation alone or $\geq 15$ Gy chest radiation plus anthracycline. In survivors with valvular disorders: Consult cardiologist to advise regarding need for endocarditis prophylaxis. Female patients only: For patients who are pregnant or planning to become pregnant, additional cardiology evaluation is indicated in patients who received: - $\geq 250$ mg/m <sup>2</sup> anthracyclines - $\geq 35$ Gy chest radiation, or - Anthracycline (any dose) combined with chest radiation ( $\geq 15$ Gy) Evaluation should include a baseline echocardiogram (pre- or early-pregnancy). For those without prior abnormalities and with normal pre- or early-pregnancy baseline echocardiograms, follow-up echocardiograms may be obtained at the provider's discretion. Those with a history of systolic dysfunction or with pre- or early-pregnancy systolic dysfunction are at highest risk for pregnancy-associated cardiomyopathy. Such individuals should be monitored periodically during pregnancy and during labor and delivery due to increased risk for cardiac failure.  <div style="background-color: #00728f; color: white; padding: 5px; text-align: center;"> <b>SYSTEM = Cardiovascular</b>  <b>SCORE = 1</b> </div>
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	$\geq 15$ Gy	Every 2 years																							
$\geq 250$ mg/m <sup>2</sup>	Any or none	Every 2 years																							

>150 sections

Individual sections for each type of treatment, including radiation & surgeries

# Value of Comprehensive Survivorship Care

- Review past cancer history (and screen for recurrence)
- Review potential treatment-related complications, many of which may be preventable or treatable
- **Increase** patient / family awareness & knowledge
- **Increase** adherence to recommended screening



# Seattle Children's Survivor Program



*Erin Barthel, MD  
Aimee Foord, DO  
Danielle Hastings, ARNP  
Angie Steineck, MD  
Amy Wein, ARNP  
Kim Lowole, RN coordinator (not pictured)*

- Founded 20 yrs ago by Dr. Deb Friedman with support from the LIVEStrong foundation
- Anyone treated for childhood cancer or blood disorder requiring chemotherapy, radiation is welcome to be seen (doesn't matter if you were originally treated at SCH or elsewhere)
- Clinic in Seattle 4 days/wk, plus quarterly outreach clinics to TriCities and Federal Way, plus periodic visits to Montana
- In 2018, we had ~450 visits and are on-target to well exceed that this year
- We had our 1<sup>st</sup> Moving Beyond Cancer to Wellness event in 2008 (and this is our 5<sup>th</sup> event!!)



# Transition to Adult Care? Barriers...

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- While some pediatric survivorship programs offer life-long care, this is not an option for many...
  - Adult primary care providers often become responsible for future coordination
  - Sometimes a hybrid model (combined pediatric center + affiliated adult program)
  - Rarely medical oncologists
- Other issues...
  - Perceived lack of knowledge on part of survivor & future provider
  - Difficult “letting go” on part of pediatric team as well as patient / family



Source: CDC.gov

# Tips for Improving Transition

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- **Begin conversation early... recommended to start at age 14**
  - Discuss with your pediatric oncology team
  - Discuss with your primary care provider
  - Know what resources exist in college if applicable
  - Determine if you need adult subspecialty care and where to get it
  - Understand insurance and whether you can stay on parental insurance until age 26
  - Explore guardianship issues if applicable before age 18
  
- **Be your own advocate**
  - Have a copy of your survivorship care plan (or know where you can get one)
  - Patient-centered electronic health records

# Importance of healthier lifestyles

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## *Things to avoid:*

- Tobacco / smoking (e-cigs too)
- Sun tanning
- Excess alcohol

## *Things to get:*

- Exercise
- Fruits / vegetables
- Follow-up care



**"And then when we turn 30 and get lung cancer,  
we can sue the tobacco companies."**

PHYS ED

# For Survivors of Childhood Cancer, Walk

Regular exercise, such as brisk walking for an hour, improved long-term survival in those who had childhood cancers.

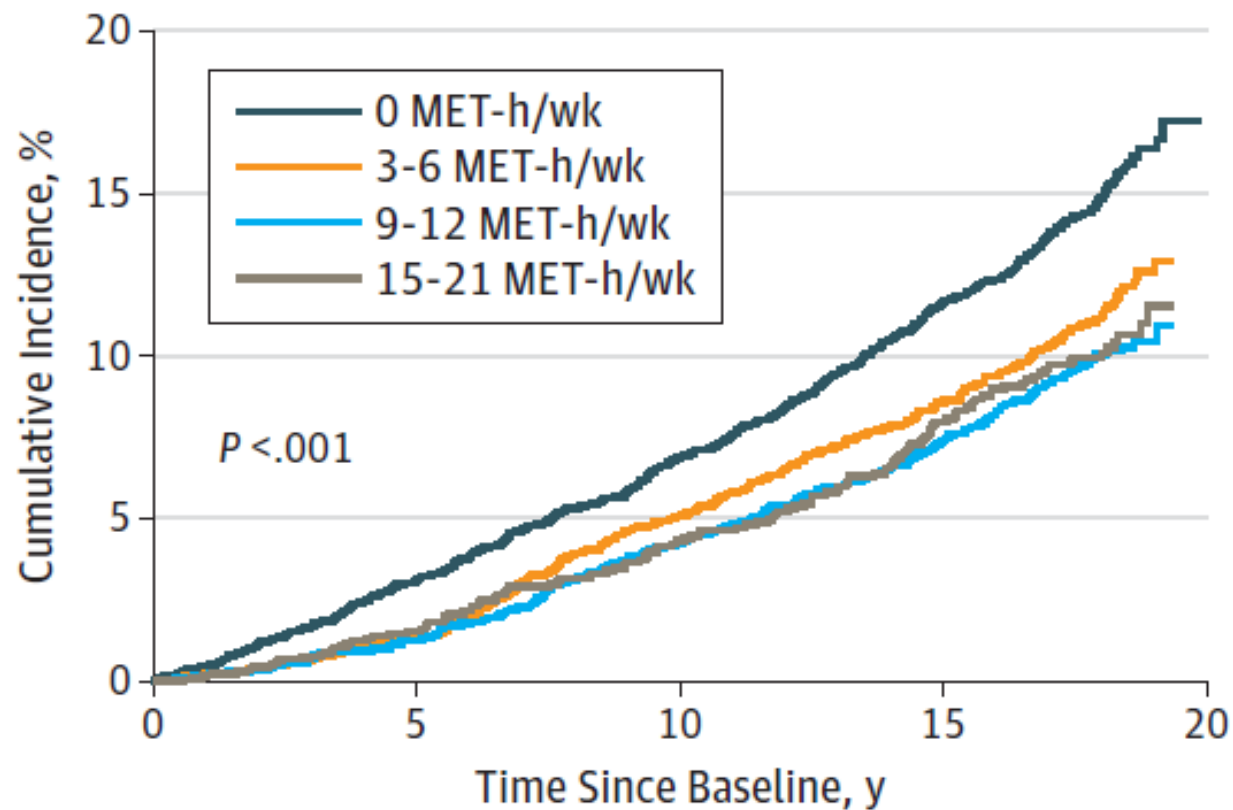


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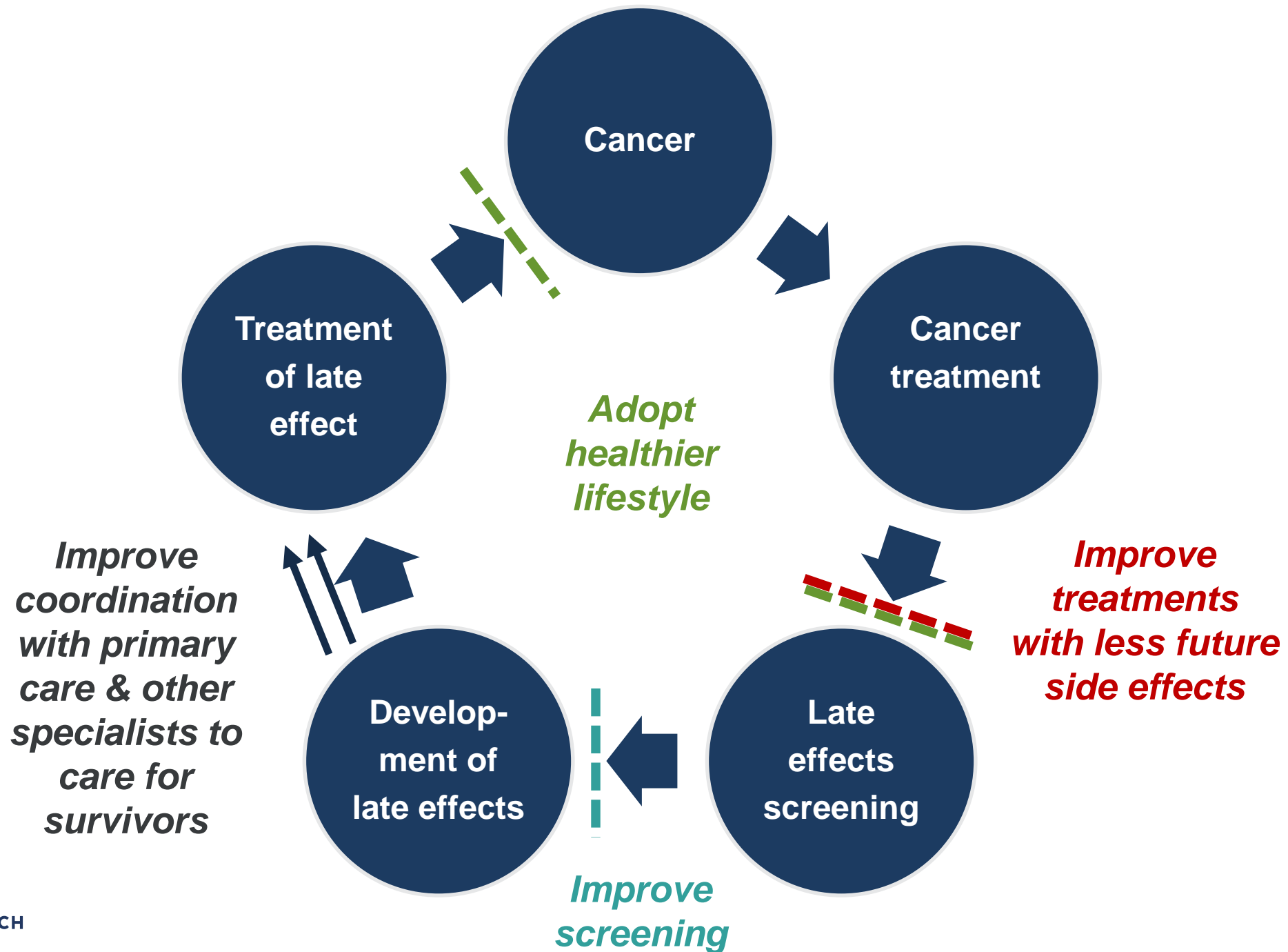


By Gretchen Reynolds

June 20, 2018



Scott, *JAMA Oncology* 2018



# Summary: 7 Tips for Success

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1. Visit survivorship clinic... and repeat
2. Share your survivorship care plan with your other providers (especially primary care... important to re-establish care)
3. If you are  $\geq 14$  years old, start talking to your pediatric providers about eventual transition (if applicable) to adult providers
4. Get more exercise (more on that from Dr. Ketter!!!)
5. Try to eat healthier
6. Don't smoke (including e-cigarettes)
7. Don't depend on your parents to organize your healthcare forever...



STANLEY  
AUTOMATIC  
CAUTION  
DOOR

OPEN

IN EM

CAUTION

Children's

***It's not the years in your life that count.***

***It's the life in your years.***

***– A. Lincoln***







*Every child begins the world again  
– Henry David Thoreau*

# Online Resources

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- Current pediatric cancer treatment
  - National Cancer Institute (NCI/NIH): [www.cancer.gov/cancertopics/pdq/pediatric/treatment](http://www.cancer.gov/cancertopics/pdq/pediatric/treatment)
- Survivorship
  - Children's Oncology Group: [www-survivorshipguidelines.org/](http://www-survivorshipguidelines.org/)
  - NCI/NIH: [www.cancer.gov/types/childhood-cancers/late-effects-pdq](http://www.cancer.gov/types/childhood-cancers/late-effects-pdq)
  - Childhood Cancer Survivor Study: <https://lifu.stjude.org/>
  - Scholarships: [www.ped-onc.org/scholarships](http://www.ped-onc.org/scholarships)
  - Young Adults:
    - Cancer Care [http://www.cancercare.org/tagged/young\\_adults](http://www.cancercare.org/tagged/young_adults)
    - First Descents <https://firstdescents.org/>
    - Stupid Cancer <http://www.stupidcancer.org/>
- Other topics
  - Guardianship: <https://thearc.org/>
  - Health insurance: Kaiser Family Foundation <http://kff.org/>

THANK YOU



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