

6th

Moving Beyond Cancer to Wellness

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The National Children's Cancer Society

The Leukemia & Lymphoma Society

Sarcoma Foundation of America



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Also visit the booths and handouts outside!

Seattle Children's Advisory Group – Introduction & Raffle

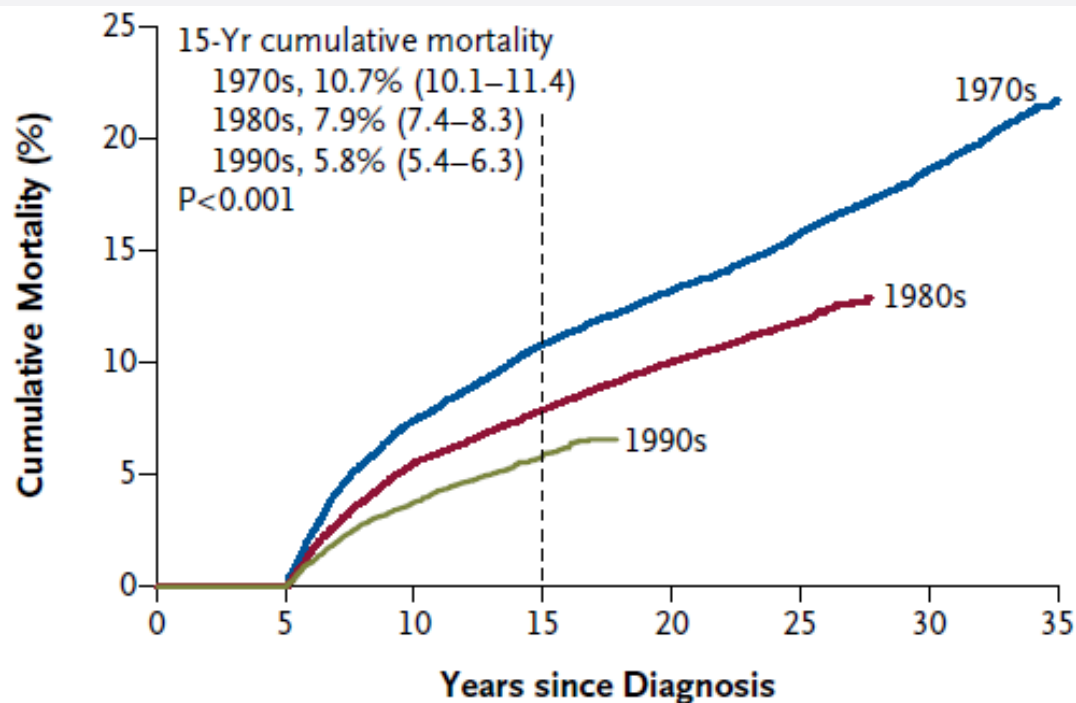
Please also remember to complete event evaluations

These can be dropped off at the check-in desk when you leave

Your feedback will help us improve future events



Long Term Survival Has Improved

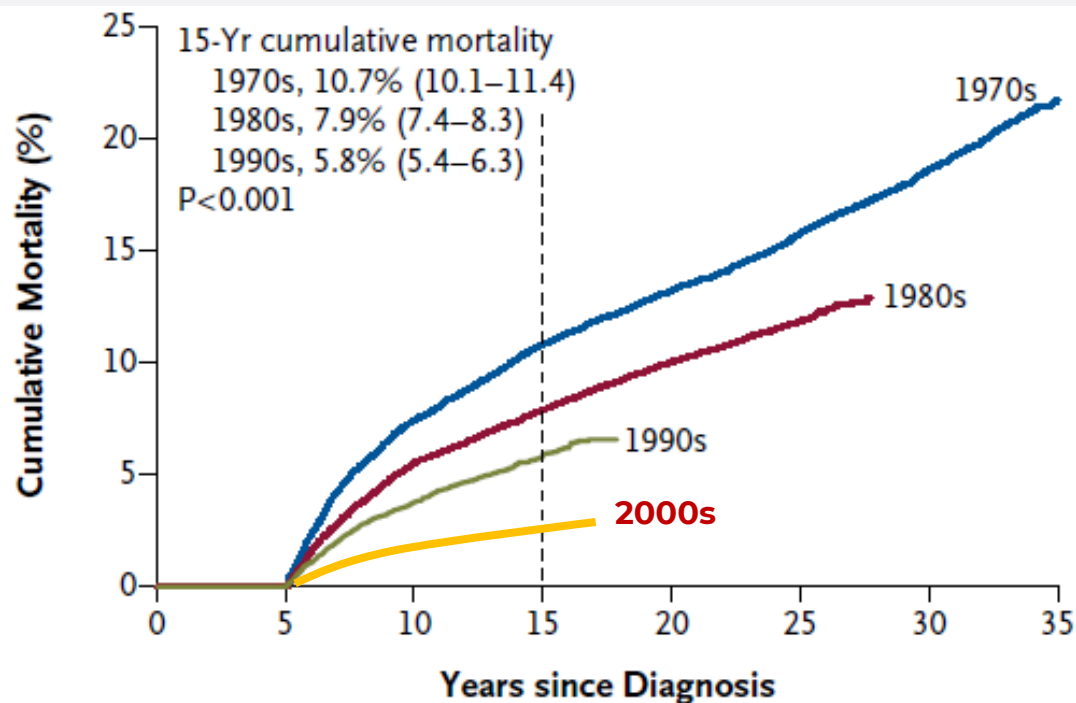


Armstrong, New England J Med 2016



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Long Term Survival Has Improved



Armstrong, New England J Med 2016



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Potential Late Effects on Growing Bodies



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

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



Potential Late Effects on Growing Bodies



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



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*No one gets all these problems
Most survivors will lead healthy lives*

Moving from Cancer Patient to Survivor

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

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 History Limited

Diagnosis

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

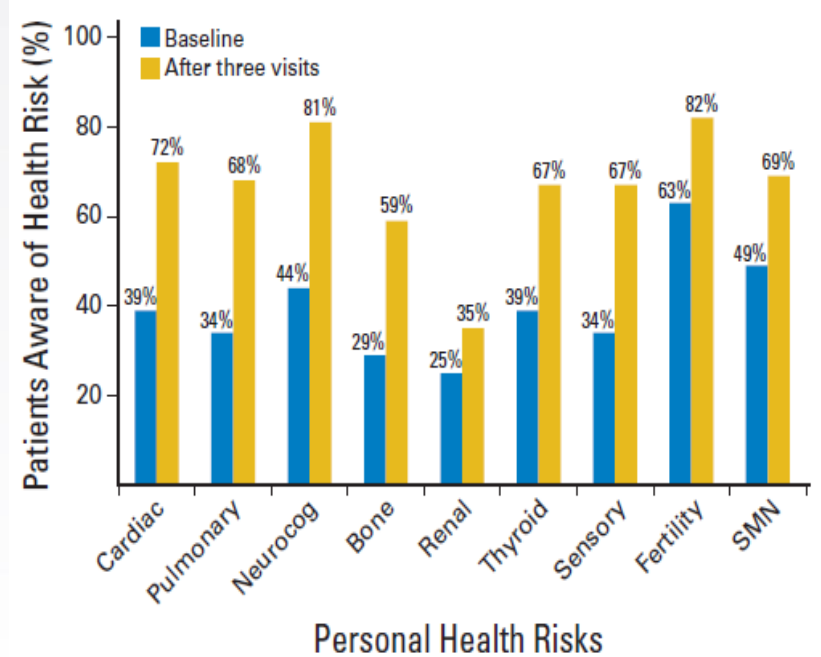
Treatment Exposures

- Radiation ~90% aware (only 70% knew site)
- Anthracycline chemotherapy <50% aware
- Splenectomy (surgery) ~66% aware



Value of Comprehensive Survivorship Care

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



**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

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Survivorship Care Plan

Your roadmap for care – updated after each appointment

Key details of cancer diagnosis & treatment

- Cancer type, location, years of treatment
- Chemotherapy, doses, if any
- Radiation, doses, if any
- Surgeries, if any

Overview of key issues related to prior treatment

- Personalized based on your individual history

Personalized follow-up Plan

- What labs you need
- What imaging or other studies you need
- Referrals
- Future appointments



Transition to Adult Care?

Difficulty “letting go” on part of pediatric team as well as patient and family

Begin conversation early... start at age 14

- Discuss with both primary care & oncology
- Figure out if you need adult subspecialty care & where to get it
- Understand insurance & if you can stay on parental insurance until age 26
- Explore guardianship issues if applicable before age 18
- Have a copy of your survivorship care plan
- Get electronic access to your medical records





Seattle Children's Survivor Program



- Features providers (MDs, NPs), nurse & team coordinators, psychologists, social worker, genetic counselor
- Clinic in Seattle 4d/wk, plus Bellevue, Everett, Federal Way, and TriCities
- Telemedicine services for residents of Alaska, Idaho, and Montana



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- Adult survivorship care available through Fred Hutch
- Graduate from Seattle Children's around age 18 to 21, or if in college, after graduating, whichever is later
- Staffed by Drs. Bhatt and Chow – so full access to pediatric records
- **Consultative model** – labs and studies need to be ordered by your **adult primary care provider**

Summary: 7 Tips for Success

1. Visit survivorship clinic
2. Share your survivorship care plan with other healthcare providers (especially primary care... make sure you go back to primary care)
3. Talk to your school if returning to school after treatment (*more on that from Dr. Bhatt*)
4. If age 14+, start making a plan for future transition
5. Don't depend on your parents to organize your healthcare forever...
6. Take care of yourself – mentally & physically (good diet, exercise)
7. Visit survivorship clinic (again)



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



AUTOMATIC
CAUTION
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Children's

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

It's the life in your years.

– A. Lincoln

