

Moving Beyond Cancer to Wellness:

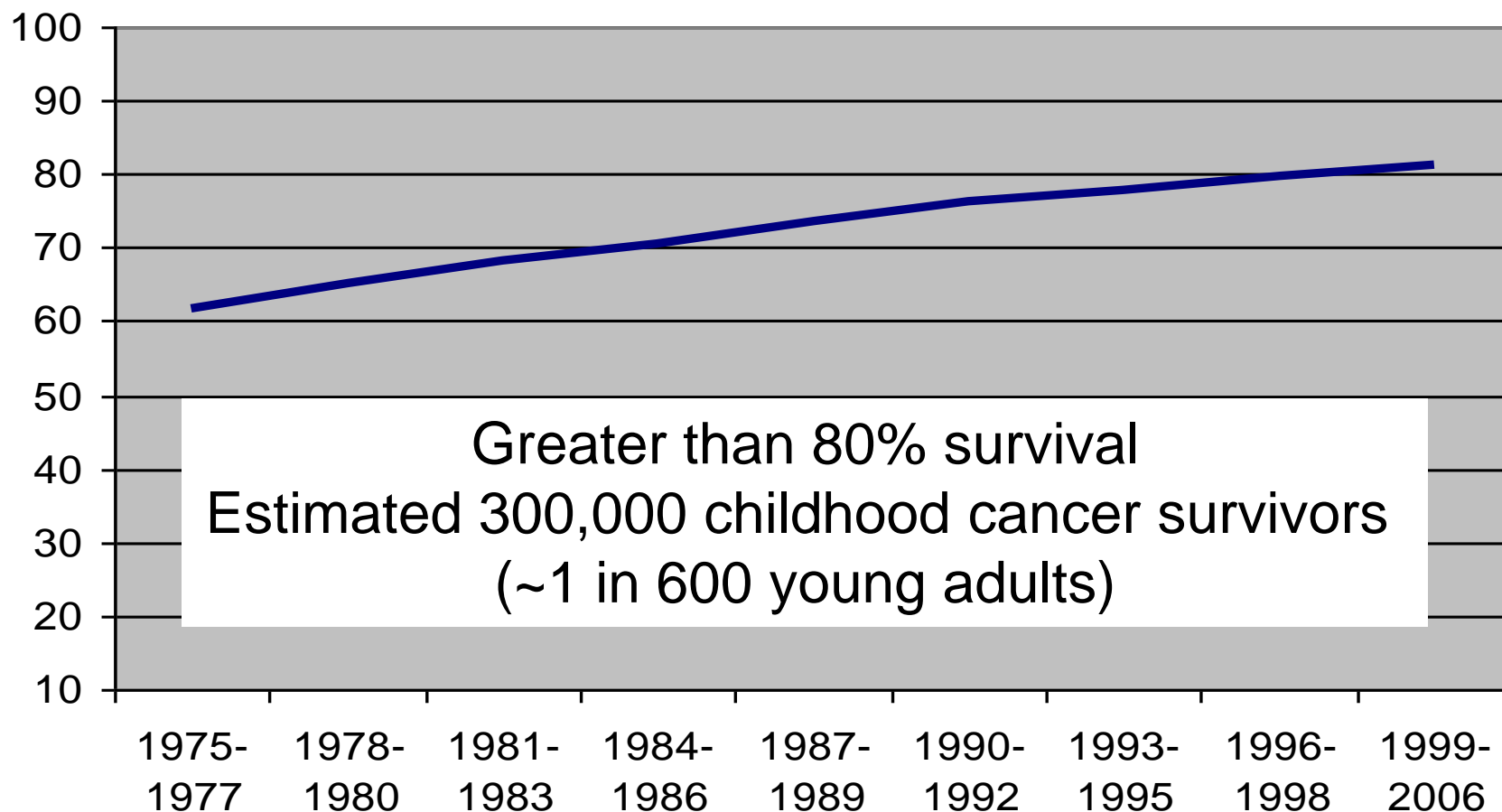
Understanding Long Term Effects of Childhood Cancer Treatment

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Cancer Survivor Program

Pediatric Cancer Survival – A Success Story



End of Treatment

- 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
 - Return to “normal”
 - Primary care provider & survivor program
 - Teens / Young Adults
- Things to learn about
 - Cancer treatment summary
 - Follow-up schedule
 - Between visits
 - Late effects ←

Survivor Health Knowledge – Often Incomplete

Kadan-Lottick, JAMA 2002

- Diagnosis
 - 91% knew (72% detailed knowledge)
 - 2% cancer
 - 7% unaware
- Treatment
 - Radiation ~90% aware (70% knew site)
 - Anthracycline chemotherapy <30%
 - Major surgery type <70% aware

Possible Long-term Effects

- **Growth & Development**
 - Growth deficiencies
 - Cognitive function
 - Hearing loss
 - Psychosocial distress
- **Fertility & Reproduction**
 - Delayed or early puberty
 - Sterility
 - Premature menopause
- **Other Organ Dysfunction**
 - Endocrine
 - Heart
 - Lungs
 - Kidney and Bladder
- **New Cancers**

No one gets all these problems

No one is completely unaffected

Most survivors lead healthy lives

Growth Issues

- Effects of treatment on growing bodies
 - Radiation
 - Chemotherapy
 - Surgery
- Bone health
- Hormone problems
 - Growth hormone
 - Thyroid
 - Sex hormones

Growth – Brain Development

- Symptoms may include
 - Academic challenges and changes
 - Difficulty with multi-step processes
 - Feeling less sharp
 - Memory problems
 - Needing more effort to do things that previously came easily
- Depends on therapy
 - Higher doses of brain radiation, some chemotherapy
 - Younger ages may be at greater risk

Growth Issues – What can you do?

- Regular preventive health care with your PCP
 - Monitoring height, weight
 - Hearing and vision screens
 - Dental care
 - Screening labs
- Work with schools / teachers
 - Some survivors may benefit from early neurodevelopmental testing

Fertility / Reproductive Concerns

- Can I have children?
- How will my body respond to pregnancy?
- Will my children be affected by prior treatment?
 - Congenital malformations **NO**
 - Cancer **NO**
 - Other birth complications **Possible**

Fertility / Reproductive Concerns

- Treatments that may affect fertility
 - **Alkylator** chemotherapy (e.g. cyclophosphamide, ifosfamide)
 - **Radiation** to brain, ovaries, testes
 - Dose dependent
- Pregnancy Health
 - Females: possible effect on heart function during pregnancy
 - Some may have greater risk of premature births, lower birth weight babies
- Offspring otherwise appear to be healthy

Fertility / Reproductive – What can you do?

- Advocate for improved fertility preservation education & resources prior to cancer treatment
 - Pre-2012: sperm banking, embryo cryopreservation
 - 2012: oocyte cryopreservation no longer “experimental”
- Discuss need for fertility testing (sperm banking, lab work) and referral to reproductive specialist, and possibly high-risk obstetrician
- Adoption and other alternatives

Heart & Lung Issues

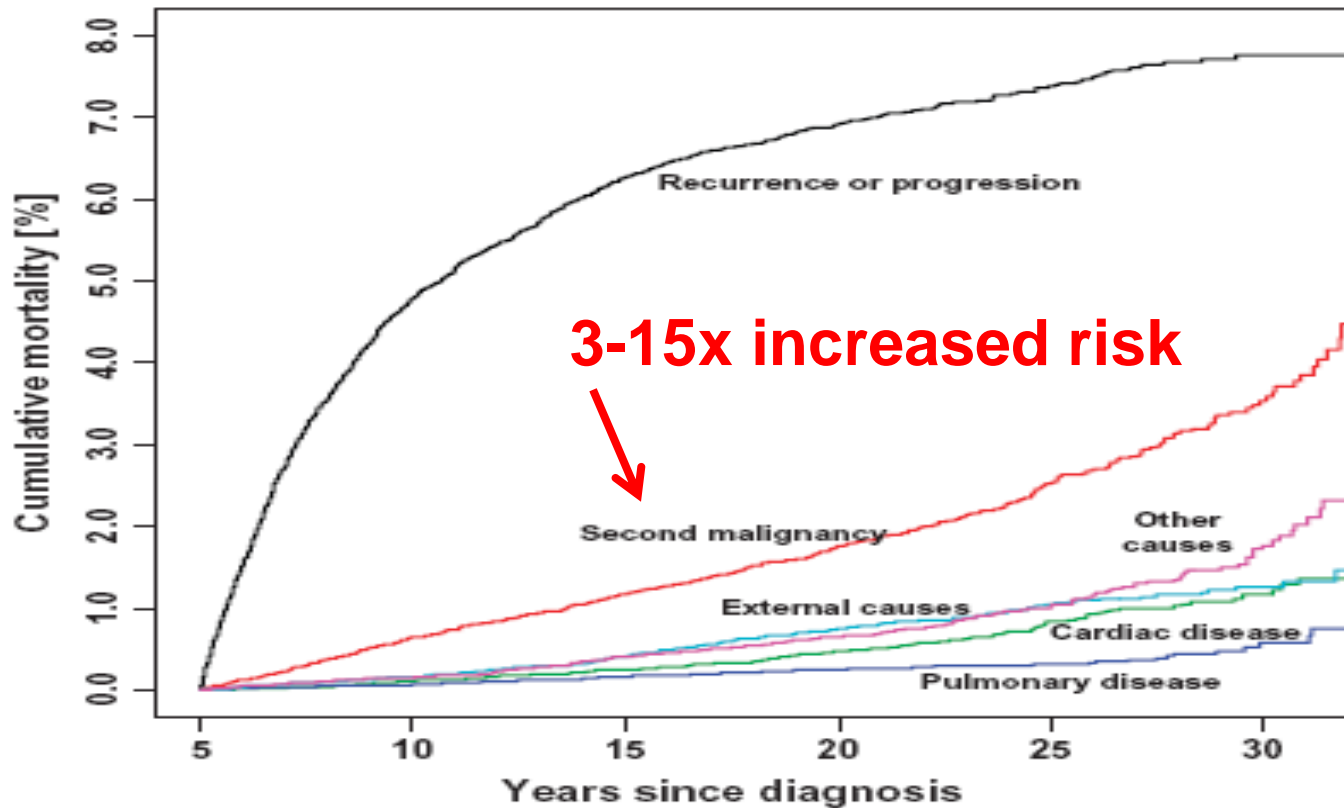
- Heart disease (cardiomyopathy)
 - Risk related to **Anthracycline** chemotherapy (e.g. doxorubicin) and **chest radiation**
 - High blood pressure or cholesterol levels also important
- Lung disease (fibrosis)
 - Risk related to **Bleomycin** chemotherapy and **chest radiation**
- May develop *decades* after exposure
 - Risk influenced by age at treatment, treatment doses, time since treatment, genetics

Heart & Lung – What can you do?

- Know if you / your child is at increased risk
- Talk to your doctor about how best to monitor for these effects
(may need life-long monitoring)
- Be aware of symptoms that may indicate heart or lung disease
 - Chest pain Fatigue
 - Shortness of breath Leg swelling
- Lifestyle issues
 - Avoid smoking, be physically active, eat healthy
 - www.zamzee.com

New Cancers

Mertens AC, et al. JNCI 2008



New Cancers – What can you do?

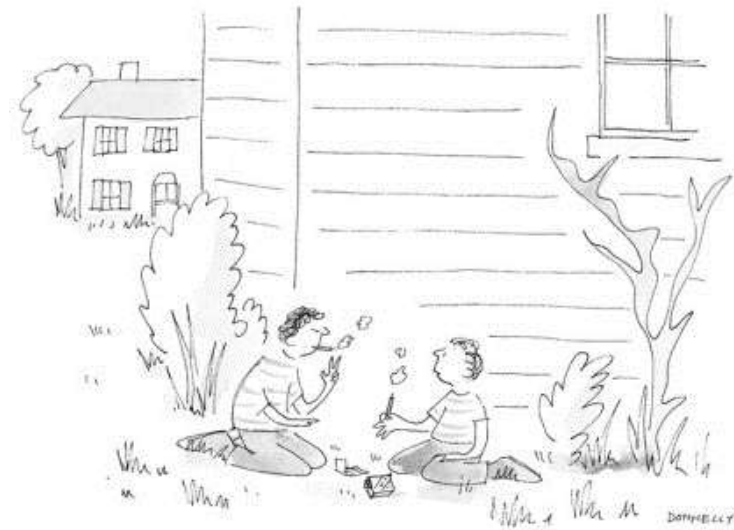
- **KNOWLEDGE:**

- Cancer and its therapy can increase risk of another cancer
- Know what may increase your/your child's risk of subsequent cancer
 - Know what kind of treatment you/your child received
 - This includes knowing your family history
- Know if you/your child needs special screening that others their age do not typically need
 - Dermatology visit after radiation exposure
 - Earlier mammograms for girls exposed to chest radiation

New Cancers – What can you do?

- **ACTION:**

- Get the proper screening done
- Lead a healthy lifestyle by **avoiding**
 - Excess sun exposure
 - Tobacco
 - Excess alcohol
 - Physical inactivity
 - Poor diet



2005 Institute of Medicine Report

“From Cancer Patient to Cancer Survivor: Lost in Transition”

Recommendation 2: Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principal provider(s) who coordinated oncology

Importance of risk-based care with Individualized recommendations

tematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts.

Survivor Program Services

- Multidisciplinary team approach with PCP as integral team member (resource for community providers)
- Comprehensive review of cancer tx records
 - All are welcome - you don't have to have been treated in Seattle
- Discussion of school/work, reproductive issues
- Individualized anticipatory guidance & screening
- Referral to appropriate subspecialties
- Case management (medical home) for those with complex needs
- Partnership and transition to adult program at FHCRC

Survivor Program Follow-up Schedule

- Based on specific disease and risk of relapse/recurrence
- Establishing care with a primary care provider is highly recommended
- Late effects and monitoring – should start by 2 years off active therapy
 - Lab work
 - Other testing (e.g. audiograms, bone density scans, heart ultrasounds, lung studies, neurocognitive testing)
- Long-Term Follow-Up guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers available at www.survivorshipguidelines.org

Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent,
and Young Adult Cancers

Version 3.0 – October 2008

CureSearch

Children's Oncology Group

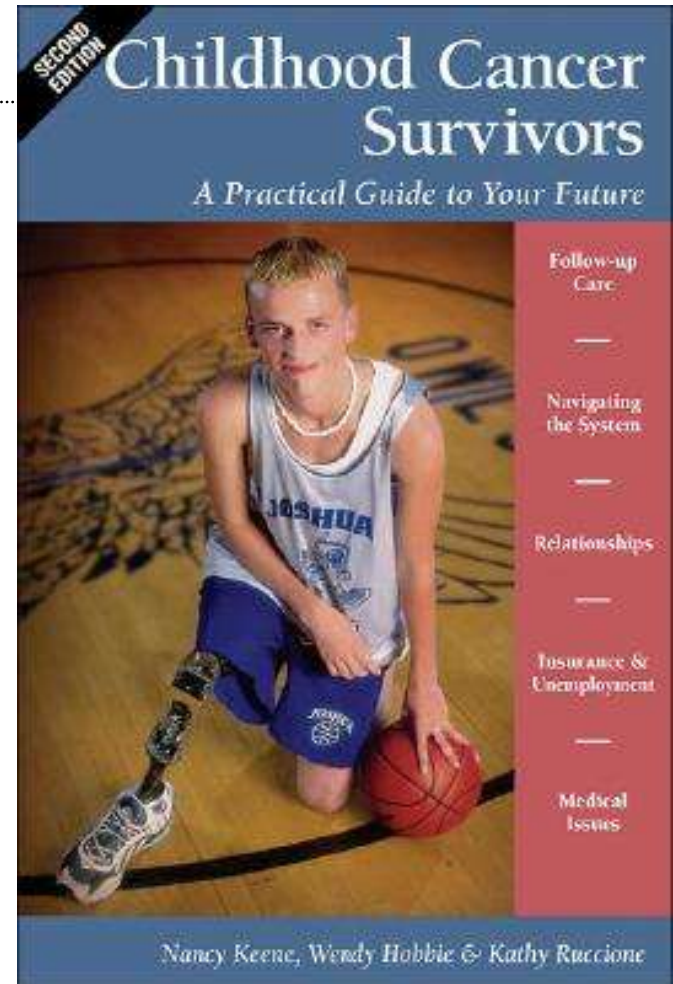
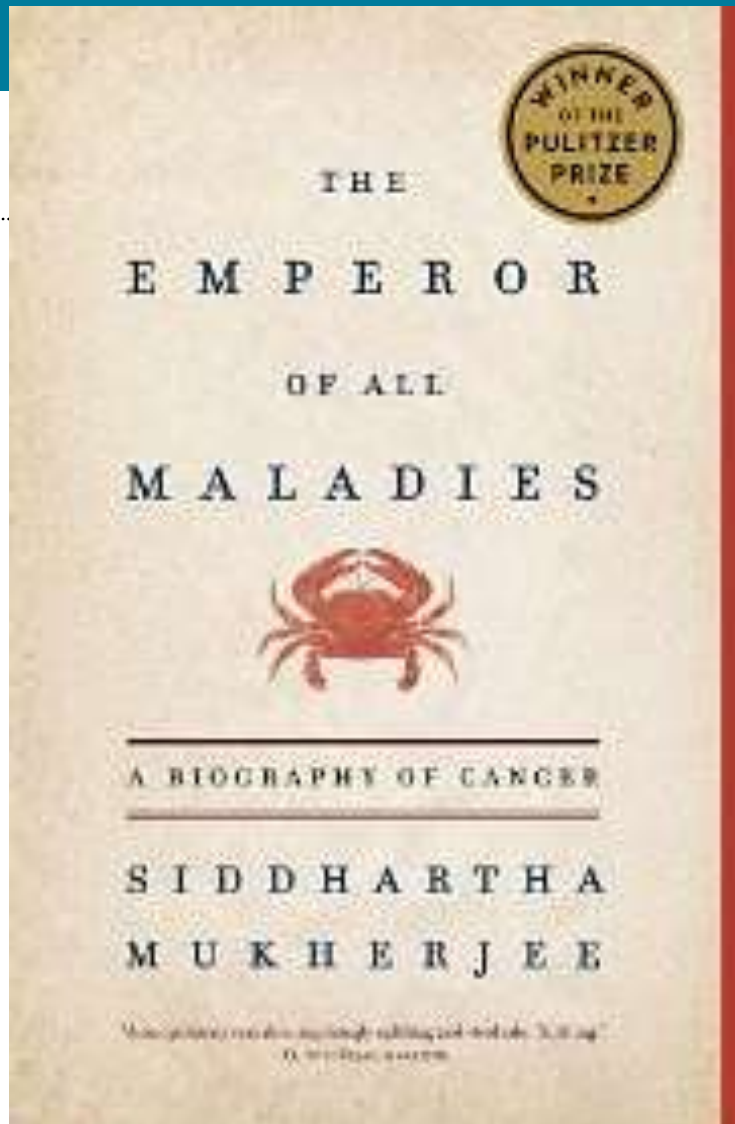
www-survivorshipguidelines.org

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Other On-line Resources

- Current pediatric cancer treatment
 - NCI <http://www.cancer.gov/cancertopics/pdq/pediatrictreatment>
- Seattle Children's Cancer Survivor Program
<http://www.seattlechildrens.org/cancersurvivorprogram/>
- Late effects screening
 - Children's Oncology Group <http://www.survivorshipguidelines.org/>
 - NCI <http://www.cancer.gov/cancertopics/pdq/treatment/lateeffects/Patient>
 - Fertile Hope <http://www.fertilehope.org/>
- General topics (American Cancer Society)
<http://www.cancer.org/treatment/survivorshipduringandaftertreatment/index>



Conclusions

- Cure is not enough
- Know what lies ahead for you and your child
- Get educated and advocate
- Participate in research
- Let us work together to help you:

Move beyond cancer to wellness!

**We thank all the patients and families who
continue to teach us and help those who
will face cancer in the future**

Survivorship Research

- Local Projects
 - Weight gain and insulin resistance during leukemia therapy
 - Male fertility after ifosfamide and cisplatin
 - Long-term metabolic and heart health after stem cell transplantation
- National Projects
 - Childhood Cancer Survivor Study
 - Predicting cardiovascular disease among survivors
 - Children's Oncology Group
 - Prevention of anthracycline-related cardiomyopathy
 - National Wilms Tumor Study – Late Effects Study

Parting Thoughts...

I have heard there are troubles of more than one kind.
Some come from ahead and some come from behind.
But I've bought a big bat. I'm all ready you see.
Now my troubles are going to have troubles with me!

~Dr. Seuss

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

~Abraham Lincoln