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

Greater than 80% survival
Estimated 300,000 childhood cancer survivors
(~1 in 600 young adults)
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
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
  - Shortness of breath
  - Fatigue
  - Leg swelling

- Lifestyle issues
  - Avoid smoking, be physically active, eat healthy
  - [www.zamzee.com](http://www.zamzee.com)
New Cancers

Mertens AC, et al. JNCI 2008

3-15x increased risk
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
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 care.

Importance of risk-based care with individualized recommendations

Systematically 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

Seattle Children's
UW Medicine
Fred Hutchinson Cancer Research Center
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
Other On-line Resources

- Current pediatric cancer treatment

- Seattle Children’s Cancer Survivor Program

- Late effects screening

- General topics (American Cancer Society)
The Emperor of All Maladies
A Biography of Cancer

Childhood Cancer Survivors
A Practical Guide to Your Future

Follow-up Care
Navigating the System
Relationships
Insurance & Unemployment
Medical Issues

Nancy Keene, Wendy Hobbie & Kathy Ruccione
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
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