2016 Moving Beyond Cancer to Wellness: Introduction to Cancer Survivorship

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Cancer Survivor Program
More than 400,000 childhood cancer survivors (~1 in 600 young adults)

Pediatric Cancer Survival – A Success Story

SEER 9 data (1975-2007)
**But… possible long-term effects**

<table>
<thead>
<tr>
<th>Growth &amp; Development</th>
<th>Other Effects</th>
<th>New Cancers</th>
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</thead>
<tbody>
<tr>
<td>• Growth deficiencies</td>
<td>• Endocrine</td>
<td></td>
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<tr>
<td>• Cognitive function</td>
<td>• Heart</td>
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<td>• Hearing loss</td>
<td>• Lungs</td>
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<tr>
<td>• Psychosocial distress</td>
<td>• Kidney and Bladder</td>
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<tr>
<td><strong>Fertility &amp; Reproduction</strong></td>
<td></td>
<td><strong>No one gets all these problems</strong></td>
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<td>• Delayed or early puberty</td>
<td></td>
<td><strong>No one is completely unaffected</strong></td>
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<td>• Reduced fertility</td>
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<td><strong>Most survivors lead healthy lives</strong></td>
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No one is completely unaffected.
Most survivors lead healthy lives.

But… possible long-term effects
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 came easily before

- Depends on therapy
  - Higher doses of brain radiation, some chemo
  - 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 neurocognitive testing
Fertility / Reproductive Concerns

- Can I have children?
  - Alkylator chemotherapy / XRT affect fertility
- How will my body respond to pregnancy?
  - May be more stressful to heart
- Will my children be affected by prior treatment?
  - Congenital malformations \textit{NO}
  - Cancer \textit{NO}
  - Other birth complications \textit{Possible}
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 & Busulfan chemotherapy and chest radiation

- May develop decades after exposure
  - Risk influenced by age at treatment, treatment doses, time since treatment, family history/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
Heart & Lung – What can you do?

>2000 Fred Hutch BMT survivors surveyed

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<th>High blood pressure</th>
<th>Cholesterol problems</th>
<th>Diabetes</th>
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<tbody>
<tr>
<td>Smoking / tobacco</td>
<td></td>
<td></td>
<td>80% more</td>
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<tr>
<td>Healthy diet</td>
<td></td>
<td>30% less</td>
<td>50% less</td>
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<tr>
<td>Physical activity/exercise</td>
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New Cancers

Things that increase risk of new cancers:

- Radiation
- Chemotherapy (rare)
- Family history / genetics

Reulens, JAMA 2011
New Cancers – What can you do?

- Get recommended screening for childhood cancer survivors – *may* include:
  - Mammograms / breast exams at an earlier age
  - Colorectal cancer screening at an earlier age
  - Skin checks

- Healthy lifestyle - *avoid*
  - Sun tanning
  - Tobacco / smoking
  - Excess alcohol
  - Physical inactivity
  - Poor diet

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

- Comprehensive review of cancer treatment records (can be treated anywhere)
- Outreach clinics to E. Washington (TriCities), Montana; telemedicine
- Individualized anticipatory guidance & screening
- Referral to appropriate subspecialties
- Case management for those with complex needs
- Coordination with primary care
- Partnership and transition to adult program at Fred Hutch / SCCA
Survivor Program Follow-up Schedule

• Based on specific disease and risk of relapse/recurrence
• Establishing care with a primary care provider is absolutely essential
• Late effects monitoring – often begins during cancer treatment & continues once off-therapy
  • Lab work
  • Other testing may be indicated at certain intervals (e.g. audiograms, bone density scans, heart ultrasounds, lung studies, neurocognitive testing)
Online Resources

• Current pediatric cancer treatment
  • National Cancer Institute (NCI)  www.cancer.gov/cancertopics/pdq/pediatrictreatment

• Seattle Children’s / Fred Hutch / Seattle Cancer Alliance
  www.seattlechildrens.org/cancersurvivorprogram  www.fredhutch.org/survivorship

• Late effects screening
  • Children’s Oncology Group  www.survivorshipguidelines.org/
  • NCI  www.cancer.gov/types/childhood-cancers/late-effects-pdq
  • Livestrong  www.livestrong.org/we-can-help/livestrong-fertility#

• Scholarships  www.ped-onc.org/scholarships

• General topics (American Cancer Society)
  www.cancer.org/treatment/survivorshipduringandaftertreatment/index
Research

- Research is a key part of Seattle Children’s mission

- Families may be contacted for interest in participating in a variety of survivorship studies:
  - Strategies to prevent of treatment-related heart problems
  - Effects of modern chemotherapy on fertility (male & female)
  - Effects of cisplatin on inner ear function
  - Increasing physical activity using wearable monitors
  - High risk neuroblastoma survivorship

- These efforts will help us learn how to better care for current & future survivors
Cancer
treatment

Late
effects
screening

Develop-
ment of late effects

Late effects
screening

Adopt healthier lifestyle

Improve coordination with primary care & other specialists to care for survivors

Improve screening

Improve treatments with less future side effects
Conclusions

- Cure is not enough
- Know what lies ahead for you and your child
- Consider participating in research
- Let us work together to help you:

*Move beyond cancer to wellness!*

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