Taking the Cue: Elements of a Well-championed Survivorship Program

Matt Ehrhardt, MD, MS
Outline

- Epidemiology of cancer survivorship
- Late effects of cancer treatment
- Models of survivorship care
- Key components of survivorship clinics
- Survivorship care plans
Cancer Survivors in the United States

As of January 1, 2016

Male
- Prostate: 3,306,760
- Colon & rectum: 724,690
- Melanoma: 614,460
- Urinary bladder: 574,250
- Non-Hodgkin lymphoma: 361,480
- Kidney & renal pelvis: 305,340
- Testis: 266,550
- Lung & bronchus: 238,300
- Leukemia: 230,920
- Oral cavity & pharynx: 229,880

Total survivors: 7,377,100

Female
- Breast: 3,560,570
- Uterine corpus: 757,190
- Colon & rectum: 727,350
- Thyroid: 630,660
- Melanoma: 612,790
- Non-Hodgkin lymphoma: 324,890
- Lung & bronchus: 288,210
- Uterine cervix: 282,780
- Ovary: 235,200
- Kidney & renal pelvis: 204,040

Total survivors: 8,156,120

As of January 1, 2026

Male
- Prostate: 4,521,910
- Colon & rectum: 910,190
- Melanoma: 848,020
- Urinary bladder: 754,280
- Non-Hodgkin lymphoma: 488,780
- Kidney: 429,010
- Testis: 335,790
- Leukemia: 318,430
- Lung & bronchus: 303,380
- Ovary: 286,300
- Kidney & renal pelvis: 284,380

Total survivors: 9,983,900

Female
- Breast: 4,571,210
- Uterine corpus: 942,670
- Colon & rectum: 885,940
- Thyroid: 885,590
- Melanoma: 811,490
- Non-Hodgkin lymphoma: 436,370
- Lung & bronchus: 369,990
- Uterine cervix: 284,380
- Kidney: 280,940
- Ovary: 280,940

Total survivors: 10,305,870

>15.5 million in 2016
Miller et al, Ca Cancer J Clin 2016

>20 million by 2026
Survival Estimates

- Childhood cancer survivors experience increased mortality risk compared to the U.S. population

Survival Estimates

• Childhood cancer survivors experience increased mortality risk compared to the U.S. population

• By 30 years from diagnosis, chronic health conditions surpass recurrent or progressive disease as the leading cause of death

Adverse Effects of Therapy

**Growth & Development**
- Height
- Bone development
- Intellectual function
- Socioemotional maturation
- Sexual development

**Fertility & Reproduction**
- Fertility
- Health of children

**Vital Organ Function**
- Heart
- Lung
- Kidney
- Endocrine
- Gastrointestinal
- Vision/hearing

**Psychosocial**
- Emotional
- Cognitive
- Social

**Second Cancers**
- Benign
- Malignant
### Table 3. Relative Risk of Selected Severe (Grade 3) or Life-Threatening or Disabling (Grade 4) Health Conditions among Cancer Survivors, as Compared with Siblings.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Survivors (N = 10,397)</th>
<th>Siblings (N = 3034)</th>
<th>Relative Risk (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major joint replacement*</td>
<td>1.61</td>
<td>0.03</td>
<td>54.0 (7.6–386.3)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>1.24</td>
<td>0.10</td>
<td>15.1 (4.8–47.9)</td>
</tr>
<tr>
<td>Second malignant neoplasm†</td>
<td>2.38</td>
<td>0.33</td>
<td>14.8 (7.2–30.4)</td>
</tr>
<tr>
<td>Cognitive dysfunction, severe</td>
<td>0.65</td>
<td>0.10</td>
<td>10.5 (2.6–43.0)</td>
</tr>
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<td>Coronary artery disease</td>
<td>1.11</td>
<td>0.20</td>
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<td>Cerebrovascular accident</td>
<td>1.56</td>
<td>0.20</td>
<td>9.3 (4.1–21.2)</td>
</tr>
<tr>
<td>Renal failure or dialysis</td>
<td>0.52</td>
<td>0.07</td>
<td>8.9 (2.2–36.6)</td>
</tr>
<tr>
<td>Hearing loss not corrected by aid</td>
<td>1.96</td>
<td>0.36</td>
<td>6.3 (3.3–11.8)</td>
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<tr>
<td>Legally blind or loss of an eye</td>
<td>2.92</td>
<td>0.69</td>
<td>5.8 (3.5–9.5)</td>
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<tr>
<td>Ovarian failure‡</td>
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# Chronic Conditions in Childhood Cancer Survivors

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Timing of Adverse Effects of Therapy

- Short-term
- Long-term
- Late-effects
Risk-Based Survivor Care

Hudson, Cancer 2005
Essential Components of Survivorship Care

- Prevention of recurrent/new cancer and late effects
- Surveillance for cancer (progression, recurrence, or secondary)
- Assessment of medical and psychosocial late effects
- Intervention for consequences of cancer and its treatment
- Coordination between specialists and primary care providers to ensure survivor’s health needs are met

Hewitt et al, IOM and NRC 2005
Models of Care

• Multidisciplinary
  – A variety of providers present same day
  – Resource intense

• Disease specific
  – Individual clinics for each primary malignancy

• Consultative
  – Single survivorship visit (general or disease specific)

Models of Care

• Integrated care model
  – Survivorship-focused extension of the cancer care continuum
  – Nurse practitioners and physician assistant visits

• Risk-stratified and shared care
  – Care based upon low, moderate, and high risk for late effects
  – Coordination between oncology and primary care with eventual transition to primary care

Logistical Considerations

- How many survivors are active in follow-up?
- Mechanisms of identification and recruitment?
- How will clinical evaluations be funded?
- Are there limitations on attained age of recruited survivors?
- Availability of clinicians with appropriate expertise?
- Follow-up of abnormalities identified by evaluation?

Barriers to Survivor Care

**Survivor-related**
- Unawareness of potential late effects and future health risks
- Incomplete knowledge of cancer therapy

**Physician-related**
- Capacity of cancer treating facilities
- Unfamiliarity of primary care providers
- Poor communication

**Healthcare System-related**
- Insurance
- System
- Policies

Oeffinger, *Curr Probl Cancer* 2003
St. Jude After Completion of Therapy Clinic

**Mission:** To improve quality of life by facilitating access to resources that optimize physical and emotional health, social functioning and educational and vocational achievement during and after transition to community care.

**Admission to ACT**
- Cancer free
- 5 years from cancer diagnosis
- 2 years after completion of therapy
- 5 years from completion of salvage therapy

**Alumnus Discharge**
- 10 years from diagnosis of cancer
- 10 years from completion of relapse therapy
- At least 18 years old
- High school graduate
St. Jude Social Work Assessment

- Comprehensive psychosocial assessment
- Health and wellness evaluation
- Family and interpersonal relationships
- Insurance and medical care access
- Educational progress/vocational plans
- Scholarship opportunities
- Information/referral to local resources
IOM Guide to Development of Adult Cancer Survivor Programs

• Recommendation 1
  – Raise awareness of survivors’ needs, establish survivorship as a distinct phase of cancer care, and ensure delivery of appropriate survivorship care

• Recommendation 2
  – Provide patients with a clearly explained, survivorship care plan

• Recommendation 3
  – Use systematically developed, evidence-based clinical practice guidelines, assessment tools, and screening instruments to identify and manage late effects of cancer and of its treatment

Hewitt et al, IOM and NRC 2005
IOM Guide to Development of Adult Cancer Survivor Programs

• Recommendation 8
  – Eliminate discrimination and minimize adverse effects of cancer on employment while supporting survivors with short-term and long-term work limitations

• Recommendation 9
  – Ensure that all cancer survivors have access to adequate and affordable health insurance

Hewitt et al, IOM and NRC 2005
Survivorship Care Plan

• Diagnostic information about cancer
• Treatment modalities/cumulative dose
• Clinical events and status
• Transfusion history
• Family history
• Cancer-related health risks
• Risk-based screening recommendations
• Health behaviors modifying cancer risks
# Survivorship Care Plan (Example)

## General Information

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
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<tr>
<td>Date of Birth</td>
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<tr>
<td>Race</td>
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</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Current Age</td>
<td></td>
</tr>
<tr>
<td>Phone</td>
<td></td>
</tr>
<tr>
<td>MLI/Patient Status</td>
<td>Active ACT Neuro-Oncology</td>
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<tr>
<td>Initial Medical Service</td>
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<tr>
<td>Initial Primary St. Jude MD</td>
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<tr>
<td>Last Medical Service Visit Date</td>
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<tr>
<td>Date of Transfer</td>
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<tr>
<td>Last ACT Clinic Visit Date</td>
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<tr>
<td>Affiliate</td>
<td>Other (Memphis)</td>
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## Diagnosis

<table>
<thead>
<tr>
<th>DDM Date</th>
<th>Age History</th>
<th>Diagnosis</th>
<th>Stage</th>
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<tbody>
<tr>
<td>1</td>
<td>3.7 yrs</td>
<td>Medulloblastoma, Posterior fossa</td>
<td>Chang (M5)</td>
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## Protocol Enrollments

<table>
<thead>
<tr>
<th>Protocol Code</th>
<th>Title</th>
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<tbody>
<tr>
<td>97BANK</td>
<td>Protocol for Collecting, Archiving, and Distributing Human Tissue</td>
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<tr>
<td>638B683</td>
<td>Treatment of Patients with Newly Diagnosed Medulloblastoma, Supratentorial Primitive Neuroectodermal Tumor, or Atypical Teratoid Rhabdoid Tumor Protocol</td>
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<tr>
<td>557TV</td>
<td>Protocol for Collecting Data on Childhood Cancer Survivors</td>
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<tr>
<td>I2QNS</td>
<td>Pharmacogenetic Determinants of Treatment Response in Children with Cancer Protocol</td>
</tr>
<tr>
<td>55LPE</td>
<td>Establishment of a Lifetime cohort of Adults Surviving Childhood Cancer Protocol</td>
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</table>

## Oncology History

- Diagnosis of Medulloblastoma, posterior fossa, following gross total tumor resection by craniotomy (Valley Baptist Medical Center, Harlingen, TX)
- Treatment with combined modality 539660 protocol therapy including consolidation with myeloblastic therapy followed by autologous hematopoietic cell rescue
- Cranio-spinal (3240 cGy), Left cerebellum (3600 cGy), Posterior fossa tumor bed boost (140 cGy)
- Radiation therapy (3900 cGy total cumulative dose)

## Therapy

<table>
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<th>Field</th>
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<tr>
<td>Surgery</td>
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**Survivorship Care Plan - Research Report**

**August 2, 2016**

**Date of Birth:**

**General Information**

<table>
<thead>
<tr>
<th>Race</th>
<th>MILLI Patient Status:</th>
<th>Active ACT</th>
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<tr>
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<td>Initial Medical Service:</td>
<td>Neuro-Oncology</td>
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<td>Initial Primary St. Jude MD:</td>
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**Diagnosis**

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<thead>
<tr>
<th>DX#</th>
<th>Date</th>
<th>Age/History</th>
<th>Diagnosis</th>
<th>Stage</th>
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<tbody>
<tr>
<td>1</td>
<td>7/12/2004</td>
<td>3.7 yrs</td>
<td>Medulloblastoma, Posterior Fossa</td>
<td>Chang (M0)</td>
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</tbody>
</table>
**Suggested Evaluations Related to Your Specific Treatment for Childhood Cancer**

**Laboratory Tests**

**Screening Recommendations**
- ALT, AST, bilirubin, ferritin
- BUN, creatinine, Na, K, Cl, CO2, Ca, Mg, PO4
- Fasting blood glucose or HgbA1c, and lipid profile
- Free T4, TSH
- FSH, LH, Estradiol
- Serum cortisol (8 am)
- Urinalysis

**Screening Frequency**
- Baseline, then as clinically indicated
- Baseline, then as clinically indicated
- Every 2 years, or as clinically indicated
- Yearly
- Baseline, at age 13, then as clinically indicated
- Yearly
- Yearly

**Diagnostic Studies**

**Screening Recommendations**
- Abdominal x-ray
- Audiogram or brainstem auditory evoked response (ABR, BAER)
- Bone density evaluation
- ECHO (2D and m-mode) or MUGA
- EKG for evaluation of QTc interval
- Neuropsychological testing

**Screening Frequency**
- At pubertal growth spurt for patients with shunts to assure appropriate placement of distal shunt tubing in peritoneum
- Yearly
- Baseline, then as clinically indicated
- Every 2 years, or as clinically indicated
- Baseline, then as clinically indicated
- Baseline, then as clinically indicated (based on age, specific treatment, and evidence of impaired educational or vocational progress)
### Radiation

<table>
<thead>
<tr>
<th>Start Date</th>
<th>Stop Date</th>
<th>Radiation Type</th>
<th>Source Type</th>
<th>Site</th>
<th>Cumulative Site Dose (cGy)</th>
<th>Boost Site Dose (cGy)</th>
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<tbody>
<tr>
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<td>Conformal</td>
<td>Linear Acceleration</td>
<td>Flank, Left</td>
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### Chemotherapy - Cumulative Dosage Summarization

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Drug Route</th>
<th>Dose /m2</th>
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<tbody>
<tr>
<td>Carboplatin</td>
<td>Intravenous</td>
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<tr>
<td>Cyclophosphamide</td>
<td>Intravenous</td>
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<td>Dactinomycin</td>
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<tr>
<td>Doxorubicin - Adriamycin</td>
<td>Intravenous</td>
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<td>Etoposide</td>
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<td>Ifosfamide</td>
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<tr>
<td>Melphalan</td>
<td>Intravenous</td>
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<tr>
<td>Topotecan</td>
<td>Intravenous</td>
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</tr>
<tr>
<td>Vincristine</td>
<td>Intravenous</td>
<td>17</td>
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Major Medical Events

**Cardiovascular (arrhythmia/general)**

- Cardiac dysfunction associated with congenital heart disease, requiring surgical intervention (sub-aortic membrane and aortic coarctation)
- Congenital cardiovascular disease, (bicuspid aortic valve)
- Pulmonary hypertension, requiring medical intervention, (PAP 38 mmHg, TR gradient 40.26 mmHg or TR Vmax 3.17 m/s)
- Conduction abnormality, (intraventricular conduction delay, QRS 144 ms, First degree heart block, PR 198 ms)
- Cardiomyopathy requiring surgical intervention, (bilateral ventricular assist devices, heart transplant)
- Congestive heart failure requiring medical/surgical intervention, (Lasix, Carvedilol, and Lisinopril)
- Ventricular diastolic dysfunction, left
- Dyslipidemia requiring medical intervention, counseled regarding need for dietary fat restriction and for regular exercise, (Pravastatin)
- Heart block, recommend follow-up with local physician, (right bundle branch block, QRSD 134 ms)
- Borderline left ventricular systolic function, (EF 54%)
Key Survivorship Clinic Components

• Clinicians (including subspecialists) experienced in long-term follow-up care
• Comprehensive survivorship care plan
• Resources to address psychosocial concerns
• Effective communication between survivorship clinic, primary care, and patient