Surviving Sarcoma: The Rest of the Story.

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SCCA Survivorship Clinic
Fred Hutch Survivorship Program
Objectives

• Describe what you might expect going forward, after cancer treatment is completed.
• Have increased awareness of the long term and late effects of cancer treatments that may impact your health.
• Help you get *in the driver’s seat* on your survivorship journey, survivorship care planning.
Who are Survivors?
Defines someone as a cancer survivor from the time of diagnosis and for the balance of life.
National Coalition for Cancer Survivorship (NCCS) [www.canceradvocacy.org](http://www.canceradvocacy.org)

What is Survivorship?
A separate and distinct phase of cancer care addressing the unique needs of survivors after active treatment is completed.
Long Term Effects

Effects or complications during treatment that can continue into the future

Example – fatigue, sexual problems, worry

Late Effects

Effects from treatment that may not show up for months or years after treatment ends

Example – secondary cancers, heart disease
Percentage of Respondents who report physical concerns

- Energy (N = 1,356): 59%
- Concentration (N = 1,261): 55%
- Neuropathy (N = 1,058): 46%
- Pain (N = 780): 42%
- Lymphedema (N = 527): 34%
- Incontinence (N = 503): 23%
- Oral health (N = 458): 22%
- Lungs (N = 362): 20%
- Vision (N = 298): 16%
- Thyroid (N = 207): 13%
- Hearing (N = 183): 9%
- Heart (N = 184): 8%
- Infertility (N = 138): 8%
- Graft-versus-host (N = 1): 3%
- Other (N = n/a): 1%
Lack of care: Percentage of respondents who did not feel they received help for their concerns

- Graft-versus-host (N = 0): 0%
- Thyroid (N = 23): 11%
- Oral health (N = 105): 23%
- Heart (N = 59): 32%
- Lymphedema (N = 174): 33%
- Hearing (N = 68): 37%
- Vision (N = 110): 37%
- Pain (N = 289): 37%
- Lungs (N = 173): 47%
- Infertility (N = 69): 50%
- Energy (N = 759): 56%
- Neuropathy (N = 578): 60%
- Incontinence (N = 347): 69%
- Sexual functioning (N = 751): 71%
- Concentration (N = 1,047): 83%
Percentage of respondents who experienced emotional concerns

- Fear of recurrence (N = 1,827) 80%
- Grief and identity (N = 1,563) 68%
- Personal appearance (N = 1,426) 62%
- Family member risk (N = 1,174) 51%
- Personal relationships (N = 1,169) 51%
- Sadness and depression (N = 709) 31%
- Social relationships (N = 666) 29%
- Faith and spirituality (N = 183) 8%
Lack of care: percentage of respondents who did not feel they received help for their emotional concerns.
IOM Report Identified Survivorship Needs:

1. Every survivor should receive a treatment summary and care plan at the end of treatment.

2. Prevention, surveillance and detection of new and recurrent cancers.


4. Coordination between specialists and primary care providers to ensure that survivor health needs are met.
Inclusion of Survivorship in COC Accreditation Standards

Cancer Program Standards 2012: Ensuring Patient-Centered Care

Phase in for 2015.

STANDARD 3.3 Survivorship Care Plan

The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes.

DEFINITION AND REQUIREMENTS

The IOM and National Research Council 2005 report, From Cancer Patient to Cancer Survivor: Lost in Transition, recommends that patients with cancer who are completing the first course of treatment be “provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.” The recommendation suggests that these plans would help cancer survivors who may otherwise get “lost” in the transitions from the care they received during treatment through the phases of their life or stages of their disease course. The purpose of this standard is to have cancer programs develop and implement a process to monitor the dissemination of a survivorship care plan as a part of the standard care of patients with cancer. The process is implemented, monitored, evaluated, and presented annually to the cancer committee. The presentation is documented in minutes.

PROCESS REQUIREMENTS

(a) A survivorship care plan is prepared by the principal provider(s) who coordinated the oncology treatment for the patient with input from the patient’s other care providers.

(b) The survivorship care plan is given to the patient on completion of treatment.

SPECIFICATIONS BY CATEGORY

All programs fulfill the standard as written.

DOCUMENTATION

The program completes the SAR.

During the on-site visit, the surveyor will discuss with the cancer committee the methods implemented to create and disseminate a survivorship care plan.

MONITORING COMPLIANCE

Rating

(1) Compliance: The program fulfills the following criteria:

1. The cancer committee has developed a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment.

2. Each year, the process is implemented, monitored, evaluated, and presented to the cancer committee.

(5) Noncompliance: The program does not fulfill 1 or more of the following criteria:

1. The cancer committee has developed a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment.

2. Each year, the process is implemented, monitored, evaluated, and presented to the cancer committee.
So, What Does a Treatment Summary and Care Plan Look Like??
# Seattle Cancer Care Alliance
Cancer Treatment Summary and Survivorship Care Plan

**Test_Emil0316 Test Rajotte**

<table>
<thead>
<tr>
<th>Dx</th>
<th>Cancer Diagnosis</th>
<th>Values with * are estimated</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bone-Osteosarcoma</td>
<td>Date of Diagnosis 2/15/1987 [Age 47]</td>
</tr>
</tbody>
</table>

**Laterality** Left

**Subtype/Staging**

- **Histopathologic Subtype**: No data reported
- **Stage**: II
- **Size**: T0 - No evidence of primary tumor
- **Histologic Grade**: Grade cannot be assessed
- **Regional Lymph Nodes**: N0 - No regional lymph node metastasis
- **Metastases**: M0 - No distant metastasis
- **Staging or Other Comments**: No data reported

**Receptor Status**

- **Other**: No data reported

**Genetic/Molecular Markers**

- **Other**: No data reported

**Tumor Biomarkers**

- **Other**: No data reported

**Significant Past Medical History**

- 10/1/2002 - Hypertension
- Smoking/Nicotine Use: 4 pack years [Past: age 19]

**Family History**: Mother had facial melanoma diagnosed in her 80's.

## Cancer Treatment

**Treatment Facility**

Seattle Cancer Care Alliance
University of Washington Medical Center

### Surgery

<table>
<thead>
<tr>
<th>Dx</th>
<th>Procedure</th>
<th>Site</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Partial amputation of limb</td>
<td>Lower Proximal Extremity: Bone, joint, soft tissue (Left)</td>
<td>4/9/1987</td>
</tr>
</tbody>
</table>

### Systemic Therapy

<table>
<thead>
<tr>
<th>Dx</th>
<th>Agent</th>
<th>Dose</th>
<th>Start</th>
<th>Stop</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Doxorubicin (Adriamycin, hydroxydaunorubicin)</td>
<td>800.00 mg/m2 [Total] - IV</td>
<td>3/2/1987</td>
<td>3/31/1987</td>
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<tr>
<td>1</td>
<td>Cisplatin (Platinol, Platinol AQ)</td>
<td>1200.00 mg/m2 [Total] - IV</td>
<td>4/15/1987</td>
<td>5/12/1987</td>
</tr>
<tr>
<td>Wellness Topic</td>
<td>Recommendation</td>
<td></td>
<td></td>
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<tr>
<td>---------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Coordination of Care/Health Maintenance</td>
<td>It is important to have a primary care provider to coordinate and manage your general health care. They will help you stay current on wellness visits, immunizations, tests, and coordination with specialists.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Health</td>
<td>Annual visit to include physical exam, blood work, and wellness screening are recommended.</td>
<td></td>
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</tr>
<tr>
<td>Body Image</td>
<td>Surviving cancer impacts how you see yourself both physically and psychologically. Body image and roles at home or in the workplace are frequently changed by cancer. A counselor or support group can help you cope with these changes.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist or Test</td>
<td>Last Done</td>
<td>Frequency</td>
<td>Provider to Contact</td>
<td>Next Due</td>
</tr>
<tr>
<td>----------------------------------------</td>
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<td>--------------</td>
</tr>
<tr>
<td>Screening Labs - CBC, CMP, lipids, TSH, vitamin D</td>
<td>01/2016</td>
<td>Yearly</td>
<td>Horesh</td>
<td>01/2017</td>
</tr>
<tr>
<td>Oncology Follow-up</td>
<td></td>
<td>As per Oncologist</td>
<td>Byrd</td>
<td>04/2017</td>
</tr>
<tr>
<td>Radiation Oncology</td>
<td></td>
<td>As per Oncologist</td>
<td></td>
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<tr>
<td>Surgery</td>
<td></td>
<td>As per Oncologist</td>
<td></td>
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<tr>
<td>Survivorship</td>
<td></td>
<td>As per Oncologist</td>
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<tr>
<td>Long Term Follow-up (LTFU)</td>
<td></td>
<td>As per Oncologist</td>
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<tr>
<td>Genetic Counseling</td>
<td></td>
<td>As per Oncologist</td>
<td></td>
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<tr>
<td>Labs:</td>
<td></td>
<td>As per Oncologist</td>
<td></td>
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<tr>
<td>Vitamin D</td>
<td></td>
<td>As per Oncologist</td>
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<tr>
<td>Imaging:</td>
<td></td>
<td>As per Oncologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast Imaging:</td>
<td>12/2015; Mammogram - 12/2015</td>
<td>Yearly</td>
<td>Horesh</td>
<td>12/2016</td>
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<tr>
<td>Colonoscopy</td>
<td>04/2011</td>
<td>Every 10 years</td>
<td>Horesh</td>
<td>04/2021</td>
</tr>
<tr>
<td>Cardiac:</td>
<td></td>
<td></td>
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<tr>
<td>Pulmonary Function (PFT)</td>
<td></td>
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<tr>
<td>Thyroid Eval (Exam and Labs)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Skin Exam</td>
<td>01/2016</td>
<td>6-12 months</td>
<td>Horesh</td>
<td>01/2017</td>
</tr>
<tr>
<td>Bone Density (DEXA)</td>
<td>01/2016</td>
<td>Baseline, then as indicated</td>
<td>Horesh</td>
<td>01/2017</td>
</tr>
</tbody>
</table>
Ewing’s Sarcoma

11 year old boy diagnosed with Ewing’s sarcoma of left hip. Treatment included:

- Neoadjuvant and adjuvant chemotherapy with Vincristine, Doxorubicin, Cyclophosphamide, Ifosfamide, Etoposide.
- Radical resection left hip, allograft.
- Radiation to left hip.

Concerns 10 years after diagnosis transitioning from Pediatric Oncology:

Chronic left hip pain, exercise intolerance, afraid to exercise due to pain
Chronic kidney disease secondary to chemotherapy
Depression, anxiety, fatigue
Memory and concentration concerns
Questions about nutrition, lifestyle

9/1/2017
Ewing’s Sarcoma

Potential long term and late effects:

- Cardiac risk secondary to anthracycline exposure
- Musculoskeletal concerns – bone density, pain, weakness.
- Risk of second cancers – radiation field, annual skin exam.

Coordination of care:

Provide information about heart health, kidney health, bone health
Wellness exams, establish primary care at student health center, consider emotional care, nephrology, dermatology
Echocardiograms, DEXA
Consider neurocognitive testing, accommodations for school
Physical therapy, Physiatrist or Physical Medicine
What Can Effect Your Risk?

- Age
- Gender
- Genetics
- Social
- Other Health
- Lifestyle
- Radiation
- Chemotherapy
- Surgery
Rhabdomyosarcoma

4 year old girl diagnosed with unresectable nasopharyngeal rhabdomyosarcoma.

Treatment included:

- Chemotherapy with Vincristine, Doxorubicin, Cyclophosphamide, Ifosfamide, Etoposide
- Radiation to nasopharynx, base of skull

Concerns 18 years after diagnosis:

Panhypopituitarism, growth hormone deficiency, hypothyroid, adrenal insufficiency.
Decrease ejection fraction on ECHO
Concerns about Fertility, dating
Recurrent depression, anxiety, post traumatic distress, social isolation
Dental concerns
Transitioning from Pediatric Oncology, Endocrinology, Cardiology

9/1/2017
Rhabdomyosarcoma

Coordination of care:

• Transition to adult care providers, establish primary care, necessary blood and urine tests
• Referred for Onco-Fertility assessment
• Recommended counseling, ophthalmology
• Consider onco-cardiology referral
Undifferentiated pleomorphic sarcoma

70 year old woman with sarcoma, right thigh.

Treatment included:

• Neo-adjuvent pazopanib study, Doxorubicin, Ifosfamide
• Radiation to right thigh sarcoma
• Excision of tumor, pathology 95% necrosis.

Concerns 6 months off therapy:

• Indeterminate lung nodules
• Deconditioning
• Comorbidities – hyperlipidemia, hypertension, GERD, increased worry/fear of recurrence.
• Relationship stress
“Someone likened cancer to a pink elephant, and the pink elephant initially is right there in front of your face, you know... and then as you get better, the pink elephant maybe goes to another room. And then as you get much better, the pink elephant goes down the street, but it’s always there and you always know it’s there.

Prevention Works!
Control the things you can control...

• Keep blood pressure, cholesterol, blood sugar, weight and stress under control
  – Good nutrition is vital
  – Increased activity
  – Addressing emotional needs
  – Manage stress
  – Alcohol and substance use
  – Quit smoking
  – Adequate sleep is critical for physical and emotional well-being, immune function, and coping
Lifestyle Guidelines

Nutrition and Physical Activity Guidelines for Cancer Survivors

Cheryl L. Rock, PhD, RD; Colleen Doyle, MS, RD; Wendy Domark-Wannefriid, PhD, RD; Jeffrey Meyersart, MD, MPH; Kerry S. Courneya, PhD; Anna L. Schwartz, FNP, PhD, FAAN; Elisa V. Bandara, MD, PhD; Kathryn K. Hamilton, MA, RD, CSO, CDN; Barbara Grant, MS, RD, CSO, LD; Marji McCullough, ScD, RD; Tim Byers, MD, MPH; Ted Gansler, MD, MBA, MPH

Cancer survivors are often highly motivated to seek information about food choices, physical activity, and dietary supplements to improve their treatment outcomes, quality of life, and overall survival. To address these concerns, the American Cancer Society (ACS) convened a group of experts in nutrition, physical activity, and cancer survivorship to evaluate the scientific evidence and best clinical practices related to optimal nutrition and physical activity guidelines during the continuum of cancer care, briefly including those with advanced cancer, but focusing largely on the needs of the survivor following their recovery from treatment. It also discussed food choices, food safety, and dietary supplements; issues related to physical activity, and cancer survivorship. CA Cancer J Clin 2012;62:242-274

Nutrition and Physical Activity Guidelines for Cancer Survivors

It is not only safe and feasible during cancer treatment, but that it can also improve physical functioning, fatigue, and multiple aspects of quality of life.26 Some studies have also suggested that physical activity may even increase the rate of completion of chemotherapy.29 Current evidence is unclear on the interaction of exercise and chemotherapy efficacy, but in at least one randomized controlled exercise study, there was no evidence of a negative exercise effect on response to chemotherapy in a cohort of lymphoma survivors.50 One animal study also reported that exercise did not interfere with the efficacy of chemotherapy.51

The decision regarding when to initiate and how to maintain physical activity should be individualized to the patient’s condition and personal preferences. Exercise during cancer treatment improves multiple posttreatment adverse effects on bone health, muscle strength, and other quality-of-life measures.32-36 Persons receiving chemotherapy, radiation, hormone therapy, and other cancer treatments may benefit from an exercise program, although the specifics depend on therapy-related toxicities and disease stages.52

### Table 2. American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Survivors

<table>
<thead>
<tr>
<th>Guideline</th>
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<tbody>
<tr>
<td>Achieve and maintain a healthy weight.</td>
</tr>
<tr>
<td>• If overweight or obese, limit consumption of high-calorie foods and beverages and increase physical activity to promote weight loss.</td>
</tr>
<tr>
<td>Engage in regular physical activity.</td>
</tr>
<tr>
<td>• Avoid inactivity and return to normal daily activities as soon as possible following diagnosis.</td>
</tr>
<tr>
<td>• Aim to exercise at least 150 minutes per week.</td>
</tr>
<tr>
<td>• Include strength training exercises at least 2 days per week.</td>
</tr>
<tr>
<td>Achieve a dietary pattern that is high in vegetables, fruits, and whole grains.</td>
</tr>
<tr>
<td>• Follow the American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention.</td>
</tr>
</tbody>
</table>

neuropathy, changed sense of taste, difficulty chewing and swallowing, difficulty in replenishing lean body mass after the completion of therapy, and persistent bowel changes such as diarrhea or constipation.
Patient: Doctor, I don't feel well and I'm not sure why.

Doctor: I want you to meditate for 20 minutes, twice a day, exercise for at least 30 minutes a day, avoid processed foods, eat plenty of organic fruit and veg, spend more time in nature and less indoors, stop worrying about things you can't control and ditch your T.V. Come back in 3 weeks.
Survivors Quality of Life Issues Can Be Multiple and Complex

Medical Problems:
- Cardiovascular disease and cardiac failure
- Fatigue
- Osteoporosis / osteopenia
- Hypothyroidism
- Premature menopause
- Pulmonary function
- Lymphedema
- Urinary incontinence
- Infertility
- Neurologic problems (balance, neuropathy, memory)
- GI (bowels, bloating, acid reflux)
- Dental impairments
- Recurrence/Increased risk of 2nd cancers
- Accelerated aging

Emotional and Functional Concerns:
- Restricted social and physical activities
- Memory loss
- Fear of recurrence/living with uncertainty
- Muscle and joint stiffness, weakness, cramps or pain
- Sexual dysfunction
- Intimacy/relationship issues
- Distress and worry
- Job loss/Job lock
- Role changes at home
- School concerns
- Insurance problems
- Financial concern or crisis
- Sleep disorders
Cancer Advocacy Groups

• Northwest Sarcoma Foundation
• National Leiomyosarcoma Foundation
• Cancer Care – www.cancercare.org
• American Cancer Society – www.cancer.org
• ACS Cancer Action Network-advocacy arm
• Livestrong – www.livestrong.org
• National Coalition of Cancer Survivorship- www.canceradvocacy.org
• Cancer Legal Resource Center – www.disabilityrightslegalcenter.org
SCCA Survivorship Clinic
Fred Hutch Survivorship Program

K. Scott Baker, MD, Director
Karen Syrjala, PhD, Co-Director
Emily Rajotte, Associate Director
Jennie Crews, MD
Leslie Heron, ARNP
Debra Loacker, RN
Gabriella Emond, Admin Assistant
Joli Bartell, Project Coordinator
Sheri Ballard, Project Manager
Vanessa Barone, Project Manager
Thank You!
You don’t have to go ‘round in circles... Learn to manage your Survivorship and be in the drivers seat!

Questions?