Survivorship 101:
Late effects from Cancer,
Survivorship Care Planning

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Survivorship Program, Fred Hutchinson Cancer Research Center
Objectives

• Describe what you might expect *along the road* after cancer treatment is completed.

• Have increased awareness of *common hazards* – the long term and late effects of cancer and cancer therapies.

• How you can *be in the driver’s seat* on your survivorship journey, survivorship care planning.
Who are Survivors?

“...anyone who has been diagnosed with cancer from the time of diagnosis through the balance of his or her life”

What is Survivorship?

Addressing the unique needs of survivors after active treatment ends
After Treatment: The Difference Between Late and Long Term Effects

- **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
Late and Long Term Effects May Include...

Medical Problems:
- Cardiovascular disease and heart failure
- Fatigue
- Pain
- 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

Emotional and Functional Concerns:
- Memory loss
- Restricted social and physical activities
- 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
- Cognitive processing disruption
But, How Do I Know What My Own Risk Is?
What Can Effect *Your* Risk?

- Age
- Gender
- Genetics
- Social
- Other Health
- Lifestyle
- Surgery
- Radiation
- Chemotherapy
Lifestyle Changes: Potentially Preventable Causes of Death


• 2/3 of deaths in the United States were caused by heart disease, cancer, stroke, chronic lower respiratory disease, and accidents. (2010-2014)

• Potentially Preventable –
  • 30% of heart disease deaths
  • 15% of cancer deaths (30% of cancer diagnoses)
  • 28% of stroke deaths
  • 36% of chronic lower respiratory disease deaths
  • 43% of accident deaths
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
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.
IOM Report Identified Survivorship Needs:

1. Every survivor should receive a patient 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 suggested 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.
Inclusion of Survivorship in COC Accreditation Standards

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

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

(c) The written or electronic survivorship care plan contains a record of care received, important disease characteristics, and a follow-up care plan incorporating available and recognized evidence-based standards of care, when available.
So, What Does a Treatment Summary and Care Plan Look Like??
# Seattle Cancer Care Alliance

## Cancer Treatment Summary and Survivorship Care Plan

**Test_**

**Test_**

**MRN:** NA  
**Date of Birth:** 2/15/1947

### Cancer Diagnosis

<table>
<thead>
<tr>
<th>Dx</th>
<th>Cancer Type</th>
<th>Laterality</th>
<th>Values with * are estimated</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Unknown</td>
<td>No data reported</td>
<td>Date of Diagnosis 5/17/1998 [Age 51]</td>
</tr>
</tbody>
</table>

#### Subtype/Staging

- **Histopathologic Subtype:** No data reported
- **Stage:** No data reported
- **Size:** No data reported
- **Histologic Grade:** No data reported
- **Regional Lymph Nodes:** No data reported
- **Metastases:** No data reported

#### Staging or Other Comments

**Receptor Status:**

- **Other:** No data reported

**Genetic/Molecular Markers**

- **Other:** No data reported

**Tumor Biomarkers**

- **Other:** No data reported

### Significant Past Medical History:

- 6/1/2005 - Cataracts
- 2011 - Pacemaker
- 1/5/1998 - Anemia (unrelated to cancer therapy)

### Family History:

- No data reported

## 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>
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</thead>
<tbody>
<tr>
<td></td>
<td>No data reported</td>
<td></td>
<td></td>
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</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>Paclitaxel (Abraxane, Taxol)</td>
<td>5800.00 mg/m2 [Total] - IV</td>
<td>2/12/2001</td>
<td>2/28/2001</td>
</tr>
</tbody>
</table>

### Radiation Therapy

<table>
<thead>
<tr>
<th>Dx</th>
<th>Radiation Type</th>
<th>Site</th>
<th>Dose</th>
<th>Start</th>
<th>Stop</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>External Beam (conventional)</td>
<td></td>
<td>2590 centigray (cGy)</td>
<td>4/1/2001</td>
<td>4/17/2001</td>
</tr>
<tr>
<td>Long Term Effects and Follow Up Care</td>
<td>Recommendation</td>
<td></td>
<td></td>
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<td>-------------------------------------</td>
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<tr>
<td>Oncology Care</td>
<td>Your oncologist will determine how often and for how long you should be seen based on your specific needs, including the need for blood tests and radiology exams. Most patients diagnosed with cancer continue to be followed by their oncologist for at least 5 years from diagnosis.</td>
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<tr>
<td>Eye/Vision</td>
<td>Radiation, steroids, and other medications increase the risk of cataracts, dry eyes, and changes in the blood vessels in your eyes. Annual eye exams are recommended. If you experience blurred vision, light sensitivity, difficulty with reading or night vision, or sudden vision changes, more urgent evaluation may be needed.</td>
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<tr>
<td>Hearing</td>
<td>Treatment of your cancer with certain chemotherapy agents, head/neck radiation, and other drugs used during your treatment may affect your hearing. Audiology evaluation is recommended if you are noticing changes in your hearing. Symptoms can include ringing in your ears, hearing loss, or changes in balance.</td>
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<tr>
<td>Oral/Dental</td>
<td>Chemotherapy and/or radiation may increase the risk for cavities, tooth and mouth sensitivity, and oral cancer. Twice yearly dental exams and cleanings are recommended. Things to watch for include dry mouth, change in sense of taste, gum irritation or bleeding, tooth or jaw pain, and delayed healing following dental work.</td>
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<tr>
<td>Speech/Swallowing</td>
<td>Radiation and surgery to your head and neck can cause changes in your speech, dry mouth, and difficulty swallowing. Speech or occupational therapists can help with rehabilitation of these problems. New or sudden changes in speech or swallowing need to be addressed more urgently with a medical provider.</td>
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<tr>
<td>Thyroid</td>
<td>Surgery and/or radiation to the thyroid can impact your thyroid gland. Blood tests for thyroid function and physical exam of the neck are recommended annually. Changes in metabolism such as unexpected weight gain or loss, irregular heart rate, fatigue, mood changes, and bowel or menstrual changes require evaluation by your provider. If thyroid function abnormalities are found, medication may be recommended and an endocrinology referral might be considered.</td>
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<tr>
<td>Long Term Effects and Follow Up Care</td>
<td>Recommendation</td>
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<tr>
<td>Cardiac (Heart) with high exposure</td>
<td>Heart problems can occur after certain chemotherapy drugs (anthracyclines) or after chest radiation depending on the doses you have received. An electrocardiogram (ECG), echocardiogram, and/or other cardiac studies may be recommended on a routine schedule based on your level of exposure. Annual evaluation of blood pressure, cholesterol, weight, blood sugar, carotid vessel and heart health is recommended. Be aware of your heart beating too fast (tachycardia), irregular heart rate (arrhythmias), shortness of breath or increased fatigue and report these to your health care provider. Please call 911 for sudden onset of chest pain, pressure or shortness of breath.</td>
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<table>
<thead>
<tr>
<th>Wellness Topic</th>
<th>Recommendation</th>
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<tbody>
<tr>
<td>Heart Health</td>
<td>Eat a low fat diet, get regular aerobic exercise, avoid smoking and maintain a healthy weight. Monitor blood pressure and cholesterol levels. Be aware of your family history and personal risks for diabetes, stroke, and heart disease.</td>
</tr>
<tr>
<td>Intimacy/Sexual Health</td>
<td>Intimacy can be hard to initiate after cancer treatments. Communicate with your partner and allow time for talking and re-learning about each other. Discuss what does and does not feel good now and plan time for intimacy. Vaginal lubricants, moisturizers or localized estrogen therapy may be helpful for dry or painful tissues. Consider the assistance of a counselor for intimacy issues and a woman’s health specialist for help with vaginal atrophy or other physical issues if needed.</td>
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<tr>
<td>Nutrition</td>
<td>Nutrition is critical to optimize health, improve fatigue and mental acuity, and reduce cancer risk. Eat a wide variety of fruits, vegetables and whole grains, stay well-hydrated, and limit fat, salt, and alcohol intake. A nutritionist can assist you in customizing dietary recommendations for your needs.</td>
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<tr>
<td>Test</td>
<td>Last Done</td>
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<td>------------------------------</td>
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<tr>
<td>Survivorship</td>
<td>2011</td>
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<tr>
<td>Complete Physical Exam</td>
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<tr>
<td>Oncology Follow-up</td>
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<tr>
<td>Surveillance for Risk of Recurrence</td>
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<tr>
<td>Bone Density Test</td>
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<td>Colonoscopy</td>
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<td>Screening Labs</td>
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<td>Gynecological Exam</td>
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<td>Pap Smear</td>
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<td>Mammogram</td>
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<tr>
<td>Breast MRI</td>
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<tr>
<td>Skin Exam</td>
<td>1998</td>
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<tr>
<td>Cardiac Screening</td>
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<tr>
<td>Vision Exam</td>
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<td>Dental Exam</td>
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<tr>
<td>Immunizations</td>
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**Contact/Resources**

Seattle Cancer Care Alliance (SCCA) Survivorship Clinic
825 Eastlake Ave East Seattle, WA 98109
survivor@seattlecca.org
Phone: 206-288-1021 Fax: 206-667-1502
http://www.seattlecca.org/survivorship
SCCA Survivorship Clinic
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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?