Knowledge is Power: Why You Need a Treatment Summary and Survivorship Care Plan

Leslie Heron, RN, BSN, MN, APRN, FNP-BC, NC-BC

Moving Beyond Cancer to Wellness
June 2, 2018
Objectives

• Learn about Treatment Summary and Survivorship Care Plans

• Understand why this document is recommended for cancer survivors

• Learn how to use a Treatment Summary and Survivorship Care Plan to advocate for yourself
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
Transition to Survivorship
Why *Plan* for Survivorship?

- There are more people surviving cancer
  - Screening tests for cancer are better
  - Earlier screening is happening
  - More effective treatments are available

- Cancer survivors are living longer
  - Both childhood and adult survivors are living long lives after treatment has been completed

*But...*
...There can be Long Term and Late Effects

**Medical Problems:**
- Heart disease
- Fatigue
- Pain
- Osteoporosis / osteopenia
- Hypothyroidism
- Premature menopause
- Pulmonary function
- Lymphedema
- Urinary incontinence
- Infertility
- Neurologic problems
- GI (bowels, bloating, acid reflux)
- Dental impairments
- Recurrence
- Risk of 2nd cancers
- Accelerated aging

**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
So, Cancer Survivors Spoke Up!
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.
Standard 3.3: Survivorship Care Plan

- Provided to you at the end of treatment
- Prepared by Oncology team
- Contains
  - Diagnosis and all treatments
  - Surveillance and screening
  - Actual and potential late effects
    - And what to look for
  - Healthy lifestyle information
  - Your healthcare providers
  - Resources
The standard requires that the survivors be, “provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.”

Treatment Summary Goal

• Increase knowledge of your diagnosis and the treatment you have received

• Assist transition back to primary care and other healthcare providers
Survivorship Care Plan Goal

• Increase knowledge for patient and providers
• Recommend health screenings and cancer surveillance
• Promote a healthy lifestyle and illness prevention
What Might a Treatment Summary and Care Plan Look Like?
# Diagnosis and Medical History

## Seattle Cancer Care Alliance
Cancer Treatment Summary and Survivorship Care Plan

### Jane Smith

- **Date of Birth:** 9/7/1975

<table>
<thead>
<tr>
<th>Dx</th>
<th>Cancer Diagnosis</th>
<th>Values with * are estimated</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Breast</td>
<td>Date of Diagnosis 3/15/2015 [Age 39]</td>
<td></td>
</tr>
</tbody>
</table>

**Laterality:** Right

### Breast Right

- **Histopathologic Subtype:** Invasive: Infiltrating Ductal
- **Stage:** II
- **Size:** T2 Tumor > 2 cm but <= 5 cm in greatest dimension
- **Histologic Grade:** G3 (High grade or poorly differentiated)
- **Regional Lymph Nodes:** N0 No regional lymph node metastasis
- **Metastases:** M0 No distant metastasis

**Staging or Other Comments:** No data reported

### Receptor Status

- **Estrogen:** Positive
- **Progesterone:** Positive
- **Her2 neu:** Negative
- **IHC:** Borderline (2+)
- **FISH:** Negative for over-expression

### Genetic/Molecular Markers

- **BRCA1:** Negative
- **BRCA2:** Negative
- **BART:** Negative
- **BROCA:** No data reported
- **P53:** Negative

**Oncotype Diagnosis:** No data reported

**Other Molecular Markers:**

**Significant Past Medical History:**

- Skin: Chronic eczema

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*Survivors Program*
Cancer Treatment

**Treatment Facility:**
Mount Talbert Medical Office  
10100 SE Sunnyside Rd  
Clackamas, OR 97015

Cancer Center Radiation Oncology  
4514 B Cornell St  
Clackamas, OR 97895

<table>
<thead>
<tr>
<th>Dx</th>
<th>Procedure</th>
<th>Site</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Biopsy of suspicious left breast mass revealed benign sclerosing adenosis</td>
<td>Breast (Left)</td>
<td>4/7/2015</td>
</tr>
<tr>
<td>1</td>
<td>Lymphectomy or excisional biopsy</td>
<td>Breast (Right)</td>
<td>4/19/2015</td>
</tr>
<tr>
<td>1</td>
<td>Sentinel Lymph Node Biopsy (Nodes positive: 0, removed: 2)</td>
<td>Breast (Right)</td>
<td>4/19/2015</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>240.00 mg/m² [Total] - IV</td>
<td>5/8/2015</td>
<td>6/20/2015</td>
</tr>
<tr>
<td>1</td>
<td>Cyclophosphamide (Cytoxan, Neosar)</td>
<td>IV</td>
<td>5/8/2015</td>
<td>6/20/2015</td>
</tr>
<tr>
<td>1</td>
<td>Pegfilgrastim (Neulasta)</td>
<td></td>
<td>5/8/2015</td>
<td>6/20/2015</td>
</tr>
<tr>
<td>1</td>
<td>Goserelin (Zoladex)</td>
<td></td>
<td>4/27/2015</td>
<td>9/2015</td>
</tr>
<tr>
<td>1</td>
<td>Paclitaxel (Abraxane, Taxol)</td>
<td>IV</td>
<td>7/3/2015</td>
<td>9/16/2015</td>
</tr>
</tbody>
</table>

Complications:
Grade 2 peripheral neuropathy, Taxol held.  
Stopped Tamoxifen secondary to vasomotor symptoms, declined further hormonal therapy.

**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>6200 centigray (cGy)</td>
<td>10/16/2015</td>
<td>12/12/2015</td>
</tr>
<tr>
<td>1</td>
<td>External Beam (conventional)</td>
<td>Breast</td>
<td>4600 centigray (cGy)</td>
<td>11/16/2015</td>
<td>12/29/2015</td>
</tr>
</tbody>
</table>

**Providers**

**General Medical Care**
Primary Care Provider: Richard Foxlee, MD  
UW Neighborhood Clinic  
1123 Northgate Way  
Shenando Beach, WA 98368

**Oncology Care**
Medical Oncologist: Dawn Reardon, MD  
Surgeon: David Richardson, MD  
Mount Talbert Medical Office  
10100 SE Sunnyside Rd  
Clackamas, OR 97015

Radiation Oncologist: Sheila Bailey, MD  
Cancer Center Radiation Oncology  
4514 B Cornell St  
Clackamas, OR 97895
### Survivorship Care Plan

<table>
<thead>
<tr>
<th>Long Term Effects and Follow Up Care</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<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>
</tr>
<tr>
<td>Lymphedema</td>
<td>Surgery and/or radiation can damage or disrupt your lymph nodes causing accumulation of fluid particularly in your arms or legs. Air travel or prolonged immobility may worsen symptoms. If you have been given a diagnosis of lymphedema, physical or occupational therapy, massage, stretching exercises, compression garments, and proper skin care may help with symptoms. Unexpected or abnormal swelling in any part of your body should be discussed with your healthcare provider.</td>
</tr>
<tr>
<td>Skin</td>
<td>Cancer treatments may cause skin changes. There may be residual pain or scarring at surgical sites. Late affects from radiation include discoloration and thickening of the skin. Chemotherapy agents can lead to dryness and hypersensitivity. Both of these treatments can increase your risk of skin cancer over time. Annual skin examination, limiting exposure to sun, and avoiding smoking and indoor tanning are recommended. Use of sunscreen SPF 30+ and protective clothing are strongly encouraged. Report skin changes of any kind to</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wellness Topic</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<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>
</tr>
<tr>
<td>General Health</td>
<td>Annual visit to include physical exam, blood work, and wellness screening are recommended.</td>
</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 work place are frequently changed by cancer. A counselor or support group can help you cope with these changes.</td>
</tr>
<tr>
<td>Specialist or Test</td>
<td>Last Done</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Oncology Follow-up</td>
<td>10/23/2016</td>
</tr>
<tr>
<td>Radiation Oncology</td>
<td>01/11/2016</td>
</tr>
<tr>
<td>Survivorship</td>
<td>12/17/2016</td>
</tr>
<tr>
<td>Genetic Counseling</td>
<td>06/08/2015</td>
</tr>
<tr>
<td>Labs:</td>
<td>10/2016</td>
</tr>
<tr>
<td>Vitamin D</td>
<td></td>
</tr>
<tr>
<td>Imaging:</td>
<td>Breast MRI</td>
</tr>
<tr>
<td></td>
<td>11/03/2016</td>
</tr>
<tr>
<td>Breast Imaging:</td>
<td>Mammo with Tomo</td>
</tr>
<tr>
<td></td>
<td>05/01/2016</td>
</tr>
<tr>
<td>Skin Exam</td>
<td>12/13/2016</td>
</tr>
<tr>
<td>Bone Density (DEXA)</td>
<td></td>
</tr>
<tr>
<td>Immunizations:</td>
<td>Td: 2014</td>
</tr>
<tr>
<td>Echocardiogram</td>
<td></td>
</tr>
</tbody>
</table>
# Follow-Up Plan

## Wellness Screening

*Based on National Cancer Institute, U.S. Preventive Task Force, and National Institutes of Health recommendations.*

<table>
<thead>
<tr>
<th>Test or Exam</th>
<th>Frequency</th>
<th>Provider to Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well Physical</td>
<td>Yearly</td>
<td>Primary Care</td>
</tr>
<tr>
<td>Skin, eyes, mouth, thyroid, carotids, heart, lungs, breast, abdomen, lymphatics, blood pressure, immunization status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental and Oral</td>
<td>Twice a year or as indicated</td>
<td>Dentist</td>
</tr>
<tr>
<td>Vision</td>
<td>Yearly or as indicated</td>
<td>Ophthalmology or Optometry</td>
</tr>
<tr>
<td>Gynecologic</td>
<td>Yearly pelvic and rectal exam, Pap/HPV screening every 3 years age 21–65, or as indicated by risk factors</td>
<td>Primary Care or Gynecology</td>
</tr>
<tr>
<td>Screening Labs</td>
<td>Every 1 - 5 years depending on baseline lab values, age, and risk factors</td>
<td>Primary Care</td>
</tr>
<tr>
<td>CBC, liver, kidney, blood sugar, lipids, thyroid, urinalysis, fecal occult blood</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colonoscopy / Sigmoidoscopy</td>
<td>Every 3 – 10 years depending on risk factors, begin age 50 unless earlier symptoms</td>
<td>Primary Care or Gastroenterology</td>
</tr>
</tbody>
</table>

## 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

For more detailed information on many of these topics, please see Health Links at http://www.seattlecca.org/survivorship
Now...
Let’s See How a Treatment Summary and Care Plan Can Help Empower YOU!
Mike’s dentist had been seeing him for a few years, and was surprised Mike had so many new cavities and receding gums. Mike brushed, flossed, came in for dental visits regularly. What Mike’s dentist didn’t know was that Mike had chemotherapy and radiation for prostate cancer about a year ago.

Mike came in for a Survivorship Clinic visit and finally understood what was going on, and why!

When Mike brought his Treatment Summary and Care Plan to a dental visit, his dentist was able to come up with a better preventative plan, now Mike is coming in for cleanings every 4 months.
Lois had colon cancer last year. She has done physical therapy for the past few months to get her strength back after surgery, chemo and radiation. She has been getting stronger, but her legs feel “heavy” after she takes a long walk or after being in the car a long time.

Lois tried not exercising for a few days in a row, but her symptoms didn’t change. Now her pants feel tighter on her legs. What is going on?

She read back through her Survivorship Care Plan and took it in with her to a medical visit. Her nurse practitioner realized Lois had lymphedema! Lois went back to physical therapy to have lymphedema massage and to be fitted with compression stockings. She is doing her own massage now and is back to exercising without problems.
Karl was treated in his teens for Hodgkin lymphoma, and now is in his mid-40’s and has been healthy and well. He has put on a little weight and wanted to get back in shape, but found he was feeling more fatigued after exercise. He thought he should feel better after exercise! He did not have a primary care provider, but he’d heard about Survivorship Clinic from his support group.

After reviewing his Treatment Summary, Karl realized he had been treated with Doxorubicin. This chemotherapy may have put him at risk for heart problems, even years after treatment. He has gotten in to see a primary care provider for a physical exam and blood work, and is scheduled for an echocardiogram to look.
Sandra had a transplant 8 years ago, and she had been doing great. She got in for routine check-ups, had blood tests done yearly, and had routine mammograms. Then she started feeling tired, and noticed her hair was getting thinner. Then her fatigue got worse and her shoulders felt achy. She began to worry that her cancer may have come back!

When she went in to see her primary care provider, they looked over her Treatment Summary and Care Plan together. Sandra had both chemotherapy and radiation during treatment. Her doctor realized they hadn’t checked her blood work for thyroid hormone levels with her yearly labs last year.

Sandra’s exam and tests all came back normal, except her thyroid labs. She was put on thyroid medication and is feeling great again.
Treatment Summary & Care Plans

• Ask your Oncology team for a Treatment Summary and Survivorship Care Plan of your own!

• Ask if your cancer center has a Survivorship Clinic

• Come to the Fred Hutch/SCCA Survivorship Clinic
Or...Make Your Own Treatment Summary!

• **LIVESTRONG™ Care Plan**
  [www.livestrongcareplan.org](http://www.livestrongcareplan.org)
  – Patient-oriented tool
  – Comprehensive individualized list of recommendations specific to primary cancer diagnosis & treatment received
  – Powered by Penn Medicine’s OncoLink

• **Journey Forward**
  [www.journeyforward.org](http://www.journeyforward.org)
  – Providers & Patients
  – Collaborative effort of:
    • National Coalition for Cancer Survivorship
    • The UCLA Cancer Survivorship Center, Wellpoint, Inc., Genentech
Making Your Care Plan

A treatment summary and survivorship plan are the pieces that have been missing in my care since finishing treatment.

A survivorship care plan is the formerly missing step to help us survivors regain our dignity and confidence moving forward with a plan with our eyes open.

After my cancer treatment, I knew there were tests I needed and illness I was at an increased risk for, but I didn’t know the specifics. Now I know exactly what I need to do to be as healthy as possible in the future.
Thank you!