

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

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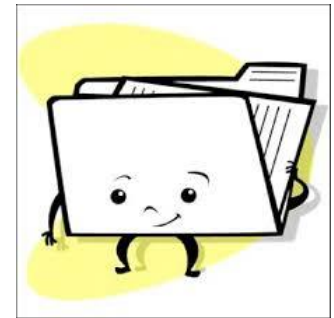
Moving Beyond Cancer to Wellness

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.”

American Cancer Society definition

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

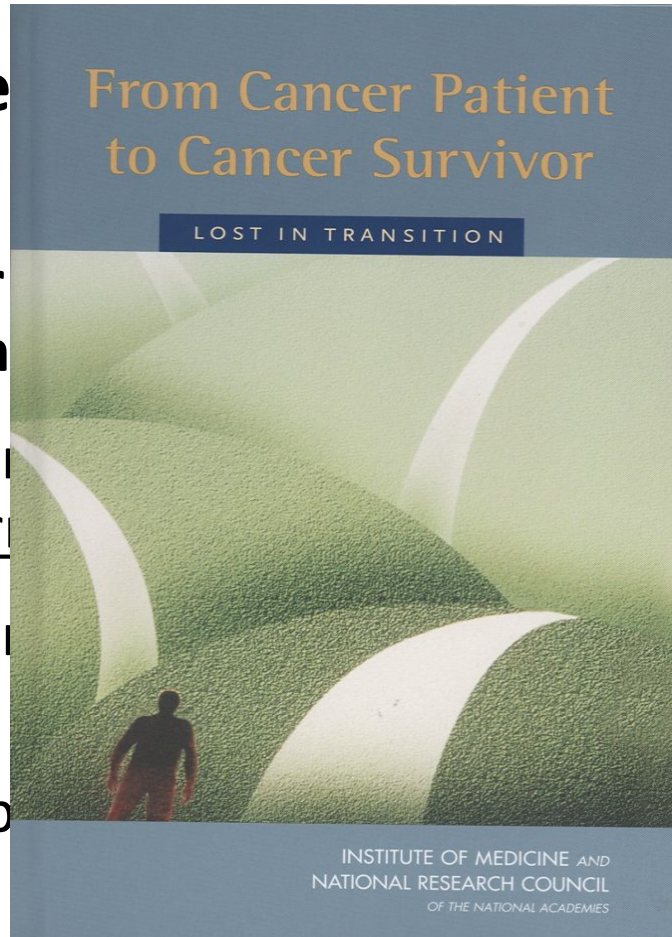
So, Cancer Survivors Spoke Up!



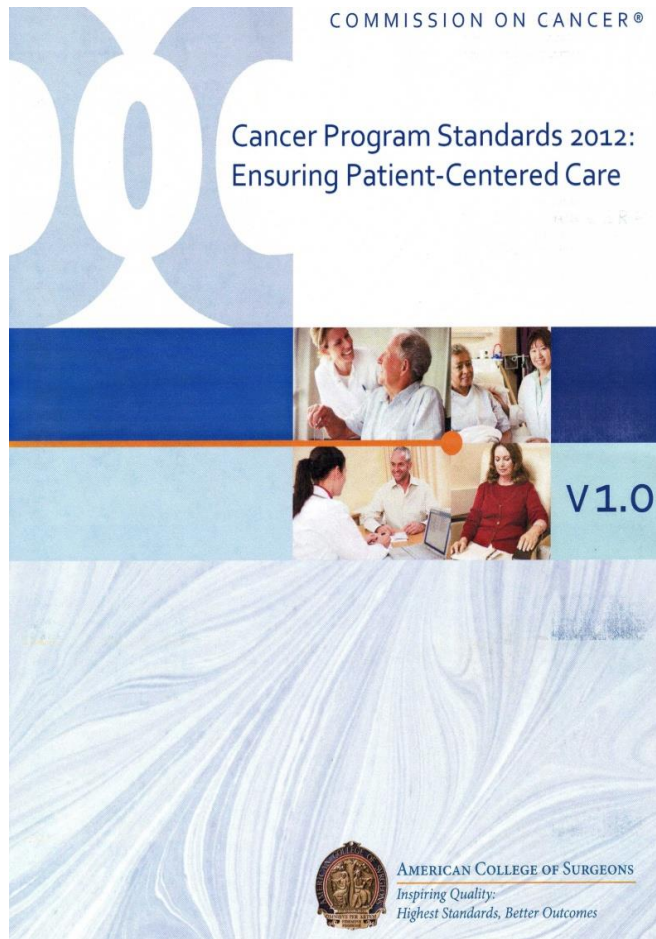
IOM: From Cancer Patient to Cancer Survivor: Lost In Transition (2006)

IOM Report Ideas Needs:

1. Every survivor has a care plan at the time of diagnosis that includes a summary and
2. Prevention, surveillance, and management of new and recurring
3. Prevention, surveillance, and management of long-term consequences
4. Coordination between primary care providers to ensure that 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.”



<https://www.facs.org/publications/newsletters/coc-source/special-source/standard33>

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		MRN [REDACTED] Date of Birth: 9/7/1975
Dx	Cancer Diagnosis	Values with * are estimated
1	Breast	Date of Diagnosis 3/15/2015 [Age 39]
	<i>Laterality</i>	Right
	Breast Right	
	<i>Histopathologic Subtype</i>	Invasive: Infiltrating Ductal
	<i>Stage</i>	II
	<i>Size</i>	T2 Tumor > 2 cm but <= 5 cm in greatest dimension
	<i>Histologic Grade</i>	G3 (High grade or poorly differentiated)
	<i>Regional Lymph Nodes</i>	N0 No regional lymph node metastasis
	<i>Metastases</i>	M0 No distant metastasis
	<i>Staging or Other Comments</i>	No data reported
	Receptor Status	
	<i>Estrogen</i>	Positive
	<i>Progesterone</i>	Positive
	<i>Her2 neu</i>	Negative
	<i>IHC</i>	Borderline (2+)
	<i>FISH</i>	Negative for over- expression
	<i>Other Receptors</i>	No data reported
	Genetic/Molecular Markers	
	<i>BRCA1</i>	Negative
	<i>BRCA2</i>	Negative
	<i>BART</i>	Negative
	<i>BROCA</i>	No data reported
	<i>P53</i>	Negative
	<i>Oncotype Diagnosis</i>	No data reported
	<i>Other Molecular Markers</i>	BreastNext panel 7/2015 negative for mutations
Significant Past Medical History: Skin: Chronic eczema		

Treatment Summary...

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					
Surgery					
Dx	Procedure	Site	Date		
1	Biopsy of suspicious left breast mass revealed benign sclerosing adenosis.	Breast (Left)	4/7/2015		
1	Lumpectomy or excisional biopsy	Breast (Right)	4/19/2015		
1	Sentinel Lymph Node Biopsy (Nodes positive: 0, removed: 2)	Breast (Right)	4/19/2015		
Systemic Therapy					
Dx	Agent	Dose	Start	Stop	
1	Doxorubicin (Adriamycin, hydroxydaunorubicin)	240.00 mg/m2 [Total] - IV	5/8/2015	6/20/2015	
1	Cyclophosphamide (Cytoxan, Neosar)	IV	5/8/2015	6/20/2015	
1	Pegfilgrastim (Neulasta)		5/8/2015	6/20/2015	
1	Goserelin (Zoladex)		4/27/2015	9/2015	
1	Paclitaxel (Abraxane, Taxol)	IV	7/3/2015	9/15/2015	
1	Tamoxifen (Novaldex)	Oral	2/8/2016	3/2016	
Complications: Grade 2 peripheral neuropathy, Taxol held. Stopped Tamoxifen secondary to vasomotor symptoms, declined further hormonal therapy.					
Radiation Therapy					
Dx	Radiation Type	Site	Dose	Start	Stop
1	External Beam (conventional)		6200 centigray (cGy)	10/16/2015	12/12/2015
1	External Beam (conventional)	Breast	4600 centigray (cGy)	11/16/2015	12/29/2015
Providers					
General Medical Care Primary Care Provider: Richard Foxlee, MD UW Neighborhood Clinic 1123 Northgate Way Sheridan 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

Long Term Effects and Follow Up Care	Recommendation
Oncology Care	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.
Lymphedema	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.
Skin	Cancer treatments may cause skin changes. There may be residual pain or scarring at surgical sites. Late effects 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

Wellness Topic	Recommendation
Coordination of Care/Health Maintenance	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.
General Health	Annual visit to include physical exam, blood work, and wellness screening are recommended.
Body Image	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.

Follow-Up Plan

Oncology Follow-up				
<i>Based on your oncologist recommendations, personal diagnosis, treatment exposures, and/or risk factors.</i>				
Specialist or Test	Last Done	Frequency	Provider to Contact	Next Due
Oncology Follow-up	10/23/2016	As per oncologist - currently every 3 months	Reardon	02/2017
Radiation Oncology	01/11/2016	As needed	Bailey	
Survivorship	12/17/2016	As needed	Heron	
Genetic Counseling	06/08/2015	If concerns		
Labs:	10/2016	Yearly CBC, BMP, urinalysis. Every 1-3 years lipids, TSH, vitamin D.	Reardon or PCP	02/2017
Vitamin D		For chemotherapy, radiation and Goserlin exposure.	Reardon	Baseline due
Imaging:	Breast MRI 11/03/2016	As per oncology	Reardon	
Breast Imaging:	Mammo with Tomo 05/01/2016	Surveillance as per oncologist	Reardon	
Skin Exam	12/13/2016	Yearly	Bailey	
Bone Density (DEXA)		Every 1-5 years, depending on baseline exam	Reardon or PCP	Baseline due
Immunizations:	Td: 2014	Yearly	Reardon or PCP	Flu recommended
Echocardiogram		Baseline, then every 5 years post anthracycline exposure	Reardon or PCP	Baseline (1 year post-treatment) recommended



Follow-Up Plan

Wellness Screening		
<i>Based on National Cancer Institute, U.S. Preventive Task Force, and National Institutes of Health recommendations.</i>		
Test or Exam	Frequency	Provider to Contact
Well Physical Skin, eyes, mouth, thyroid, carotids, heart, lungs, breast, abdomen, lymphatics, blood pressure, immunization status	Yearly	Primary Care
Dental and Oral	Twice a year or as indicated	Dentist
Vision	Yearly or as indicated	Ophthalmology or Optometry
Gynecologic	Yearly pelvic and rectal exam Pap/HPV screening every 3 years age 21–65, or as indicated by risk factors	Primary Care or Gynecology
Screening Labs CBC, liver, kidney, blood sugar, lipids, thyroid, urinalysis, fecal occult blood	Every 1 - 5 years depending on baseline lab values, age, and risk factors	Primary Care
Colonoscopy / Sigmoidoscopy	Every 3 – 10 years depending on risk factors, begin age 50 unless earlier symptoms	Primary Care or Gastroenterology
Contact/Resources		
<p align="center"> 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 </p> <p align="center"> <i>For more detailed information on many of these topics, please see Health Links at</i> http://www.seattlecca.org/survivorship </p>		





Now...

Let's See How a Treatment
Summary and Care Plan Can
Help Empower YOU!

Long Term Effects and Follow Up Care	Recommendation
Oral/Dental	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.

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.

Long Term Effects and Follow Up Care	Recommendation
Lymphedema	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.

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.

Long Term Effects and Follow Up Care	Recommendation
Cardiac (Heart) with high exposure	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.

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.

Wellness Topic	Recommendation
Heart Health	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.

Long Term Effects and Follow Up Care	Recommendation
Thyroid	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.

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

- 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

- 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!