



Survivorship Care:

Your Unique Survivorship Care Plan

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Survivorship Program
Fred Hutch Cancer Center

Moving Beyond Cancer to Wellness

June 1, 2024 - Fred Hutch Campus

- 1** Who is a Cancer Survivor.
- 2** Overview of challenges for the patient and their providers.
- 3** Surgery/Radiation/Chemotherapy/immunotherapy/targeted
- 4** Long Term and Late effects- Challenges.
- 5** Building your unique plan

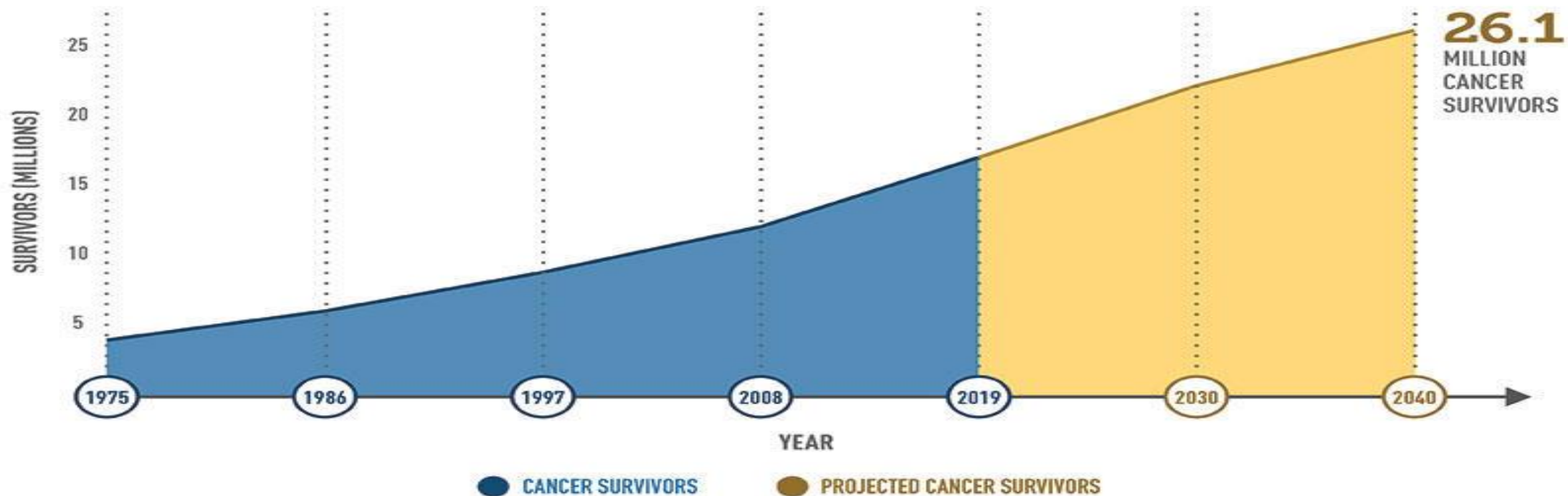
Who is a Cancer Survivor?

NCCN (National Comprehensive Cancer Network) Guidelines Version 1.2023

Definition of Survivorship

- **An individual is considered a cancer survivor from diagnosis, through the balance of life. This includes survivors living with cancer and those free of cancer.**
- *The panel recognizes that not all individuals with a history of cancer identify with the term "survivor." These guidelines are meant to be inclusive and use the term "survivor" to describe anyone with a history of cancer.*

NUMBER OF CANCER SURVIVORS IN THE UNITED STATES



The number of cancer survivors in the United States is projected to grow to 26.1 million by 2040. NCI considers a person to be a cancer survivor from the time of diagnosis until the end of life.

Source: Institute of Medicine and National Research Council. 2006. *From Cancer Patient to Cancer Survivor: Lost in Transition*. The National Academies Press. doi: 10.17226/11468.

de Moor JS, et al. *Cancer Epidemiol Biomarkers Prev*. 2013 Mar. doi: 10.1158/1055-9965.EPI-12-1356.

cancer.gov

Survivors do not know what they do not know

- *Many survivors do not know what they need: what is 'normal'*
 - Unaware of what tests and follow up visits they should have
 - Unsure which physician specialists they should continue to see, or see for what
 - Unsure how they 'should feel'
- *Care Coordination is unclear*
 - Oncologist may think primary care is doing monitoring beyond cancer surveillance
 - Primary care may think Oncologist is doing cancer monitoring and preventive care
 - Primary care lacking time, experience or comfort with this role
 - Assumed transitions that are being missed
 - Survivors may not know who to see when and for what – need guidance
- *Lack access to survivorship care*
 - Services are not available, or survivors do not know about services



Radiation therapy

- Cavities and tooth decay
- Early menopause
- Heart and vascular problems
- Hypothyroidism
- Increased risk of other cancers
-skin, AML
- Increased risk of stroke
- Infertility
- Intestinal problems
- Lung disease
- Lymphedema
- Memory issues
- Osteoporosis

Chemotherapy

- Dental problems
- Early menopause
- Hearing loss
- Heart problems
- Increased risk of other cancers
- Infertility
- Loss of taste
- Lung disease
- Nerve damage
- Memory issues
- Osteoporosis
- Problems with digestion
- Reduced lung capacity

Surgery	<ul style="list-style-type: none"> • Lymphedema
Hormone therapy	<ul style="list-style-type: none"> • Blood clots • Hot flashes • Increased risk of other cancers • Menopausal symptoms • Osteoporosis • Sexual side effects
Immunotherapy	<ul style="list-style-type: none"> • Arthritis • Myocarditis • Hepatitis • Pneumonitis • Rash....
Targeted therapy	<ul style="list-style-type: none"> • Blood clots • Heart and vascular problems

What's the Difference Between Long Term and Late Effects?



- **Long Term Effects**

Effects or complications that begin during treatment and persist.

Examples – fatigue, peripheral neuropathy, sexual problems, lymphedema

- **Late Effects**

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

Example – secondary cancers, heart disease, pulmonary fibrosis, early menopause



Types of Late effects

Nearly any cancer treatment can cause late effects. And different treatments can cause different late effects. Below is a list of the more common late effects.

Problems from surgery. Late side effects from surgery depend on the type of cancer and where in the body was performed.

- Survivors of Hodgkin lymphoma, especially those diagnosed before 1988, often had their spleens removed resulting in a higher risk of infections.

Cardiac:

Both chemotherapy and radiation therapy to the chest can cause heart problems. Some survivors may have a higher risk. This includes those who:

- Received treatment for Hodgkin lymphoma as a child
- Mantle Radiation
- Are 65 and older
- Received higher doses of chemotherapy
- Received certain medicines, such as trastuzumab (Herceptin, Ogivri) and doxorubicin (Adriamycin, Doxil)
- Comorbidities – obesity, HTN, DM Hyperlipidemia

Watch out for Symptoms:

- Congestive heart failure (CHF)
- Left Ventricular dysfunction
- Coronary artery disease
- Arrhythmias – A fib., Ventricular arrhythmias, Brady arrhythmias/heart block, QT Prolongation

Examples of drugs that can cause Cardiac problems:

Trastuzumab, Pertuzumab, Doxorubicin, Daunorubicin (Cerubidine), Epirubicin (Ellence), Cyclophosphamide (Genoxal, Mitoxan), Osemertinib (Tagrisso)

Consider EKG, Muga (multiple-gated acquisition scan), Echo.

Pulmonary:

Chemotherapy and Radiation therapy to the chest can affect the lungs. Cancer survivors who received both chemotherapy and radiation therapy may have a higher risk of lung damage. People who have had lung disease and older adults may have more sequelae.

Drugs that may cause lung damage include:

- Bleomycin (Blexane)
- Carmustine (Becenum, BiCNU, Carmubris)
- Methotrexate (multiple brand names)

The late effects to the lungs may include:

- Changes in pulmonary function
- Thickening of the lining of the lungs
- Inflammation of the lungs
- Difficulty breathing

Endocrine:

- **Menopause.** Many cancer treatments may cause a woman and men to experience an early Menopause. These treatments include:
 - Surgery – Oophorectomy, Prostate surgery, testicular surgery
 - Chemotherapy
 - Hormone therapy
 - Radiation therapy to the pelvic area

Menopausal symptoms caused by cancer treatment may be worse than the symptoms of natural menopause. This is because the decrease in hormones happens more quickly. Symptoms include:

- Changes in mood or sexual desire
- Hot flashes
- Osteoporosis
- Bladder control problems

- **Infertility.** Treatments that affect reproductive organs or the endocrine system increase risk of infertility. Infertility means not being able to become pregnant or father a child. Sometimes infertility from cancer treatment lasts a short time. But sometimes it is permanent. Learn more about fertility concerns and preserving fertility in both men and women.
- **Hormone problems from head and neck radiation therapy.** Radiation therapy to the head and neck area can lower hormone levels. It can also cause changes to the thyroid gland.

Bone, joint, and soft tissue problems. Chemotherapy, steroid medications, or hormonal therapy may cause Osteopenia/ Osteoporosis.

Immunotherapy may cause problems in the joints or muscles-autoimmune. People who are not physically active may have a higher risk of these conditions. Cancer survivors can lower their risk of osteoporosis in these ways:

- Avoiding ETOH, No tobacco, Eat foods rich in calcium and vitamin D, exercise regularly

Neurological:

Chemotherapy and radiation therapy can cause long-term side effects to the brain, spinal cord, and nerves. These include:

- Hearing loss from high doses of chemotherapy, especially drugs like Cisplatin (multiple brand names)
- Increased risk of stroke from high doses of radiation to the brain
- Peripheral Neuropathy- Taxanes, Anthracyclines, Platinum-based therapies

Cancer survivors should have regular physical examinations and hearing tests after treatment to check for these effects.

Learning, memory, and attention difficulties. Chemotherapy and high-dose radiation therapy to the head and other areas of the body may cause Cognitive problems occur when a person has trouble processing information. – Brain fog.

GI:

Chemotherapy, radiation therapy, and surgery may affect how a person digests food. Surgery or radiation therapy to the abdominal area can cause tissue scarring, long-term pain, and intestinal problems.

Some survivors may have chronic diarrhea that reduces the body's ability to absorb nutrients.

A registered dietitian (RD) consult recommended for all patients

GI consult may be needed.

- **GU:**
- Chemotherapy and Radiation to the abdomen and pelvis can increase the risk of Urinary Tract Toxicity
 - Hemorrhagic Cystitis
 - Bladder Fibrosis
 - Reflux Hydronephrosis
- Agents to be aware of are Cyclophosphamide and Ifosfamide
- **Skin**
 - Radiation to the affected area increases risk of Skin Cancers.
Yearly Skin exams recommended for all Cancer patients

Dental and Oral health and Vision problems:

- High doses of radiation therapy to the head and neck area may change tooth development. It can also cause gum disease and lower saliva production, causing a dry mouth.
- Immunotherapies are known to cause Salivary gland issues- dry mouth, thick saliva.
- Chemotherapy may affect tooth enamel and increase risk of long-term dental problems
- Steroid medications may increase the risk of eye problems –cataracts
- Routine Dental exams/ cleaning recommended every 6 months. Eye exams, yearly.

Genetic factors:

- Consider a referral to genetic counseling with your health care provider if your patient meets any of the following criteria:

Diagnosed with breast, ovarian or colorectal cancer before age 50.

Diagnosed with multiple cancers such as bilateral breast cancer or breast and ovarian cancer.

Diagnosed with cancer at any age and have a family member diagnosed with cancer before age 50.

Have family members in multiple generations diagnosed with cancer.

Fatigue:

Fatigue is a constant feeling of physical, emotional, or mental tiredness. It is the most common side effect of cancer treatment. Some cancer survivors have fatigue for months or even years after finishing treatment.

Insomnia:

many patients suffer this because of the therapy and the emotional aspects. Be aware of sxs. of Sleep apnea.

Intimacy /Sexual SE:

surgery, therapies, emotional and physical struggles. Many deal changes in body image that are perceived negative. Reestablishing communication after treatment can be a challenge.

Perspective

We all come from different experiences and backgrounds.

Not everyone's perspective is the same.

In Survivorship it is about navigating through and doing the best we can!



Emotional difficulties:

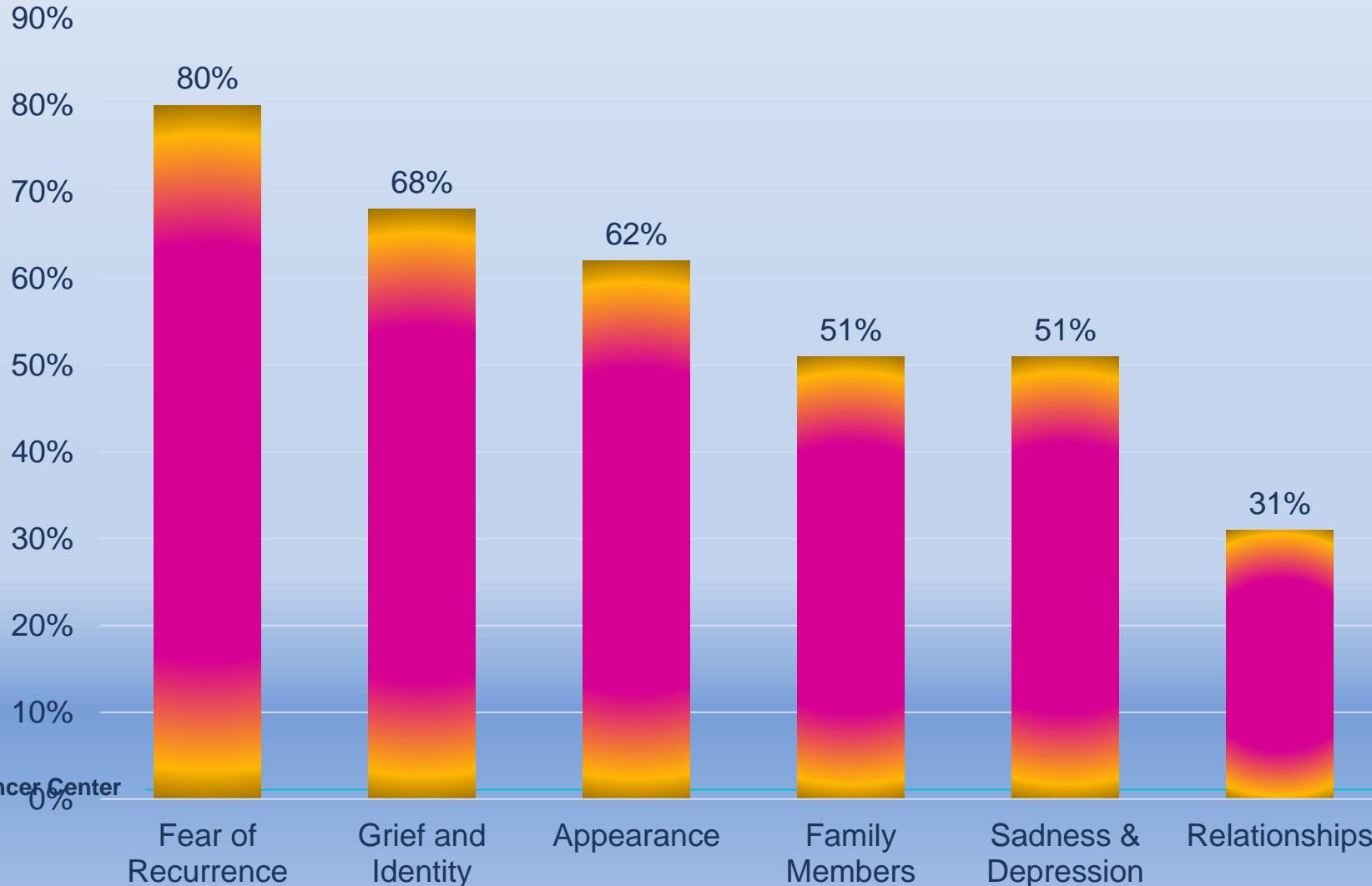
Cancer survivors often have various positive and negative emotions:

Stress, Anxiety, Depression, PTSD

- **Fear of recurrence**
- **Relief**
- **A sense of gratitude to be alive**
- **Anger**
- **Guilt**
- **Loneliness**
- **Loss of identity**
- **Grieving**
- **Changes in relationships**

Percent of survivors who report

Emotional Concerns



Fred Hutchinson Cancer Center

Prevention Works!

Control the things you can control...

- Keep blood pressure, cholesterol, blood sugar and weight under control – See your Primary care provider
 - Nutrition is vital
 - Exercise
 - Addressing emotional needs
 - Manage stress
 - Alcohol and substance use
 - Quit smoking
 - Sleep is critical for physical and emotional well-being, immune function, and coping



Caregivers

Self care

Respite

Take care of yourself

You are the true heroes

Caring
Always there
Ready to give their all
Encouraging
Gracious
Incredible
Valuable
Exceptional
Respectable

Treatment Summary Goal- for our patients



- Increase survivors' and caregivers' own knowledge of their diagnosis and the treatment they have received
- Assist transition back to, and partner with primary care and specialists with the goal of achieving their:

Best of Health

Empowering you! - Your plan

- Summary of cancer history/treatment
- Primary cancer surveillance plan
- Cancer/cancer treatment health risks
- Subsequent cancer/late effects screening
- Promote a healthy lifestyle to reduce cancer risks and maximize wellness
- Screening for/management of health conditions
- Definition of roles of involved providers
- Resources to address medical/psychosocial needs

Seattle Cancer Center Alliance
 825 Eastlake Avenue East, Seattle, WA 98109
Survivorship Clinic Treatment Summary and Care Plan
Date of Preparation:

Patient Name:	Date of Birth:
UW/SCCA medical record number:	
Cancer Diagnosis:	Date of Diagnosis:
	Age at Diagnosis:
Tumor Stage: <i>(0, I, II, III, IV)</i>	Tumor grade: <i>(1, 2, 3 or low/intermediate/high)</i>
Tumor Size (T)	Genetic Testing:
Nodes (N)	
Metastases (M)	
Tumor markers:	
Significant Past Medical History:	
Family History:	
CANCER TREATMENT	
Treatment Facility:	
Surgery	
Surgery (type/site/significant findings if noted):	Date:

Systemic Therapy (Chemotherapy, Biotherapy, Adjuvant Therapy, Other)				
Agent:	Route:	Cycles:	Date Start:	Date Stop:
Cumulative Anthracycline Dose Administered:				
Blood Products:		Growth Factors:		
Radiation Therapy				
Date Start	Date Stop	Total Dose (cGy)		
Fields included:				
Complications of therapy:				
Dose reduction:				
Complications (from which modality if known):				
Providers				
General Medical Care:		Oncologic Care:		

Long term effects and Follow-Up care	Recommendation
Cardiac Health	Heart problems can occur after certain chemotherapy drugs (anthracyclines) or after chest radiation based on the doses you have received...
Lung/Respiratory	Chemotherapy and radiation may impact lung function. If you are experiencing shortness of breath, chronic cough, pain with breathing, wheezing, increased fatigue or ...
Musculoskeletal	Muscle and joint aches, stiffness and pain are common after cancer treatment. Narcotics generally do not address the underlying cause. Regular exercise both aerobic and resistance training, stretching, and yoga...
Cognitive/Memory concerns	It is common after chemotherapy to experience some changes in memory and cognition, frequently referred to as “chemo brain”. Most often these affects improve over the first year after therapy is complete; however, ...
Fertility	Chemotherapy and radiation can affect your fertility. It is important to know your fertility status. Women should keep track of menstrual cycles and report any changes ...
Hormonal Changes	Treatment of your cancer may cause hormone changes which can lead to hot flashes, vaginal dryness, mood fluctuations, fatigue, menstrual irregularities, bone density issues , and memory changes....
Secondary cancers	There is a low risk for leukemia, or other secondary cancers related to chemotherapy and/or radiation exposure. Notify your health care provider...

WELLNESS Recommendations	
Health Maintenance	Make sure you keep up to date on vaccinations and routine health maintenance screening (cholesterol, blood pressure, skin)
Exercise and Physical Activity	The SCCA encourages breast cancer survivors to adopt a physically active lifestyle. Try to engage in at least 30 minutes of moderate
Lymphedema	Review lymphedema prevention education. Consider a referral to physical therapy for lymphedema, range of motion...
Nutrition	The SCCA supports the nutrition guidelines of the American Cancer Society to optimize health and reduce cancer risk.
Genetic counseling and testing	If there is a history of cancer in your family, or if you were diagnosed with breast cancer at a very young age,
Fear of Recurrence	Develop and strengthen coping skills. Talk to friends and family. Request a referral to a therapist and information on...
Heart Health	Low fat diet, regular aerobic exercise and maintaining weight and blood pressure. Know what your cholesterol level is.
Bone Health	Regular weight bearing exercise. Daily Calcium and vitamin D,
Pain	Regular exercise both aerobic and resistance training, stretching,
Fatigue	Adequate sleep, regular exercise and good nutrition will facilitate recovery and reduce fatigue after treatment.
Sexual Health/Body Image	Communicate with your partner. Suggest vaginal lubricants/ moisturizers and plan time for intimacy.
Memory/ cognitive concerns	Look into organizational strategies such as establishing a routine

Follow-up and Survivorship Care: pt with history of Melanoma Stage 1 pT1a p N0 M0 Ductal Carcinoma in situ: left breast

Based on your oncologist recommendations, personal diagnosis, treatment exposures, and/or risk factors.

	Last Done	Frequency	Provider to Contact	Next Due
Oncology Follow-up	Swedish	yearly	Tsai	9/2023
Plastic Surgery	2/10/2023	F/U as needed	Miranda	prn
Surgery onc	2/7/2023	F/U as needed	Crown / Ochsner	6/30/2023
Survivorship	6/22/2023	6 months	Regis	12/2023
Breast and Ovarian Prevention Clinic	6/6/2023	6 months	Nelson	12/2023
Genetic Counseling	3/23/2023	As per Oncologist	UW Medical Genetics	prn
Reproductive Medicine	Will establish	Per provider	Sienkiwwicz	7/19/2023
Labs:	Per PCP	6 month-yr	Hilderman	Per PCP
Vitamin D	Per pcp	As per PCP	Hilderman	now
Imaging:	1-5-2022 diag / proc mams	As per Oncologist	Nelson	Per ONC
Dexascan	Not due	Per PCP	PCP	Baseline age 50 or sooner if clinically indicated
Colonoscopy	2018	Every 5 years	Referred to gl	now
Gynecology /Pap	2/28/2023	Per GYN	Establishing with new GYN	Per GYN
Thyroid Eval (Exam and Labs)	U/S 4/13/2023	prn	Hilderman	prn
Skin Exam	7/11/2023	6-12 months	Park	7/11/23- appt scheduled

54 y/o WM with a h/o anal squamous cell carcinoma s/p excisional biopsy. Currently receiving Chemo and Radiation

22/2024 Office Visit Me

Based on your oncologist recommendations, personal diagnosis, treatment exposures, and/or risk factors.

	Last Done	Frequency	Provider to Contact	Next Due
Oncology Follow-up	2/22/2024	Monthly/per IOnc	Kitson / Hsieh	3/2024
Radiation Oncologist	2/22/2024	As per Rad Onc	Apisarnthanarax	In active tx
Surgery	11/3/2023	As per Oncologist	Van Eaton	
Survivorship	2/22/2024	Prn	Regis	Consider upon completion of TX
Cardiac surgery	8/15/2023	As per Cardiologist	Aldea	8/2025
CTA aneurysm	8/9/2023	2 years	Aldea	8/2025
Labs: CBC CMP lipids A1C	Summer/fall 2023 CBC CMP ongoing per Oncology	CBC CMP per ONC A1c lipids per PCP	Onc and PCP	Per provider in 2024
Colonoscopy	2020?	3 years	Kitson / Hsieh	Per Onc Per provider for consideration
Vitamin D - goal 50		As per Oncologist	Kitson/Hsieh	Per provider for consideration
Imaging:	Ongoing as in active tx	As per Oncologist	Kitson/Hsieh	Per protocol
Low dose lung CT	6/2022	Yearly	PCP	Pt is due
Imaging:	ECHO	aneurysm	Aldea	Per provider
Cardiac:	8/2022	Yearly	DERM	Consider
Skin Exam		Yearly	Oncology	Per Oncology
Bone Density (DEXA)	4/2023 normal	Per oncology	Oncology	Per Oncology
Dental	Due	6 months	Dentist	Please schedule
Ophthalmology	12/21/2023		Ophthalmology	12/2024

Wellness Screening
Based on National Cancer Institute, American Cancer Society, American Radiology Society, and American Society of Gastroenterology

- **Follow-up and Survivorship Care** 49 y/o female Invasive Ductal CA –Right breast dx 9/2022
- **Surgery Radiation and Systemic therapy with Cytoxan and Doxorubicin followed by Taxol** currently in clinical trial

• Based on your oncologist recommendations, personal diagnosis, treatment exposures, and/or risk factors.

	Last Done	Frequency	Provider to Contact	Next Due
• Oncology Follow-up	3/6/2024	2 -3 months	Onc	5/29/2024
• Radiation Oncologist	12/12/2023		Rad Onc	complete
• Imaging 1/2023	Per result		Onc	6/2024 CTA Abd
• Surgery-Plastics		Per provider	Plastic surgery	6/14/2024
• Labs-CBC CMP lipids A1c	3/6/2024	Yearly or per result	Onc/PCP-	Per provider/result
• Vit D consider recheck	11/27/2023- 16.3	Yearly or per provider	Onc/PCP-	Per provider
• Gyn/Pap	9/19/2022	5 years	Vierra	9/2027
• Audiology 3/29/2024	3/9/2024	One year	Mackenzie	4/3/2025
• ENT/Neurology	3/29/2024		Monsell	MRI brain 4/17/2024
• Cardiac: ECHO	2/21/2024	6 months -Trial	Cardio ONC	4/18-6/13 2024
• Colonoscopy	Had fit test -neg		PCP	Will discuss with PCP
• Dexascan	Had baseline	Per provider	Oncology/PCP	5/2024
• Skin Exam - Radiation	Needs baseline		PCP/DERM	consider
• Dental	> 6 months	6 months	Dentist	due

What Our Patients Say

The treatment summary and survivorship plan are the pieces that assure continuity of care and identify any preventative recommendations needed.

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.

Survivorship Program: Clinical Care

- Individualized survivorship treatment summaries and care plans to empower survivors with knowledge about their cancer diagnosis and treatment,
 - Address the chronic effects of cancer and its therapy,
 - Provide monitoring recommendations to allow for early identification of treatment-related sequelae
 - promote health-protective behaviors.
- Patient eligibility
 - Many prefer to see us as they are transitioning off active treatment but everyone in all phases are welcome.
 - All ages
 - All diseases
 - Any location of oncology treatment
 - Any referral source:
 - Oncology
 - Primary care
 - Self
- 60-min Survivorship Clinic visit - most insurances cover this service as part of the cancer care continuum.
 - Wellness Center or Telehealth – must be in WA state.



Fred Hutch Survivorship Clinic

P: (206) 606-6100

E: pccsurvivorship@fredhutch.org

FredHutch.org/adult-survivorship-clinic

The Survivorship Clinic is located within the Fred Hutch Wellness Center, which is in a separate building from the main Fred Hutch Clinic.

The Fred Hutch Wellness Center is located at:
1100 Fairview Ave. N.
Seattle, WA 98109
Level E of the Arnold Building

Survivorship Clinic

Treatment, support and education

Empowered Living After Cancer

Fred Hutchinson Cancer Center is an independent organization that serves as UW Medicine's cancer program.

UW Medicine





[NCCN Survivorship Panel Members](#)
[NCCN Survivorship Sub-Committee Members](#)
[Summary of the Guidelines Updates](#)

General Survivorship Principles

- [Definition of Survivorship \(SURV-1\)](#)
- [Standards for Survivorship Care \(SURV-2\)](#)
- [General Principles of the Survivorship Guidelines \(SURV-3\)](#)
- [Screening for Subsequent New Primary Cancers \(SURV-4\)](#)
- [Principles of Cancer Risk Assessment and Counseling \(SURV-5\)](#)
- [Assessment by Health Care Provider at Regular Intervals \(SURV-6\)](#)
- [Survivorship Assessment \(SURV-A\)](#)
- [Survivorship Resources for Health Care Professionals and Survivors \(SURV-B\)](#)
- [Principles of Screening for Treatment-Related Subsequent Primary Cancers \(SURV-C\)](#)

Preventive Health

- [Healthy Lifestyles \(HL-1\)](#)
 - ▶ [Physical Activity \(SPA-1\)](#)
 - ▶ [Nutrition and Weight Management \(SNWM-1\)](#)
 - ▶ [Supplement Use \(SSUP-1\)](#)
- [Immunizations and Infections \(SIMIN-1\)](#)

Late Effects/Long-Term Psychosocial and Physical Problems

- [Cardiovascular Disease Risk Assessment \(SCVD-1\)](#)
- [Anthracycline-Induced Cardiac Toxicity \(SCARDIO-1\)](#)
- [Anxiety, Depression, Trauma, and Distress \(SANXDE-1\)](#)
- [Cognitive Function \(SCF-1\)](#)
- [Fatigue \(SFAT-1\)](#)
- [Lymphedema \(SLYMPH-1\)](#)
- [Pain \(SPAIN-1\)](#)
- [Hormone-Related Symptoms \(SHRS-1\)](#)
- [Sexual Health \(SSH-1\)](#)
- [Fertility \(SF-1\)](#)
- [Sleep Disorders \(SSD-1\)](#)
- [Employment and Return to Work \(SWORK-1\)](#)

Clinical Trials: NCCN believes that the best management for any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

Find an NCCN Member Institution:
<https://www.nccn.org/home/member-institutions>.

NCCN Categories of Evidence and Consensus: All recommendations are category 2A unless otherwise indicated.

See [NCCN Categories of Evidence and Consensus](#).



Questions?

Thanks so much for the opportunity!

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