Survivorship Care Plans: Being an Empowered Patient

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Survivorship Program
Fred Hutch Cancer Center

Moving Beyond Cancer To Wellness
June 3, 2023
Today’s Topics

● Understanding survivorship

● Common late and long-term effects of cancer and cancer treatment

● Cancer treatment summaries and care plans

● Survivorship Consult visit


Who is a “Cancer Survivor”?

• **NCI** definition

  “An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted and included in this definition.”
Growth in the number of cancer survivors over time in the United States
Surviving and Thriving:
Comes in many shapes, sizes, needs and capabilities
Cancer Survivors are ALL OF US.

We will have cancer

or people we love will have cancer.

Survivorship is about living life as healthy as possible and as well as possible with and beyond cancer.
The Good News!

- Most cancer survivors describe themselves as having good-excellent health (60-80%)

- Most cancer survivors are psychologically healthy before and after treatment
Those who function well may have needs that are not observable.
Cancer Survivor Challenges

**Wellness & PsychoSocial**
- Mental health
- Employment
- Education
- Social interactions/support
- Chronic symptoms: Fatigue, Cognition, Insomnia, Neuropathy
- Lifestyle
- Physical function

**Environment & Finances**
- Family / Caregiver function
- Access to health & resources
- Insurance
- Financial toxicity

**Organ Function**
- Cardiac
- Endocrine
- Musculoskeletal
- Genitourinary
- GI/Hepatic
- Neurologic
- Pulmonary

**Subsequent Malignancies**
- Recurrent cancer
- New cancers

**Fertility & Reproduction**
- Fertility
- Health of offspring
- Sexual functioning

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Fred Hutchinson Cancer Center
Percent of survivors who report

*Physical Concerns*

- Energy: 59%
- Concentration: 55%
- Sexual Function: 46%
- Neuropathy: 42%
- Pain: 34%
- Incontinence: 22%
- Mouth and Teeth: 20%
Percent of survivors who report

**Emotional Concerns**

- Fear of Recurrence: 80%
- Grief and Identity: 68%
- Appearance: 62%
- Family Members: 51%
- Sadness &…: 51%
- Relationships: 31%
# Distress Reactions of Survivors

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Uncertainty</strong></td>
<td>* Not knowing what the future will bring</td>
</tr>
<tr>
<td></td>
<td>* Thoughts and feelings about recurrence</td>
</tr>
<tr>
<td><strong>Grief and Loss</strong></td>
<td>* What will never be (fertility/pregnancy)</td>
</tr>
<tr>
<td></td>
<td>* What is changed forever (hair, work, energy)</td>
</tr>
<tr>
<td></td>
<td>* Includes body image, self-esteem</td>
</tr>
<tr>
<td><strong>Fear of</strong></td>
<td>* Intrusive thoughts about cancer recurring</td>
</tr>
<tr>
<td><strong>Recurrence</strong></td>
<td>* Worry encroaches on activities, sleep, enjoyment</td>
</tr>
<tr>
<td></td>
<td>* Afraid to rebuild life - disappointment</td>
</tr>
</tbody>
</table>
In the Words of a Non-Hodgkin's Survivor

“After I was in remission a few years, I was told to call my doctor if I had a problem. But after cancer, you starting imagining the worst with every little twinge: is this something I should watch for or be concerned about?”
Fear of Recurrence

“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.
Assessment of Risk

- Age
- Gender
- Genetics
- Social
- Other Health
- Lifestyle

Methods:
- CHEMO-THERAPY
- RADIATION
- SURGERY
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.
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
  • Survivors may not know who to see when and for what
  • If survivors look fine and are not complaining, assume all is well

• Lack access to survivorship care
  • Services are not available or survivors do not know about services
Survivorship Treatment Summary and Care Plan Goals

- 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/managers of health conditions
- Definition of roles of involved providers
- Resources to address medical/psychosocial needs
1. TREATMENT SUMMARY
# Systemic Therapy (Chemotherapy, Biotherapy, Adjuvant Therapy, Other)

<table>
<thead>
<tr>
<th>Agent:</th>
<th>Route:</th>
<th>Cycles:</th>
<th>Date Start:</th>
<th>Date Stop:</th>
</tr>
</thead>
</table>

| Cumulative Anthracycline Dose Administered: | Growth Factors: |
| Blood Products: | |

## Radiation Therapy

<table>
<thead>
<tr>
<th>Date Start</th>
<th>Date Stop</th>
<th>Total Dose (cGy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fields included:</td>
<td></td>
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</tr>
</tbody>
</table>

## Complications of therapy:

- Dose reduction:

- Complications (from which modality if known):

## Providers

<table>
<thead>
<tr>
<th>General Medical Care:</th>
<th>Oncologic Care:</th>
</tr>
</thead>
</table>
Recommendations

**Heart 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...

2. CARE PLAN

### Specific Exposure
- Gender
- Age
- Diagnosis

### Driven by
Recommendations
- Secondary cancers
- Hormonal Changes
- Fertility
- Cognitive
- Musculoskeletal

### Long term effects and follow-up care
Recommendation
- Modified by:
  - Diagnosis
  - Age
  - Gender
## WELLNESS Recommendations

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td><strong>Health Maintenance</strong></td>
<td>Make sure you keep up to date on vaccinations and routine health maintenance screening (cholesterol, blood pressure, skin)</td>
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<tr>
<td><strong>Exercise and Physical Activity</strong></td>
<td>The SCCA encourages breast cancer survivors to adopt a physically active lifestyle. Try to engage in at least 30 minutes of moderate exercise.</td>
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<tr>
<td><strong>Lymphedema</strong></td>
<td>Review lymphedema prevention education. Consider a referral to physical therapy for lymphedema, range of motion…</td>
</tr>
<tr>
<td><strong>Nutrition</strong></td>
<td>The SCCA supports the nutrition guidelines of the American Cancer Society to optimize health and reduce cancer risk.</td>
</tr>
<tr>
<td><strong>Genetic counseling and testing</strong></td>
<td>If there is a history of cancer in your family, or if you were diagnosed with breast cancer at a very young age,</td>
</tr>
<tr>
<td><strong>Fear of Recurrence</strong></td>
<td>Develop and strengthen coping skills. Talk to friends and family. Request a referral to a therapist and information on…</td>
</tr>
<tr>
<td><strong>Heart Health</strong></td>
<td>Low fat diet, regular aerobic exercise and maintaining weight and blood pressure. Know what your cholesterol level is.</td>
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<tr>
<td><strong>Bone Health</strong></td>
<td>Regular weight bearing exercise. Daily Calcium and vitamin D,</td>
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<tr>
<td><strong>Pain</strong></td>
<td>Regular exercise both aerobic and resistance training, stretching,</td>
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<tr>
<td><strong>Fatigue</strong></td>
<td>Adequate sleep, regular exercise and good nutrition will facilitate recovery and reduce fatigue after treatment.</td>
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<tr>
<td><strong>Sexual Health/Body Image</strong></td>
<td>Communicate with your partner. Suggest vaginal lubricants/ moisturizers and plan time for intimacy.</td>
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<tr>
<td><strong>Memory/ cognitive concerns</strong></td>
<td>Look into organizational strategies such as establishing a routine</td>
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<tr>
<td><strong>Plan</strong></td>
<td>✓</td>
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Fred Hutchinson Cancer Center
<table>
<thead>
<tr>
<th>TEST</th>
<th>LAST DONE</th>
<th>FREQUENCY</th>
<th>PROVIDER TO CONTACT</th>
<th>NEXT DUE</th>
</tr>
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<tbody>
<tr>
<td>Complete Physical Exam</td>
<td>Yearly</td>
<td></td>
<td></td>
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<tr>
<td>Oncology Follow-up</td>
<td>As per oncologist</td>
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<tr>
<td>Surveillance for Risk of Recurrence</td>
<td>Set by your Oncologist</td>
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<tr>
<td>Bone Density Test (DEXA)</td>
<td>Every 2-5 years</td>
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<td>Colonoscopy</td>
<td>Every 10 years</td>
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<td>Screening Labs</td>
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<td>Gynecological Exam</td>
<td>Yearly</td>
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<tr>
<td>Pap Smear</td>
<td>Every 3 years</td>
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<tr>
<td>Mammogram</td>
<td>Every 2 years</td>
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<tr>
<td>Breast MRI</td>
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<td>Skin Exam</td>
<td>Yearly</td>
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<tr>
<td>Cardiac Screening</td>
<td>TBD</td>
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<tr>
<td>Vision Exam</td>
<td>Yearly</td>
<td></td>
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<tr>
<td>Dental Exam</td>
<td>Twice a year</td>
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<td>Immunizations</td>
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<tr>
<td>Immunizations</td>
<td>Yearly</td>
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**CONTACT/RESOURCES**

| Education                          | Survivorship Notebook provided |
| Contact Survivorship Clinic        | survivor@seattlecca.org or 206-288-1021 |
| Resources                          |                                  |
Prevention Works!
Control the things you can control…

- Keep blood pressure, cholesterol, blood sugar and weight under control
  - 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
Benefits of Survivorship Care

Cancer survivors are best served when they have the support of both primary care and their oncology team after they complete treatment.

The TS/SCP is shared with the patient, patient’s primary care provider, oncologist and other specialists in order to:

• Improve communication and collaboration of health care team
• Empower the patient and entire care team
• Educate community providers, limiting fear of accepting survivors as patients
• Support patient self-advocacy through knowledge of surveillance, prevention, early detection and wellness needs
And, It’s What Our Patients Need

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.
Fred Hutch Cancer Center Survivorship Program

• The mission of the Fred Hutch Survivorship Program is to improve the lives of cancer survivors through integrated research, education and advancements in clinic care.

• Clinical care
• Research
• Outreach
Fred Hutch Survivorship Clinic

- 60 minute visit in person or telehealth
  - **Eligibility**: Any one with a history of cancer treatment, does not need to have received treatment at Fred Hutch Cancer Center.
  - Recommended after treatment has been completed and before surveillance visits are completed to assist transition to primary care.
  - Can be referred by oncology team, primary care or **self-refer**.

- Evaluation and assessment of your Survivorship needs
- Review individualized Treatment Summary and Survivorship Care Plan
- Most insurance plans consider this a necessary visit for individuals who have received treatment for cancer; prior to appointment, patients are counseled about contacting insurance provider to review coverage
NCCN Guidelines Version 1.2023
Survivorship

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.

https://www.nccn.org/guidelines/category_3
### Major Research Domains (Current / Recent Grants)

#### mHealth / Telehealth
- **Syrjala/Baker (R01):** Integrating health informatics & stepped care self-management program for HCT survivors
- **Syrjala/Baker (U01):** An INteractive Survivorship Program to Improve Healthcare RESources [INSPIRE] for AYA cancer survivors
- **Chow/Ceballos (R21/CCSG):** Improving cancer survivorship care delivery in rural & Latino cancer survivors: telehealth & lay health educators
- **Chow (R01):** SALSA Study of Active LifeStyle Activation for survivors of childhood cancer
- **Mendoza/Baker/Chow (U01):** Randomized Mobile Health and Social Media Physical Activity Intervention Among Adolescents and Young Adult Cancer Survivors (COG)
- **Rosenberg (Cambia):** mHealth Intervention ("mPRISM") to Build Resilience among AYA Survivors

#### BMT
- **Baker (R01):** Prevention of bone loss after pediatric HCT
- **Baker (St. Baldrick's):** Natural history, biology, and treatment of long-term late effects following HCT in children & YAs
- **Bhatt (ASCO YIA):** Facilitating return to school after pediatric HCT
- **Ketterl (SCH CRSP, ASCO YI):** Pilot resistance training intervention In AYA HCT survivors
- **Rosenberg (R01):** Promoting Resilience in AYAs receiving HCT
- **Lee (P01):** Acute Leukemia Research Center: HCT Long Term Follow-up
- **Lee (R01):** Improving outcomes assessment for cGVHD

#### Cardiovascular
- **Chow (R01/LLS/St. Baldrick's):** Dexrazoxane & anthracycline-related cardiomyopathy (COG)
- **Chow (R01):** Improving treatment of CV risk factors in childhood cancer survivors
- **Chow (Rally):** Echocardiographic changes in cancer survivors at risk for cardiomyopathy
- **Chow (FH):** Tele/mHealth intervention to reduce CV risk in heme malignancy survivors
- **Greenlee/Kwan (R01):** Predictors of CV risk in breast cancer survivors (Kaiser)
- **Greenlee (R01):** Cook for your Life: maintaining dietary & physical activity change among Latina breast cancer survivors
- **Leger (LLS/BIQSFP/COG):** AAML1831 Cardiac Core: CPX351 vs ADE+DRZ
- **Reding (R21):** Oxidative stress, inflammation, CV damage after breast cancer

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**AYA Focused Studies**

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Thank you