Survivorship Care Planning and Late Effects of Treatment

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Who/what is a cancer survivor?

• **Survivor** definition: From the moment of diagnosis through the balance of their life.*

• Cancer **survivorship** is the journey that takes a person from the diagnosis onward.

• It is the experience of living with, through, and beyond the diagnosis of cancer.

* The National Coalition of Cancer Survivorship (NCCS)
Estimated and projected number of cancer survivors in the United States from 1977 to 2022 by years since diagnosis

Are Survivors Needs Being Met?
Lack of care: Percentage of respondents who did **not** receive help for their concerns

- Graft-versus-host (N = 0): 0%
- Thyroid (N = 23): 11%
- Oral health (N = 105): 23%
- Heart (N = 59): 32%
- Lymphedema (N = 174): 33%
- Hearing (N = 68): 37%
- Vision (N = 110): 37%
- Pain (N = 289): 37%
- Lungs (N = 173): 47%
- Infertility (N = 69): 50%
- Energy (N = 759): 56%
- Neuropathy (N = 578): 60%
- Incontinence (N = 347): 69%
- Sexual functioning (N = 751): 71%
- Concentration (N = 1,047): 83%
Lack of care: percentage of respondents who did not receive help for their emotional concerns

- Sadness and depression (N = 689): 59%
- Fear of recurrence (N = 1,206): 66%
- Personal appearance (N = 955): 67%
- Family member risk (N = 822): 70%
- Grief and identity (N = 1,172): 75%
- Personal relationships (N = 539): 76%
- Social relationships (N = 506): 76%
- Faith and spirituality (N = 146): 80%
Survivors Lost in Transition
(from cancer patient to survivor)

• Many survivors don’t necessarily know what they need
  – Unaware of what tests and follow up visits they should have or which physician specialists they should continue to see

• Lack access to survivorship care
  – Services are not available in their community
  – Survivors not able to take advantage of service due to practical constraints (e.g. lack of insurance, lack of transportation, disability)

• Poor coordination between providers
  – For example, a patient’s oncologist may assume that the patient is receiving screenings for secondary cancers from their primary care provider when in fact they are not
A survivorship care plan can help survivors make the transition from cancer patient to cancer survivor.
What does a survivorship care plan include?

- Treatment summary
- Information about the on-going care you need
- Personalized set of recommendations
- Full contact info of your health care team
Why are they important?

- Empower you to take care of yourself and remain healthy
- Understanding your cancer treatment and follow-up needs
- Provide important information to you and other healthcare providers who need to know your health history
- Continuity if you switch doctors, change health insurance plans, move to another town or state
Survivorship Care Plan (1)

- **Diagnosis**: Cancer type, stage, histology, date and age at diagnosis

- **Care Providers**: Treatment facility and oncology health care providers and PCP with contact information

- **Treatment details**: Chemotherapy or other cancer medications received, radiotherapy doses and fields, surgical procedures
Survivorship Care Plan (2)

- **Complications** on/off treatment with long-term implications

- Associated **potential risks** of treatment including second malignancy or specific organ toxicity with screening and follow-up recommendations

- Sent to survivor and healthcare providers
Where to get one?

Treatment Summary & Care Plan Templates

• Your oncologist/clinic
• SCCA Survivorship Clinic
• Journey Forward (www.journeyforward.org)
  – Providers (and Patients)
  – Requires detailed information regarding diagnosis and treatments received
Treatment Summary & Care Plan Templates

• LIVESTRONG™ Care Plan Powered by Penn Medicine’s OncoLink
  – Patient-oriented tool
  – Comprehensive individualized list of recommendations specific to primary cancer diagnosis & treatment received

www.livestrongcareplan.org
1. TREATMENT SUMMARY
<table>
<thead>
<tr>
<th>Systemic Therapy (Chemotherapy, Biotherapy, Adjuvant Therapy, Other)</th>
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<tbody>
<tr>
<td><strong>Agent:</strong></td>
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<td>---------------------------------------------------------------</td>
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<table>
<thead>
<tr>
<th>Cumulative Anthracycline Dose Administered:</th>
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<tr>
<td>Blood Products:</td>
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<tr>
<th>Radiation Therapy</th>
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<tr>
<td><strong>Date Start</strong></td>
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<td>------------------------------------------------</td>
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<tr>
<td>Fields included:</td>
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<td>------------------------------------------------</td>
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<table>
<thead>
<tr>
<th>Complications of therapy:</th>
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<tr>
<td>Dose reduction:</td>
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<th>Complications (from which modality if known):</th>
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<tr>
<th>Providers</th>
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<tr>
<td>General Medical Care:</td>
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<td>------------------------------------------------</td>
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<tr>
<th>Long term effects and Follow-Up care</th>
<th>Recommendation</th>
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<tr>
<td><strong>Cardiac Health</strong></td>
<td>Heart problems can occur after certain chemotherapy drugs (anthracyclines) or after chest radiation based on the dose you have received…</td>
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<tr>
<td><strong>Lung/Respiratory</strong></td>
<td>Chemotherapy and radiation may impact lung function. If you are experiencing shortness of breath, chronic cough, pain with breathing, wheezing, increased fatigue or…</td>
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<tr>
<td><strong>Musculoskeletal</strong></td>
<td>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…</td>
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<tr>
<td><strong>Cognitive/Memory concerns</strong></td>
<td>It is common after chemotherapy to experience some changes in memory and cognition, frequently referred to as &quot;chemo brain&quot;. Most often these affects improve over the first year after therapy is complete; however…</td>
</tr>
<tr>
<td><strong>Fertility</strong></td>
<td>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…</td>
</tr>
<tr>
<td><strong>Hormonal Changes</strong></td>
<td>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.…</td>
</tr>
<tr>
<td><strong>Secondary cancers</strong></td>
<td>There is a low risk for leukemia or other secondary cancers related to chemotherapy and/or radiation exposure. Notify your health care provider…</td>
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</tbody>
</table>

2. CARE PLAN

**Recommendations driven by:**
- **Specific Exposure:** Chemo (type/dose), Radiation (site/dose), Surgery
- **Modified by:** Diagnosis, Age, Gender
Common Late Effects Facing Survivors

**Medical Problems:**
- Cardiovascular disease
- High triglycerides/cholesterol
- Diabetes
- Osteoporosis / osteopenia
- Hypothyroidism
- Premature menopause
- Pulmonary (lung) function
- Lymphedema
- Urinary incontinence
- Infertility
- Neurologic problems (balance, neuropathy, memory)
- GI (diarrhea, constipation, reflux)
- Dental impairments
- Increased risk of 2nd cancers

**Symptoms and Functions:**
- Restricted social and physical activities
- Memory loss, cognitive concerns
- Muscle and joint stiffness, weakness, cramps or pain
- Sexual dysfunction
- Fatigue / lack of stamina
- Distress and worry

**Psychosocial Issues**
- School
- Work
- Insurance
- Relationships
Cardiovascular Disease: who is at risk?

1. Were there treatment exposures that can impact heart function?
   – Chemotherapy
     • Cardiomyopathy (weakening of heart muscle)
       – “Anthracyclines” – Daunorubicin, Doxorubicin
       – “Alkylators” – Cyclophosphamide
   – Radiation
     • Coronary arteries, heart valves, Pericardium
     • Dependent on dose and radiation field, age at exposure, effects can be delayed

2. What other factors might impact risk?
   • Age, sex, family history, obesity, sedentary lifestyle, diet
Cardiovascular Effects

Screening
- Lipid profile (triglycerides, cholesterol)
- Echocardiogram, ECG, (if indicated)
  • Determine frequency
- Possible cardiology referral

Risk modification
- Avoid smoking
- Limit alcohol
- Diet – low fat, low cholesterol
- Exercise
- Medications for preserving heart function, treating high cholesterol, etc
Osteopenia/Osteoporosis: who is at risk?

- Risks
  - Steroids
  - Methotrexate
  - Radiation therapy
  - Low estrogen/testosterone
  - Early menopause
  - Other hormone deficiency
  - Hyperthyroidism

Can all be secondary to chemotherapy or radiation
Osteopenia/Osteoporosis

Screening
- Dual energy X-ray absorptiometry (DEXA)

Risk modification
- Hormone replacement therapy
- Vitamin D
- Calcium
- Bisphosphonates
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<th>WELLNESS Recommendations</th>
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<td><strong>Coordination of Care/Health Maintenance</strong></td>
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<tr>
<td><strong>Emotional Health</strong></td>
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<td><strong>Intimacy/Sexual Health</strong></td>
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<td><strong>Nutrition</strong></td>
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<td><strong>Body Image</strong></td>
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<td><strong>Genetics</strong></td>
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<tr>
<td><strong>Exercise/Physical Activity</strong></td>
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<td><strong>Sleep</strong></td>
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<tr>
<td>TEST</td>
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<td>-----------------------------------------</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 (DEXA)</td>
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<tr>
<td>Colonoscopy</td>
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<tr>
<td>Screening Labs, Lipids, etc</td>
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<tr>
<td>Gynecological Exam</td>
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<tr>
<td>Pap Smear</td>
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<tr>
<td>Mammogram</td>
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<tr>
<td>Breast MRI</td>
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<td>Skin Exam</td>
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<td>Cardiac Screening</td>
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<td>Vision Exam</td>
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<td>Dental Exam</td>
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<td>Immunizations</td>
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CONTACT/RESOURCES
Goals of a Survivorship Care Plan

• Increase survivors own knowledge of their diagnosis and the treatment they have received and potential consequences of that treatment
• Promote a healthy lifestyle
• Inform survivor of recommended surveillance practices for new or recurrent cancers, other health concerns
• Facilitate transition back to , and inform, primary care providers
SCCA Survivorship Clinic

Use your smartphone to scan the QR code on the back of the clinic brochure in your welcome bag to request to be contacted about scheduling an appointment.
Survivorship Program

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