POST-TRANSPLANT SURVIVORSHIP CARE: SURVEILLANCE, SIDE EFFECTS, RESOURCES

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Who is a Cancer Survivor?

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. There are many types of survivors, including those living with cancer and those free of cancer.

This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals.

(National Cancer Institute, 2019)
The Evolution of Cancer Survivorship

In 1986, the founders of National Coalition for Cancer Survivorship (NCCS) set out to establish an organization that replace the words “cancer victim” with “cancer survivor,” and bring about a different notion of the cancer experience. The founders envisioned an organization that would deal with the full spectrum of survivorship issues related to living with, through and beyond a cancer diagnosis.
Survivorship Spans the Cancer Journey

Needs vary between individuals
Needs vary within individuals along the continuum

Adapted from NCI, 2006
“From Cancer Patient to Cancer Survivor: Lost in Transition” (IOM report)

• 2005 Institute of Medicine report highlighting the lack of quality care for cancer survivors in the US

• A transition point where cancer survivors fall through the cracks of our health care system

• Provided a blueprint for the standard of care that should be considered for all cancer survivors

Oeffinger, Argenbright, Levitt, McCabe, Anderson, Berry, Maher, Merrill, Wollins, ASCO 2014
Revised CoC Survivorship Requirements
2020

New Standard 4.8: Survivorship Program: Focuses on the development of a survivorship program to oversee and meet the needs of a cancer survivor

The cancer program has a survivorship care program in place that includes the following elements documented in a written plan:

- Designed program director and team that is responsible for the development of survivorship care delivery models and activities, and for evaluation of the program
- A survivorship program that addresses the needs of cancer survivors, through care and consultative services provided either on-site or by referral
Components of a Survivorship Program

**Services** (may be available on-site or by referral):

- Treatment summaries • Survivorship care plans • Screening programs for cancer recurrence, new cancers • Seminars for survivors • Rehabilitation services • Nutritional services • Psychological support & psychiatric services

- Support groups and services • Formalized referrals to experts in cardiology, pulmonary services, sexual dysfunction, fertility counseling • Financial support services • Physical activity programs

*Treatment Summaries and Survivorship Care Plans (SCP):* patients should receive a treatment summary and survivorship care plan (SCP), but delivery of such plans is not a required component of this standard
Model of Survivorship Care

One size does not fit all in survivorship care at…

- Patient level
- Type of cancer/treatment level
- Institution and region/country level

Risk based approach based on needs of populations and resources available seems prudent

More than one model of care may be necessary to meet the diverse survivors needs most appropriately
Four Major Areas of Focus in Cancer Survivorship

- Recurrence and new cancers
- Long-term and late effects
- Modifiable health behaviors
- Coordination of care
DFCI BMT Survivorship Clinic

**On-Site Providers**
- BMT Specialists: MD and NP – Endocrine, cardiovascular, respiratory, bone, sexuality, cancer screening
- Dermatology
- Oral Medicine
- Ophthalmology
- Exercise Physiology
- Nutrition
- Psychosocial Counselor

**Available Specialists for Referral**
- Cardiology
- Endocrine
- Nephrology
- Sexual Health and Gynecology
- Sleep
Treatment Summary And Survivorship Care Plans

This is an important component of the initial survivorship visit

Multi-page document that outlines the cancer history, surveillance to be done, reasons to call, important lifestyle behaviors and health guidance, resources online and in person
What Information is in a Treatment Summary?

- Patient Demographics
- Background Information: Family History, Genetics, Tobacco
- Diagnostic tests performed and results
- Tumor characteristics: site, stage, grade, markers
- Dates of treatment: initiation and completion for radiotherapy, chemotherapy, and dates of surgery
- Treatment regimen: total dosage, clinical trials, and toxicities
- Support services accessed: Psychosocial, nutritional, other
- Care Team contact information: Identification of a key coordinator of continuing care
Survivors Often Experience a Roller Coaster of Emotions
Health Concerns After Cancer

Photo courtesy of the NCI
Transplant Patient Survivorship Issues

- Physical Functioning/Symptoms (Performance Status, Strength, Stamina, Pain)
  - Psycho-Emotional (Anxiety, Depression, Fear)
    - Cognitive (Memory/Concentration)
- Social (Roles, Leisure Activities, Sexual Desire/Performance, Appearance)
  - Functional (Return to work/school, sleep difficulties)
- Spiritual/Existential (Religious affiliations, Life meaning, Survivor guilt)
- Financial (Tremendous financial burden, disability, continued insurance issues)
## Medical Monitoring

<table>
<thead>
<tr>
<th>Organ</th>
<th>Risk</th>
<th>Outcome</th>
<th>What To Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mouth</td>
<td>Radiation, cGVHD</td>
<td>Dryness, Caries</td>
<td>Regular dental exams</td>
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<td></td>
<td></td>
<td></td>
<td>Monitor for oral cancers</td>
</tr>
<tr>
<td>Eyes</td>
<td>Radiation, cGVHD, steroids</td>
<td>Dryness, Cataracts</td>
<td>Regular eye exams</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Schirmer test for dryness</td>
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<tr>
<td>Bones</td>
<td>Radiation, steroids, low</td>
<td>Osteoporosis, fracture</td>
<td>Bone densitometry</td>
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<td></td>
<td>estrogen/testost.</td>
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<td>Calcium/vitamin D</td>
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<td>Hormone replacement</td>
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<tr>
<td>Lungs</td>
<td>Radiation, Immune</td>
<td>Pneumonitis</td>
<td>Quit smoking</td>
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<tr>
<td></td>
<td>suppression</td>
<td></td>
<td>Regular lung function test</td>
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<tr>
<td>Endocrine</td>
<td>Radiation, Chemo, steroids</td>
<td>Hypothyroidism</td>
<td>Screening</td>
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<td></td>
<td></td>
<td>Hypoadrenalism</td>
<td>Slow steroid tapers</td>
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<tr>
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<td>cGVHD, Immune Suppression</td>
<td>Prophylaxis</td>
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<tr>
<td>Second Cancers</td>
<td>Radiation, Chemotherapy, cGVHD, Immune Suppression</td>
<td>Screening exams</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>Steroids, Hypogonadal state, Medications, Glucose Intolerance</td>
<td>Routine BP monitoring Routine Glucose monitoring</td>
</tr>
<tr>
<td>General Health</td>
<td>Survivorship</td>
<td>See your PCP !</td>
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