Primary Care For Cancer Survivors

Rich Boyajian, APRN, ANP
Virtual PSA Monitoring Program Director
Nurse Innovator/Entrepreneur
Dana Farber / Brigham and Women’s Cancer Center

New England Regional Nurse Practitioner Conference
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• I was going to give this important but very boring lecture about every potential long-term effect survivors could have.
• I then realized I did not want to put you in a coma at 11:00 AM.
• I will provide you with the tools to find the answers.
• This lecture's focus is on the critical thinking framework for caring for individual survivors.
• I will start by taking a few minutes to tell you why this topic is so important to me.
1996-1997
Part I
What is a cancer survivor?
Why Now?
Why should you care about this sub population of patients?
What caused this shift?
Survivor Definition: “Who” is a cancer survivor

NED 5 yrs after completion of therapy

My loose definition:
• Survivorship care begins after completion of primary therapy through end of life

Anyone with a cancer diagnosis- from day of diagnosis and for the rest of their life. The NCCS founders recognized the impact a diagnosis has on family, friends and caregivers, and later extended this definition to identify them as survivors as well.

NCCS: National Coalition for Cancer Survivorship
http://www.canceradvocacy.org/
Why Now: The Not So Good Old Days

Diagnosis  Treatment  Death
Why Now: Paradigm Changer

Diagnosis ➔ Treatment ➔ Survivor ➔ Death

Cancer Treatment “Essential Elements”
Since the 1990s:
Mortality Down, Survivorship Up

In the United States...

Growing # of Cancer Survivors = ↑ % of your Patient Population

Why Now: Cancer Treatment “Essential Elements”

Essential Elements = Standards of care / Treatment Guidelines
Part II
What are the cancer survivor’s needs? Risk?
Q O L

- **Quantity of life** - linear birth to death
- **Quality of life** - variable based on variables 😊
Cancer Survivors Needs- 4 Domain Summary

Physical Well-being
- Functional status
- Fatigue & Sleep
- Overall physical
- Overall physical health
  - Fertility
  - Pain

Psychological Well-being
- Control
- Anxiety / Depression
- Enjoyment/leisure
  - Fear of recurrence
- Cognition/attention
- Distress of diagnosis
- Control of treatment

Social Well-being
- Family distress
- Roles & relationships
  - Affection/sexual function
  - Appearance
  - Enjoyment
  - Isolation
  - Finance
  - Work

Spiritual Well-being
- Meaning of illness
  - Religiosity
  - Transcendence
  - Hope
  - Uncertainty
  - Inner strength

Quality of Life

Survivor’s Risks varies in intensity
• Many definition of “risk”

• What I consider risk to be:
  
  • “The chance that a long-term/late effect resulting from a therapeutic exposure impacts a survivor's health”.

These therapeutic exposures, **while necessary** may adversely affect the patients to whom they are administered.
Examples of late/long term effects of Chemotherapy and radiotherapy

<table>
<thead>
<tr>
<th>Organ system</th>
<th>Late effect of chemotherapy (agents)</th>
<th>Late effect of radiotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone and soft tissues</td>
<td>Avascular necrosis (corticosteroids)</td>
<td>Short stature</td>
</tr>
<tr>
<td></td>
<td>Osteoporosis (Premature Menopause)</td>
<td>Atrophy</td>
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<tr>
<td></td>
<td>(Long term Androgen deprivation)</td>
<td>Fibrosis</td>
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<td>Osteonecrosis</td>
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<td></td>
<td></td>
<td>Second cancers</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>Cardiomyopathy (anthracyclines, trastuzumab, other agents)</td>
<td>Pericardial effusion</td>
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<td></td>
<td></td>
<td>Pericarditis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Coronary artery and peripheral vascular disease</td>
</tr>
<tr>
<td>Pulmonary</td>
<td>Pulmonary fibrosis</td>
<td>Pulmonary fibrosis</td>
</tr>
<tr>
<td></td>
<td>Interstitial pneumonitis (bleomycin)</td>
<td>Decreased lung volumes</td>
</tr>
<tr>
<td>Central nervous system</td>
<td>Leukoencephalopathy (methotrexate)</td>
<td>Neurocognitive impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Radiation necrosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Second malignancies</td>
</tr>
<tr>
<td>Peripheral nervous system</td>
<td>Peripheral neuropathy</td>
<td>Brachial plexopathy</td>
</tr>
<tr>
<td></td>
<td>Hearing loss (cisplatin, taxanes, vinca alkaloids)</td>
<td>Lumbosacral plexopathy</td>
</tr>
<tr>
<td>Hematological</td>
<td>Myelodyplastic syndromes and secondary leukemias (alkylating agents)</td>
<td>Myelodysplasia</td>
</tr>
<tr>
<td>Renal</td>
<td>Decreased creatinine clearance (cisplatin, methotrexate)</td>
<td>Decreased creatinine clearance</td>
</tr>
<tr>
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<td></td>
<td>Hypertension</td>
</tr>
</tbody>
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<tr>
<td></td>
<td>(cisplatin, methotrexate)</td>
<td>Hypertension</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>Bladder fibrosis</td>
<td>Bladder fibrosis</td>
</tr>
<tr>
<td></td>
<td>Hemorrhagic cystitis</td>
<td>Contractures</td>
</tr>
<tr>
<td></td>
<td>Bladder cancer</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(cyclophosphamide)</td>
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<tr>
<td>Gastrointestinal</td>
<td>Abnormal liver function tests</td>
<td>Malabsorption</td>
</tr>
<tr>
<td></td>
<td>Hepatic fibrosis</td>
<td>Stricture</td>
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<tr>
<td></td>
<td>Cirrhosis (methotrexate)</td>
<td>Radiation proctitis</td>
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<tr>
<td></td>
<td></td>
<td>Second cancers</td>
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<tr>
<td>Pituitary</td>
<td>–</td>
<td>Growth hormone deficiency</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pituitary deficiency</td>
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<tr>
<td></td>
<td></td>
<td>Metabolic syndrome</td>
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<td></td>
<td>Obesity</td>
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<td></td>
<td></td>
<td>Diabetes</td>
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<tr>
<td>Thyroid</td>
<td>Hypothyroidism (sunitinib)</td>
<td>Hyperthyroidism</td>
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<tr>
<td></td>
<td></td>
<td>Hypothyroidism</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Thyroid nodules</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Thyroid cancer</td>
</tr>
</tbody>
</table>
Examples of late/long term effects of Chemotherapy and radiotherapy

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</tr>
</thead>
<tbody>
<tr>
<td><strong>Gonadal</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>Sterility</td>
<td>Sterility</td>
</tr>
<tr>
<td></td>
<td>(alkylating agents)</td>
<td>Leydig cell dysfunction</td>
</tr>
<tr>
<td>Women</td>
<td>Sterility</td>
<td>Ovarian failure</td>
</tr>
<tr>
<td></td>
<td>Premature menopause</td>
<td>Early menopause</td>
</tr>
<tr>
<td></td>
<td>(alkylating agents)</td>
<td></td>
</tr>
<tr>
<td><strong>Opthalmologic</strong></td>
<td>Cataracts (steroids)</td>
<td>Cataracts Retinopathy</td>
</tr>
<tr>
<td><strong>Skin</strong></td>
<td></td>
<td>Second cancers</td>
</tr>
</tbody>
</table>

• Cataracts
• Skin Cancer
• Sinus Problems
• Hypothyroidism
• Growth Hormone Deficiency
• Central Adrenal Deficiency
• Hyperprolactinemia
• Gonadotropin Deficiency
• Ototoxicity/Hearing Loss
• Neurocognitive Issues

• Tooth root agenesis (if radiation before full permanent teeth eruption)
• Enamel dysplasia
• Carotid Artery Stenosis
• Problems of the Thyroid gland (e.g., nodules, hypothyroidism, hyperthyroidism, thyroid cancer)
• Atrophy of neck muscles

• Skin cancers
• GI malignancies
• Secondary bladder malignancies
• Bladder fibrosis
• Sterility
• Low testosterone levels
• Erectile dysfunction
• Radiation nephritis
  • Otototoxicity/Hearing Loss
• Neurocognitive Issues
Part III
Oncology and/or primary care?
Resources for providers?
Why primary care is better suited to care for Cancer survivors than Oncology is

**Definition #1 - Primary Care**

Primary care is that care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern (the "undiagnosed" patient) not limited by problem origin (biological, behavioral, or social), organ system, or diagnosis.

Primary care includes health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in a variety of health care settings.

Primary care

Primary care is the day-to-day healthcare given by a health care provider. Typically, this provider acts as the first contact and principal point of continuing care for patients within a healthcare system, and coordinates other specialist care that the patient may need.\[1\] [2] [3]
Biggest Barrier: Onco-dependent relationship

The opinions of Rich Boyajian do not in any way represent any other oncology provider

Oncology providers, perhaps more so in academic medical centers, believe they are the only ones that will do things right.

They and the medical system put up barriers that reinforces their belief- Self-Fullfilling sabotage
When, if ever, do you stop needing to see your oncologist for follow-up care?

<table>
<thead>
<tr>
<th>Duration</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>At the completion of primary treatment</td>
<td>2.44</td>
</tr>
<tr>
<td>In the first year after treatment</td>
<td>2.44</td>
</tr>
<tr>
<td>In the second year after</td>
<td>1.22</td>
</tr>
<tr>
<td>2-5 years after treatment</td>
<td>7.32</td>
</tr>
<tr>
<td>5 years or more after treatment</td>
<td>29.27</td>
</tr>
<tr>
<td>Never</td>
<td>35.37</td>
</tr>
<tr>
<td>Not sure</td>
<td>21.95</td>
</tr>
</tbody>
</table>

DFCI Protocol 10-132 - Needs Assessment of Survivorship Care
85 of 105 patients completed survey (81% participation)
In general, when do you discharge your pts from your service back to the PCP?

<table>
<thead>
<tr>
<th>Low Risk</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Within 1 year</td>
<td>6.1%</td>
</tr>
<tr>
<td></td>
<td>1-2 years</td>
<td>8.6%</td>
</tr>
<tr>
<td></td>
<td>3-5 years</td>
<td>14.1%</td>
</tr>
<tr>
<td></td>
<td>6-10 years</td>
<td>31.9%</td>
</tr>
<tr>
<td></td>
<td>More than 10 years</td>
<td>9.8%</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>29.5%</td>
</tr>
<tr>
<td>N=163</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>High Risk</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Within 1 year</td>
<td>1.8%</td>
</tr>
<tr>
<td></td>
<td>1-2 years</td>
<td>2.4%</td>
</tr>
<tr>
<td></td>
<td>3-5 years</td>
<td>9.5%</td>
</tr>
<tr>
<td></td>
<td>6-10 years</td>
<td>14.3%</td>
</tr>
<tr>
<td></td>
<td>More than 10 years</td>
<td>13.7%</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>58.3%</td>
</tr>
<tr>
<td>N=168</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

DFCI Protocol 10-132 – Needs Assessment of Survivorship Care

Oncology providers have expertise and the barrier being placed in front of primary care is not making their expert risk based guidelines easily available
Why primary care is better suited to care for Cancer survivors than Oncology is

NCCN Guidelines Version 1.2019
Survivorship

DEFINITION OF SURVIVORSHIP

- An individual is considered a cancer survivor from the time of diagnosis, during and immediately after treatment, and through the balance of his or her life. Family members, friends, and caregivers are also affected by cancer.¹
- These guidelines focus on the vast and persistent impact both the diagnosis and treatment of cancer have on the adult survivor. This includes the potential impact on health, physical and mental states, health behaviors, professional and personal identity, sexuality, and financial standing.
- These guidelines are applicable to survivors across the continuum of care, including those on endocrine therapy, with chronic cancers (eg, metastatic disease), and long-term survivors.

STANDARDS FOR SURVIVORSHIP CARE²

- Care of the cancer survivor should include:
  1. Prevention of new and recurrent cancers and other late effects
  2. Surveillance for cancer spread or recurrence, and screening for subsequent primary cancers (SURV-3)³
  3. Assessment of late psychosocial and physical effects
  4. Intervention for consequences of cancer and treatment (eg, medical problems, symptoms, psychologic distress, financial and social concerns)
  5. Coordination of care between primary care providers and specialists to ensure that all of the survivor's health needs are met.

- Survivorship care planning:⁴
  1. Develop and provide to survivor and key health care providers a survivorship care plan that includes:
    - Summary of treatment received
    - Information regarding follow-up care, surveillance, and screening recommendations
    - Information on post-treatment needs, including information regarding treatment-related effects and health risks when possible (See NCCN Disease-Specific Guidelines)
    - Delineation regarding roles of oncologists, primary care physicians (PCPs), and subspecialty care physicians in long-term care and the timing of transfer of care if appropriate
    - Healthy behavior recommendations (See HL-1)

²Adapted with permission from the National Coalition for Cancer Survivorship as shown in the National Cancer Institute’s Office of Cancer Survivorship Definitions webpage, available at http://cancercontrol.cancer.gov/ccs/statistics/definitions.html.
⁴Surveillance testing (eg, labwork, imaging, other studies) should be based on cancer diagnosis and individualized patient risk. A small excess risk of cancer has been linked to frequent radiographic imaging. Surveillance testing should be performed as per disease-specific NCCN Guidelines. Additional labwork, imaging, or other studies to evaluate for recurrence should be based on clinical presentation and judgment.

Note: All recommendations are category 2A unless otherwise indicated. Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.
Results
With the screening, 68% showed a malignancy. All but one of the screening breast cancers. After 68% as compared with 90%, respectively.

Prospective Study of the Efficacy of Lymphoma Andrea K. Ng, et al.

Note: For more information including Clinical Trials: NCCN believes that all recommendations are appropriate medical management.
based guidelines for the treatment of acute ischemic stroke. Long-term prospective studies are lacking.

NCCN Guidelines Version 1.2019
Invasive Breast Cancer
NCCN Evidence Blocks™

SURVEILLANCE/FOLLOW-UP

Exam:
• History and physical exam 1–4 times per year as clinically appropriate for 5 y, then annually

Genetic screening:
• Periodic screening for changes in family history and genetic testing indications and referral to genetic counseling as indicated, see NCCN Guidelines for Genetic/Familial High-Risk Assessment: Breast and Ovarian

Post surgical management:
• Educate, monitor, and refer for lymphedema management, see NCCN Guidelines for Survivorship: Lymphedema

Imaging:
• Mammography every 12 mo
• Routine imaging of reconstructed breast is not indicated
• Screening for metastases:
• In the absence of clinical signs and symptoms suggestive of recurrent disease, there is no indication for laboratory or imaging studies for metastases screening

Endocrine therapy:
• Assess and encourage adherence to adjuvant endocrine therapy
• Women on tamoxifen: annual gynecologic assessment every 12 mo if uterus present
• Women on an aromatase inhibitor or who experience ovarian failure secondary to treatment should have monitoring of bone health with a bone mineral density determination at baseline and periodically thereafter

Lifestyle:
• Evidence suggests that active lifestyle, healthy diet, limited alcohol intake, and achieving and maintaining an ideal body weight (20–25 BMI) may lead to optimal breast cancer outcomes

Communication:
• Coordination of care between the primary care provider and specialists is encouraged. Additionally, a personalized survivorship treatment plan including personalized treatment summary of possible long-term toxicity and clear follow-up recommendations is recommended. See NCCN Guidelines for Survivorship

Engagement:
• Patients frequently require follow-up encouragement in order to improve adherence to ongoing screening and medication adherence

XIX The use of estrogen, progesterone, or selective estrogen receptor modulators to treat osteoporosis or osteopenia in women with breast cancer is discouraged. The use of a bisphosphonate (oral/IV) or denosumab is acceptable to maintain or to improve bone mineral density and reduce risk of fractures in postmenopausal (natural or induced) patients receiving adjuvant endocrine therapy. Optimal duration of either therapy has not been established. Duration beyond 3 years is not known. Factors to consider for duration of anti-osteoporosis therapy include bone mineral density, response to therapy, and risk factors for continued bone loss or fracture. Women treated with a bisphosphonate or denosumab should undergo a dental examination with preventive dentistry prior to the initiation of therapy, and should take supplemental calcium and vitamin D.
Key Components of Survivorship Care
Survivorship care is a specific approach taken to address the long-term needs of cancer survivors and includes monitoring for and managing long-term and late effects, as well as health promotion.

The 2005 Institute of Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost In Transition, embraces four components of survivorship care:
1. Prevention and detection of new cancers and recurrent cancer;
2. Surveillance for recurrence or new primaries;
3. Interventions for long-term and late effects (hereafter referred to as late effects) from cancer and its therapies; and
4. Coordination between specialists and primary care providers to ensure that all of the survivor’s needs are met.¹

High Quality Survivorship Care
Specifically, high quality care includes:
- Surveillance for recurrence
- Monitoring for and managing psychosocial and medical late effects
- Providing screening recommendations for second cancers
- Providing health education to survivors regarding their diagnoses, treatment exposures, and potential late- and long-term effects
- Providing referrals to specialists and resources as indicated
- Familial genetic risk assessment (as appropriate)
- Guidance about diet, exercise and health promotion activities
- Providing resources to assist with financial and insurance issues
- Empowering survivors to advocate for their own healthcare needs

LIVESTRONG Essential Elements of Survivorship Care
In 2011, LIVESTRONG convened the Essential Elements of Survivorship Care Meeting, attended by over 150 community leaders, stakeholders, cancer survivors and advocates, with a goal of building consensus around best practices to address the needs of post-treatment survivors. Consensus was reached on 20 essential elements of survivorship care delivery, which were organized into three tiers according to their level of priority. Levels #1 and #2 mirror the four IOM components of survivorship care.

References
Survivorship Compendium

The Survivorship Care Compendium has been developed to serve as a repository of advice and resources to enable oncologists and primary care providers implement or improve survivorship care within their practice. The compendium serves as an accompaniment to the educational opportunities and clinical guideline ASCO offers on survivorship care. Although ASCO endorses the National Coalition for Cancer Survivorship’s definition of a cancer survivor as starting at the point of diagnosis, the focus of this compendium is on individuals who have completed active treatment or who have transitioned to maintenance or prophylactic therapy.

Key Components of Survivorship Care
- Building a Survivorship Care Program
- Models of Long-Term Follow-Up Care

Determining the Best Model for You
- Conducting a Needs Assessment
- Challenges to Implementing a Survivorship Program
- Providing Survivorship Care in Practice

Measuring the Quality of Survivorship Care
- Survivorship Clinical Tools & Resources
- Coverage & Reimbursement for Survivorship Care Services

Survivorship Care Educational Opportunities
- Survivorship Patient & Family Resources

THE LIVESTRONG ESSENTIAL ELEMENTS OF SURVIVORSHIP CARE:
DEFINITIONS AND RECOMMENDATIONS

The Essential Elements

Tier 1 Consensus Elements
All medical settings MUST provide direct access or referral to these elements of care.
- Survivorship care plan, psychosocial care plan and treatment summary
- Screening for new cancers and surveillance for recurrence
- Care coordination strategy that addresses care coordination with primary care physicians and primary oncologists
- Health promotion education
- Symptom management and palliative care

Tier 2 High-Need Elements
All medical settings SHOULD provide direct access or referral to these elements of care for high-need patients and to all patients when possible.
- Late effects education
- Psychosocial assessment
- Comprehensive medical assessment
- Nutrition services, physical activity services and weight management
- Transition visit and cancer-specific transition visit
- Psychosocial care
- Rehabilitation for late effects
- Family and caregiver support
- Patient navigation
- Educational information about survivorship and program offerings

Tier 3 Strive Elements
All medical settings should STRIVE to provide direct access or referral to these elements of care.
- Self-advocacy skills training
- Counseling for practical issues
- Ongoing quality-improvement activities
- Referral to specialty care
- Continuing medical education

https://www.livestrong.org/what-we-do/our-research
Journey

We have online resources available to help you at any point on your cancer journey. Select your stage and concern below to get started.

I am in post treatment

looking for help with effects of cancer

SEE RESULTS

money & insurance

practical needs

feelings & emotions

health & wellness

effects of cancer

fertility

care & support

Family-Building

A cancer and fertility

Men: After Cancer Treatment

Discussing options for men.
Patient Care and Research

Guidelines and Consensus Documents

Clinical practice guidelines and consensus documents are evidenced-based or consensus-based documents developed to assist healthcare professionals and patients with decision making related to choosing, preventing and/or treatment in a specific health condition, and to promote high quality and appropriate care. They are developed from the body of standard literature supplemented by expert opinion.

Documents are posted based on information available at the time of publication, subject to literature review and discussions on the boards. These may be updated or amended that are not addressed in the current version and may, over time, be revised and updated. The website provides links to the current clinical practice guidelines, consensus guidelines and other Patient, Practice Parameters, and Role Models, depending on the topic and evidence available.

https://www.astro.org/Patient-Care-and-Research
Clinical Practice Guidelines

*Statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options* as defined by the National Academy of Medicine (formerly Institute of Medicine).

<table>
<thead>
<tr>
<th>CNS</th>
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<tbody>
<tr>
<td>Breast</td>
<td>▼</td>
</tr>
<tr>
<td>Genitourinary</td>
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<tr>
<td>Gastrointestinal</td>
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<tr>
<td>Gynecologic</td>
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<tr>
<td>Head and Neck</td>
<td>▼</td>
</tr>
<tr>
<td><strong>Palliative / Supportive / Survivorship</strong></td>
<td></td>
</tr>
</tbody>
</table>

- Palliative Thoracic Radiation Therapy In Lung Cancer (ASTRO) – 2018
- Palliative Radiation Therapy for Bone Metastases (ASTRO) – 2017
- Radiation Therapy and Surgery for Newly Diagnosed Brain Metastases (ASTRO) – 2012

<table>
<thead>
<tr>
<th>Skin / Soft Tissue / Benign</th>
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</thead>
<tbody>
<tr>
<td>Thoracic</td>
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</table>
Cancer Survivors

Provider Education
For Mental Health Care
of Cancer Survivors

Patients and Survivors
Learn how you can stay healthy
during your treatment, and after
your treatment is finished.

Cancer Caregivers
Get tips for staying healthy
while you support a survivor’s
physical and emotional health.

Health Care Providers
Get information on caring for
cancer survivors, including
those with obesity and those
who use tobacco.

Carletta: My Own Best Advocate

Cancer Survivor Stories

https://www.cdc.gov/cancer/survivors/index.htm
Caring for Cancer Survivors: Obesity and Wellness

Obesity, poor nutrition, and physical inactivity contribute to about 40% of cancer cases in the United States and can negatively affect cancer treatment and survival. We offer tips for helping cancer survivors improve their health.

https://www.cdc.gov/cancer/survivors/health-care-providers/

Caring for Cancer Survivors Who Use Tobacco

Tobacco use is the leading preventable cause of cancer and cancer deaths. Cigarette smoking not only causes cancer, but also negatively affects cancer treatment and survival. We offer tips for helping cancer survivors quit tobacco use.

Provider Education Training to Improve Mental Health Care of Cancer Survivors

The Provider Education for Mental Health Care of Cancer Survivors (EMHCCS) Training was created to support health care providers, improve knowledge about cancer survivors’ mental health care, and promote recommended distress screening.
Provider Education
for Mental Health Care of Cancer Survivors

Access this interactive experience on your desktop or laptop to practice talking with cancer survivors about their mental health, psychosocial distress and appropriate referral options.

START

This program and its contents were developed in partnership with the National Association of Chronic Disease Directors (NACDD) with funding from the Centers for Disease Control and Prevention-Division of Cancer Prevention and Control (CDC-DCCPC) agreement number U38 OT000225. The simulation is powered by the Kognito proprietary simulation platform and methodology ("Kognito IP"). All rights reserved. ©2018

Learn more about CDC’s work on Cancer Survivorship at https://www.cdc.gov/cancer/survivors/index.htm.

About

Centers for Disease Control and Prevention (CDC)
CDC works 24/7 protecting America’s health, safety and security. Whether disease starts at home or abroad, is curable or preventable, chronic or acute, or from human activity or deliberate attack, CDC responds to America’s most pressing health threats. CDC is headquartered in Atlanta and has experts located throughout the United States and the world. For more information, please visit cdc.gov.

Kognito
Kognito is a health simulation company. Our evidence-based simulations harness the power of conversations with virtual humans to improve social, emotional, and physical health. Learn more at kognito.com.

National Association of Chronic Disease Directors
The National Association of Chronic Disease Directors (NACDD) is a national, public health nonprofit, serving the health departments of all 50 states and US Territories working in chronic disease prevention and control. Founded in 1988, its membership totals over 7,000 public health practitioners and includes associate members from local health departments, federal agencies, universities and private industry. Learn more at chronicdisease.org.

https://simulations.kognito.com/pemhccs/
Survivorship Guidelines

The Children’s Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers were developed as a collaborative effort of the Nursing Discipline and the Late Effects Committee. The purpose of these guidelines is to:

- Provide recommendations for screening and management of late effects that may potentially arise as a result of the treatment for childhood cancer
- Increase awareness of potential late effects
- Standardize and enhance follow-up care provided to survivors

These guidelines were developed as a resource for clinicians who provide ongoing healthcare to survivors of pediatric malignancies. They are appropriate for asymptomatic survivors of childhood, adolescent or young adult cancers presenting for routine exposure based medical follow-up. More extensive evaluations are presumed, as clinically indicated, for survivors presenting with signs and symptoms suggesting illness or organ dysfunction.

As a companion to the Long Term Follow-up Guidelines a series of Health Links have been developed to provide more in-depth information about some of the more common late effects.

https://www.childrensoncologygroup.org/index.php/research-257/survivorship-guidelines
Our Mission
To cure and prevent childhood and adolescent cancer through scientific discovery and compassionate care.

Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers

The Children’s Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers (COG LTFU Guidelines) are a resource for healthcare professionals who provide ongoing care to survivors of pediatric malignancies. The screening recommendations in these guidelines are appropriate for asymptomatic survivors of childhood, adolescent, or young adult cancer, preventing routine unplanned medical follow-up. More extensive evaluations are proposed, as clinically indicated, for survivors presenting with signs and symptoms suggesting disease or organ dysfunction. A basic knowledge of ongoing issues related to the long-term follow-up needs of this patient population is essential. Healthcare professionals who do not regularly care for survivors of pediatric malignancies are encouraged to consult with a pediatric oncology long-term follow-up center if questions or concerns arise when reviewing or using these guidelines. A companion set of patient education materials, known as “HealthLink,” accompany the guidelines in order to enhance patient follow-up rates and improve the application of these guidelines. These clinical information regarding development and application of the COG LTFU Guidelines and related materials is available by accessing the Children’s Oncology Group website:

http://www.survivorshipguidelines.org/

Although the information within these guidelines will certainly prove valuable to the survivors themselves, the only version currently available is targeted to healthcare professionals. Therefore, survivors who choose to review these guidelines are strongly encouraged to do so with the assistance of a healthcare professional knowledgeable about long-term follow-up care for survivors of childhood, adolescent, and young adult cancers.

Click below to download the COG LTFU Guidelines and Appendices, Version 5.0:

- Online Follow-Up Guidelines
- Appendix A: Screening for Chronic Myelogenous Leukemia
- Appendix B: Follow-Up of Health Link

Click below to download the following clinical tools:

- Summary of Cancer Treatment (Children’s Cancer Group)
- Who is at Risk for Cancer?

Click below to download individual HealthLink:

- General and Psychosocial
- Diet and Physical Activity
- Exercise
- Emotional Issues
- Finding and Paying for Healthcare
- Introduction to Long-Term Follow-Up

DataBank:
- Dental Health
- Ophthalmology
- Radiation

Cardiac System:
- Heart Health
- Cardiovascular Risk Factors

Endocrine System:
- Central Adrenal Insufficiency
- Growth Hormone Deficiency
- Hypothyroidism
- Hypogonadism
- Hyperparathyroidism
- Thyroid Problems

Gastrointestinal System:
- Gastroesophageal Health
- Hepatitis
- Liver Health

Immune System:
- Allergy
- Immunodeficiency

Musculoskeletal System:
- Arthritis
- Bone Health
- Limb Differences

AUSC AVAILABLE:

COG Long-Term Follow-Up Programs

This comprehensive guide is designed for institutions interested in establishing and enhancing long-term follow-up programs for childhood cancer survivors. Collaboratively developed by the Children’s Oncology Group Research and the Effect Committee, COG Long-Term Follow-Up provides a broad perspective from a variety of long-term follow-up programs within the Children’s Oncology Group.

AUSC here to download a free PDF copy of the COG LTFU Resource Guide

Directory of Long-Term Follow-Up Services

The Children’s Oncology Group maintains a directory of long-term follow-up programs by COG. Visit this page to access the COG Late Effects Directory of Survivors.
About the Adult Survivorship Program

Dana-Farber's adult survivorship program, part of the adult survivorship program, is here to help you find answers, education, and support to help manage issues related to surviving cancer. This includes managing the risk of second cancers, understanding the long-term effects of treatment, and addressing social, physical, or psychological concerns.

Our physicians, nurses, researchers, and psychologists are experts in survivorship, and will work with you and your primary care physician to create a plan for living well beyond cancer.

If you were treated for cancer as an adult (age 18 or older), you may benefit from our expertise and services.

You do not need to have been treated at Dana-Farber in order to be seen in our adult survivorship program.

Our services

The staff at our adult survivorship clinic can help you manage long-term and late effects of cancer treatment and guide you in living a healthier lifestyle.

At your appointment, we will review your medical records, including past cancer diagnosis and treatment, current health status, and general quality of life.

We'll provide you with a comprehensive summary of recommendations that can serve as a useful guide to you and your primary care doctor, outlining potential late effects and offering helpful medical information related to your past treatment and future care.

We offer specialized expertise and services including:

- **Cardiologists** who work to treat and prevent heart damage and related problems sometimes associated with cancer treatments.
- **Community resource specialists** to help you find survivorship resources near your home, such as advocacy, employment rights, fertility resources, financial support, health insurance, and support groups.
- **Endocrinologists** who diagnose and treat issues related to endocrine glands, such as the thyroid, adrenal glands, and pituitary glands.
- **Exercise recommendations** with an exercise physiologist, to help survivors of any cancer diagnosis experience the benefits of safe, effective, regular physical activity, answer fitness-related questions, and provide personalized exercise tips.
- **Gynecologists** to help with fertility issues and sexual health.
- **Lymphologists** to diagnose and treat issues related to the immune system in cancer survivors.
- **Neurologists** who work with survivors to diagnose and treat issues related to the kidneys.
- **Nutrition counseling** to strengthen healthy eating habits for cancer survivors.
- **Education and support**, including classes, support groups, and individual appointments designed to help cancer survivors and their family members address the emotional, social, and spiritual aspects of surviving cancer.
- **Sexual health program** to address changes in sexual health during and after cancer treatment.

Visit our website for more information and support about survivorship at Dana-Farber.

Resources for Cancer Survivors

For Cancer Survivors

Nutrition Services
https://bethematchclinical.org/post-transplant-care/
Long-Term Care Guidelines Following HCT

Complications from hematopoietic cell transplantation (HCT) can develop long after a patient leaves the transplant center. To prevent late complications from increasing morbidity in these patients, awareness of the specialized care these patients require is essential.

6 Month, 12 Month, and Annual Care Guidelines

In 2012, experts from seven international transplant professional societies published Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation, which outlines long-term screening and preventive practice guidelines applicable to both autologous and allogeneic transplant recipients. [1]

We offer these guidelines in user-friendly, portable formats for clinicians and patients. The guidelines are organized by organ system to assist in patient care planning and include:

- Complications and tests
- Preventive measures for 6 month, 12 month and annual appointments
- Recommendations for special populations including patients with GVHD, ongoing significant corticosteroid exposure, pediatric patients, and patients who have received total body irradiation (TBI)

Access HCT Guidelines for Clinicians

- Access interactive tool for a customizable list of screening recommendations
- Download Post-HCT Care Guidelines (PDF)
- Order print version or download the HCT Guidelines mobile app

Access Patient Post-Transplant Care Guidelines

- Download HCT patient guidelines
Summary

1. Primary care can care for most survivors
2. Primary care needs proper information about survivors risks and what are the recommendations based on these risks.
3. Oncology need to let go and do a better job providing this information.
Summary

1. Primary care can care for most survivors

2. Primary care needs proper information about survivors' risks and what are the recommendations based on these risks.

3. Oncology need to let go and do a better job providing this information.
Questions?