Cancer Survivorship Resources for VA Staff and Clinicians

Developed by the Cancer Survivorship Advisory Group
VHA Cancer Care Collaborative
January 2011

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**Introduction**

There are an estimated 11.4 million cancer survivors in the U.S., or approximately 4% of the population. Approximately 14% of survivors were diagnosed 20 or more years ago. Today, 67% of adults diagnosed with cancer will be alive in five years. Among children, over 77% of childhood cancer survivors will be alive after 10 years. ¹ 524,052 veterans treated in VHA in FY 2007 were identified on the CPRS problem list as having cancer, a prevalence of 11%.²

Cancer survivor issues extend beyond traditional medical care to many, complex psychosocial needs. Cancer survivorship care is summarizing what has happened already and helping patients plan for the future, a “new normal.”

There are differences in opinion and approach on the definition of a cancer survivor (from time of diagnosis, or after active treatment). Many staff strongly support the view that a patient is a survivor from the time of diagnosis and going forward. This mirrors the position of the advocacy community (National Coalition for Cancer Survivorship and Lance Armstrong Foundation among others). From a practical standpoint, developing a plan of care once the veteran finishes “active” treatment may be easier to conceptualize within available resources.³

An advisory group on cancer survivorship was established in April 2010 within the context of the VHA Cancer Care Collaborative, Phase II. The multidisciplinary group established several goals covering program development, “spreading” the word, psychosocial assessment, and research. This resource guide, and a partner one developed for veterans and their families, is part of this body of work.

A Cancer Survivor Toolkit was developed in 2012 with assistance from the VISN 11 VA Center Applied Systems Engineering (VA CASE). This Toolkit is a big step forward into making the output of this advisory group more accessible through out the VA system. Toolkit modules include: a CPRS template to document a treatment summary and survivorship care plan, Models of Care with specific case studies on how to develop and implement a survivorship clinic at one’s facility, Community Resources and a link for entering resources in local communities, and a section on Tools and Measurements for clinicians and researchers interested in this topic. The Toolkit can be accessed at https://vaww.visn11.portal.va.gov/sites/VERC/va-case/collabs/cccop/SitePages/menu.aspx.

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VA Cancer Care Collaborative
Cancer Survivorship Advisory Group
January 2011; updated March 2012
Quality of Life Model Applied to Cancer Survivors

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<th>Physical Well Being and Symptoms</th>
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<td>Functional Activities</td>
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<td>Strength/Fatigue</td>
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<td>Sleep and Rest</td>
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<td>Overall Physical Health</td>
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<td>Fertility</td>
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<td>Pain</td>
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<th>Psychological Well Being</th>
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<td>Control</td>
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<td>Anxiety</td>
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<td>Distress of Diagnosis and Control of Treatment</td>
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<th>Social Well Being</th>
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<td>Family Distress</td>
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<td>Roles and Relationships</td>
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<td>Affect/ Sexual Function</td>
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<td>Appearance</td>
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<td>Finances</td>
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<td>Work</td>
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<th>Spiritual Well Being</th>
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<td>Meaning of Illness</td>
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<td>Religiosity</td>
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<td>Transcendence</td>
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<td>Hope</td>
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<td>Uncertainty</td>
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<td>Inner Strength</td>
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Cancer Survivorship

References

Betty R. Ferrell, PhD, FAAN, Marcia Grant, DNSc, FAAN, Karen Hassey-Dow, PhD, FAAN

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Models of Survivorship Care

Shared-care model of follow-up care: prescription back to primary care provider (PCP)
- From specialists to primary care practitioners
  - Personal communication
  - Organized (periodic) transfer of knowledge
    - Decision support tools
      - Albany, New York VA (surveillance colonoscopy)
      - Oncwatch – Columbia, South Carolina VA (colorectal screening and follow up)
      - Lebanon, Pennsylvania VA (clinical reminder for surveillance colonoscopy)
- Reasons for shared care
  - Lack of PCP knowledge of adverse effects of chemotherapy or new surveillance recommendations
  - Lack of oncologist knowledge about updates in general preventive or chronic disease care

Nurse-led model of follow-up care: Care manager (oncology nurse)
- Serves as conduit between oncology & PCP
- Prescreened for physical & psychosocial issues
  - Annual or other interval
  - Schedule to see PCP or oncology based upon screening
- Builds upon strength of nursing education/skills:
  - Patient assessment
  - Symptom management
  - Psychosocial care
  - Care planning
- Disadvantage:
  - Shortage of trained oncology nurses, especially in outpatient settings

Specialized survivorship follow-up clinics
- Specialized multidisciplinary program
  - Physician trained/experienced in care of cancer survivors (vs. active cancer care)
  - Oncology nurse practitioners (backbone of model)
  - Social workers, psychologists, network of consulting physicians
- Disadvantage:
  - Most complex and resource-intensive
  - Separation of survivorship care from other routine care

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Further details on these three models were presented by Dr. Haggstrom and Ms. Ballard at the January 2010 Learning Session of the VHA Cancer Collaborative.\(^6\)

A 2010 ASCO abstract reported the preferences by treating oncology staff for managing survivorship care. “There were significant differences in model preference by clinician type. Physicians and nurses preferred to base survivor programs in disease site clinics followed by a centralized multisite clinic with the community shared model the least preferred... All four clinician groups rated providing education about late effects, pain and symptom management, and help communicating with primary care providers as among the most important components of a survivorship program.”\(^7\)

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\(^6\) Colorectal Cancer Survivorship Care, Learning Session 4, Phase I Cancer Care Collaborative, https://srd.vssc.med.va.gov/Collaboratives/Active/Cancer%20Care%20Collaborative%20FY09/Pages/default.aspx

# Resources on Cancer Survivorship

## National guidelines:

<table>
<thead>
<tr>
<th>Organization</th>
<th>Web site URL</th>
</tr>
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<tbody>
<tr>
<td>NCCN National Comprehensive Cancer Network</td>
<td><a href="http://www.nccn.org">www.nccn.org</a></td>
</tr>
<tr>
<td>ONS Oncology Nursing Society</td>
<td><a href="http://www.ons.org">www.ons.org</a></td>
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## General Resources:

<table>
<thead>
<tr>
<th>Resource</th>
<th>URL</th>
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<tbody>
<tr>
<td>VHA – Cancer Survivorship e-Toolkit</td>
<td><a href="https://vaww.visn11.portal.va.gov/sites/VERC/va-case/collabs/survivor_toolkit/SitePages/Home.aspx">https://vaww.visn11.portal.va.gov/sites/VERC/va-case/collabs/survivor_toolkit/SitePages/Home.aspx</a></td>
</tr>
<tr>
<td>American Cancer Society</td>
<td><a href="http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/SurvivorshipCarePlans/index">http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/SurvivorshipCarePlans/index</a></td>
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</tbody>
</table>
## Resources for Cancer Survivorship Care Plans

### Care Plan Content

- **Treatment Summary**: Cancer type, treatment received, and potential toxicities
- **Surveillance**: Tailored information about timing and content of recommended follow-up
- **Recommendations**: Regarding preventive practices and how to maintain health and well-being
- **Information**: On legal protections regarding employment and access to health insurance
- **Availability**: Of psychosocial services (in VHA and in community)

<table>
<thead>
<tr>
<th>Organization/Facility</th>
<th>Web site URL</th>
<th>Cancer Sites</th>
</tr>
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<tbody>
<tr>
<td>VHA</td>
<td><a href="https://vaww.visn11.portal.va.gov/sites/VERC/vacase/collabs/survivor_toolkit/SitePages/Home.aspx">https://vaww.visn11.portal.va.gov/sites/VERC/vacase/collabs/survivor_toolkit/SitePages/Home.aspx</a> CPRS treatment summary and survivorship care plan, developed and beta tested by the VHA Cancer Survivorship Special Interest Group (SIG) 2012</td>
<td>All To be completed by oncology professionals</td>
</tr>
<tr>
<td>VHA</td>
<td>End of Treatment summary in the electronic chemotherapy ordering software (CPRS)</td>
<td>For pts who have received chemotherapy To be completed by oncology professionals</td>
</tr>
<tr>
<td>ASCO</td>
<td><a href="http://www.asco.org/ASCOv2/Practice+%26+Guidelines/Quality+Care/Quality+Measurement+%26+Improvement/Chemotherapy+Treatment+Plan+and+Summary">http://www.asco.org/ASCOv2/Practice+%26+Guidelines/Quality+Care/Quality+Measurement+%26+Improvement/Chemotherapy+Treatment+Plan+and+Summary</a></td>
<td>Breast, Colon, Non Small Cell Lung, Small Cell Lung, Lymphoma To be completed by oncology professionals</td>
</tr>
<tr>
<td>National Coalition for Cancer Survivorship - Journey Forward</td>
<td><a href="http://www.canceradvocacy.org/resources/journey-forward.html">http://www.canceradvocacy.org/resources/journey-forward.html</a></td>
<td>Breast, Colon; Resources under development for other malignancies</td>
</tr>
<tr>
<td>Institute</td>
<td>Website</td>
<td>Language Availability</td>
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<tr>
<td>University of Pennsylvania</td>
<td><a href="http://www.oncolink.org/oncolife/">http://www.oncolink.org/oncolife/</a></td>
<td>Available in English and Spanish Can be initiated by pt</td>
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<tr>
<td>Institute of Medicine (IOM)</td>
<td>IOM Template for “Cancer Survivorship Care Plan” Tested in IOM Focus Groups and Interviews, Appendix E&lt;sup&gt;8&lt;/sup&gt;</td>
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</tbody>
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<sup>8</sup> Implementing Cancer Survivorship Care Planning: Workshop summary. Institute of Medicine, National Academies, Appendix E, p. 276.
VHA Information Letter

A Department of Veterans Affair Under Secretary for Health’s Information Letter, **Cancer Survivorship Care**, is under revision. Final copy will be available on the Oncology SharePoint site:

http://vaww.infoshare.va.gov/sites/MedicalSurgical/oncology/default.aspx
Phase in for 2015

STANDARD 3.2 Psychosocial Distress Screening

The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care.

DEFINITION AND REQUIREMENTS

Cancer is a complex disease process that affects patients in a variety of ways. Patients experience psychological, social, financial, and behavioral issues that can interfere with their treatment plan and adversely affect their outcome. To address the psychosocial issues experienced by patients with cancer, the 2007 report of the IOM, Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs, emphasizes the importance of screening patients for distress and psychosocial health needs as a critical first step to providing high-quality cancer care. According to the NCCN, distress should be recognized, monitored, and documented and treated promptly at all stages of the disease. In addition, this report emphasizes that all patients with cancer need to be referred for the appropriate provision of care and that high-quality psychosocial cancer care includes systematic follow-up and reevaluation. The purpose of this standard is to develop a process to incorporate the screening of distress into the standard care of oncology patients and provide patients identified with distress with resources and/or referral for psychosocial needs.

The psychosocial representative on the cancer committee (oncology social worker, clinical psychologist, or other mental health professional trained in the psychosocial aspects of cancer care) is required to oversee this activity and report to the cancer committee annually.

PROCESS REQUIREMENTS

a) **Timing of Screening:** Patients with cancer are offered screening for distress a minimum of 1 time per patient at a pivotal medical visit to be determined by the program. Some examples of a "pivotal medical visit" include time of diagnosis, presurgical and postsurgical visits, first visit with a medical oncologist to discuss chemotherapy, routine visit with a radiation oncologist, or a post chemotherapy follow-up visit. Preference is given to pivotal medical visits at times of greatest risk for distress, such as at time of diagnosis, transitions during treatment (such as from chemotherapy to radiation therapy), and transitions off treatment.

b) **Method:** The mode of administration (such as patient questionnaire, clinician-administered questionnaire) is to be determined by the program.

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c) **Tools:** Facilities select the tool to be administered to screen for current distress. Preference is given to standardized, validated instruments with established clinical cutoffs; however, facilities may use a measure of their choice. Facilities are encouraged to use established clinical cutoffs when possible; however, facilities may determine the cutoff score used to identify distressed patients.

d) **Assessment and Referral:** As recommended in the 2007 IOM report, if there is clinical evidence of moderate or severe distress, the patient's oncology team (oncologist, nurse, social worker, and/or psychologist) is to "identify and examine the psychological, behavioral and social problems of patients that interfere with their ability to participate fully in their health care and manage their illness and its consequences." This evaluation will confirm the presence of physical, psychological, social, spiritual, and financial support needs and indicate the need to link patients with psychosocial services offered on-site or by referral.

(e) **Documentation:** Screening, referral or provision of care, and follow-up are documented in the patient medical record to facilitate integrated, high-quality care.

**SPECIFICATIONS BY CATEGORY**

All programs fulfill the standard as written.

**DOCUMENTATION**

The program completes the SAR.

The program provides cancer committee minutes along with other sources that document the methods implemented to monitor and evaluate psychosocial distress screening.

During the on-site visit, the surveyor will discuss with the designated psychosocial representative and the cancer committee the psychosocial distress screening activities and the methods implemented to offer screening, referral or provision of care, and follow-up for psychosocial distress to patients with cancer.

**MONITORING COMPLIANCE**

**Rating**

(1) **Compliance:** The program fulfills the following criterion:

The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care as the standard for patients with cancer.
(2) **Noncompliance:** The program does not fulfill the following criterion:

The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care as the standard for patients with cancer.
Phase in for 2015

**STANDARD 3.3 Survivorship Care Plan**

The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes.

**DEFINITION AND REQUIREMENTS**

The IOM and National Research Council 2005 report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, recommends that patients with cancer who are completing the first of course treatment be "provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained." The recommendation suggested that these plans would help cancer survivors who may otherwise get "lost" in the transitions from the care they received during treatment through the phases of their life or stages of their disease course. The purpose of this standard is to have cancer programs develop and implement a process to monitor the dissemination of a survivorship care plan as a part of the standard care of patients with cancer. The process is implemented, monitored, evaluated, and presented annually to the cancer committee. The presentation is documented in minutes.

**PROCESS REQUIREMENTS**

(a) A survivorship care plan is prepared by the principal provider(s) who coordinated the oncology treatment for the patient with input from the patient's other care providers.

(b) The survivorship care plan is given to the patient on completion of treatment.

(c) The written or electronic survivorship care plan contains a record of care received, important disease characteristics, and a follow-up care plan incorporating available and recognized evidence-based standards of care, when available. The minimum care plan standards are included in the Fact Sheet: Cancer Survivorship Care Planning, from the IOM.

Additional resources are available to assist programs with the development of these tools, including care planning templates. Care planning templates are available from, for example, the American Society of Clinical Oncology, National Coalition for Cancer Survivorship, and the Lance Armstrong Foundation.

**SPECIFICATIONS BY CATEGORY**

All programs fulfill the standard as written.

**DOCUMENTATION**

The program completes the SAR.

During the on-site visit, the surveyor will discuss with the cancer committee the methods implemented to create and disseminate a survivorship care plan.
MONITORING COMPLIANCE

Rating

(1) Compliance: The program fulfills the following criteria:

1. The cancer committee has developed a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment.
2. Each year, the process is implemented, monitored, evaluated, and presented to the cancer committee.

(2) Noncompliance: The program does not fulfill 1 or more of the following criteria:

1. The cancer committee has developed a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment.
2. Each year, the process is implemented, monitored, evaluated, and presented to the cancer committee.
Recommended Reading


Additional References


Downloaded 8/27/08.


