

Navigating your Health as a Cancer Survivor



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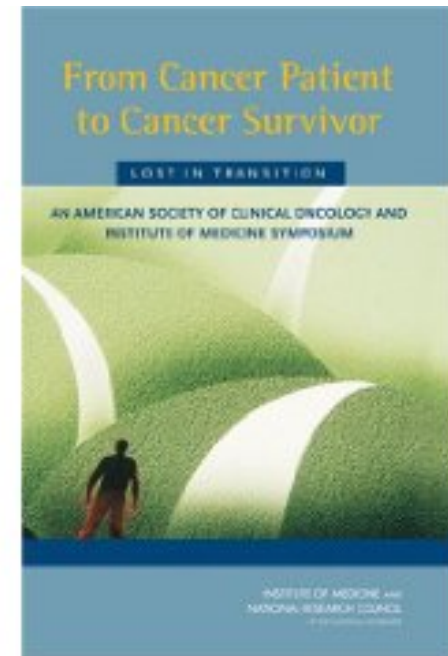
Institute of Medicine Report

November 2005

“From Cancer Patient to Cancer Survivor: Lost in Transition”

Recommendations:

- 1) Establish cancer survivorship as a distinct phase of cancer care.
- 2) Patients should be provided with comprehensive care summary and follow up plan when completing primary care.
- 3) Need to develop guidelines to help identify and manage late effects of cancer.



Who is a survivor?

- Anyone who's life has been impacted by cancer.
- Survivorship starts at time of diagnosis.



Three Stages of Cancer Survivorship

Living with...through and...

Beyond Cancer

**Ok, you've finished
treatment! Time to celebrate?**



What happens NOW?



Good news!

- Estimated 22.4 million people globally are living with a history of cancer.
- Approximately 11.2 million Americans are cancer survivors.

BUT.....

Challenges

- Many cancer survivors are living with serious long term physical, emotional, social, spiritual and financial side-effects of diagnosis or treatment
- Some late or long-term effects are not apparent for many years after treatment is completed

Challenges

- Best evidence practices have not yet been established for care of cancer survivorship issues
- Some oncology practices are too busy to see survivors routinely
- Many primary care doctors do not feel prepared to manage complex care of cancer survivors
- Transition from active treatment is a very stressful time for the survivor

Some of the common issues reported by cancer survivors

- Fear of recurrence
- Sleep disturbances
- Fatigue
- Pain (arthralgias and neuropathy)
- Hot Flashes
- Sexuality Issues
- Body Image
- Weight changes – gain or loss
- Digestive Issues
- Cognitive concerns – memory loss, depression
- Employment or financial challenges

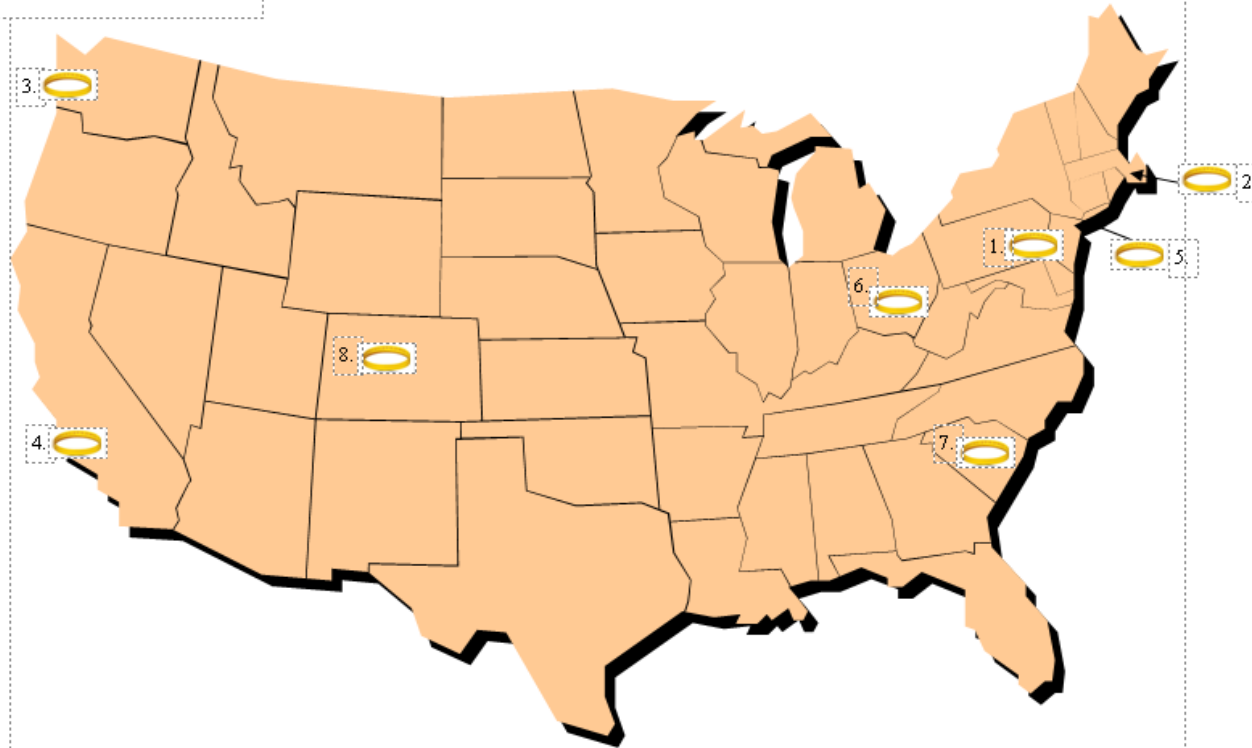
SCCA Survivorship Clinic

- Medical Oncology Survivorship Team or MOST
- Provides clinical care, education, and research opportunities to patients who have completed active cancer treatment

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2008 LIVESTRONG™ Survivorship Center's Of Excellence Network Members



1. Abramson Cancer Center, University of Pennsylvania
Linda Jacobs, Director, Living Well After Cancer Program
www.pencancer.org/cancerprograms
2. Dana-Farber Cancer Institute
Lisa Diller, Director, Perini Family Survivor's Center
www.dana-farber.org/pat/surviving/
3. Fred Hutchinson Cancer Research Center
Debra Friedman, Director, Survivorship Center
www.fhcr.org/patient/support/survivorship/
4. Jonsson Comprehensive Cancer Center at UCLA
Patricia Ganz, Director, Survivorship Program
www.cancer.ucla.edu/

5. Memorial Sloan Kettering Cancer Center
Mary McCabe, Director, Survivorship Program
www.mskcc.org/mskcc/html/58022.cfm
6. The Ohio State University Comprehensive Cancer Center -
James Cancer Hospital
Charles Shapiro, Director Survivorship Center of Excellence
www.jamesline.com/patientandvisitors/survivors
7. University of North Carolina, Lineberger Comprehensive Cancer Center,
N.C. Cancer Hospital
Marci Campbell, Director, Survivorship Program
<http://cancer.unc.edu/patient/>
8. University of Colorado Cancer Center, AMC Cancer Research Center
Al Marcus, Director, Survivorship Program
<http://www.uccc.info/for-healthcare-professional/cancer-center/prevention/Survivorship/index.aspx>

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SURVIVORSHIP CENTER
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FRED HUTCHINSON
CANCER RESEARCH CENTER

A LIFE OF SCIENCE

Patient Eligibility

- Patients who have had a previous diagnosis of cancer
- Patients who are not in active cancer treatment (excluding ongoing hormone therapy and some maintenance treatments)

Evaluation

- 60-90 minute consulting visit with ARNP dedicated to survivor issues.
- Identify issues, concerns and risks through clinic evaluation and review of past medical and treatment records, and patient survey.
- One time and/or annual visit as needed.

Education

- Risks related to treatment (i.e. lymphedema prevention education)
- Community resources
- Health links, Survivorship Notebook
- Wellness recommendations, include screening recommendations as well as lifestyle interventions to reduce risk of recurrence

Coordination

- Primary care provider strongly encouraged
- Provide “bridge” between PCP and oncology providers
- Resource for PCPs



Coordination

- Referral to specialists as necessary
 - Physical Therapy
 - Nutrition
 - Cardiology
 - Endocrine
 - Sleep Disorder clinic
 - Pain clinic
 - Cognitive Function clinic
 - And many others

Survivorship Care Plan

- A comprehensive summary of cancer diagnosis and treatment received
- Treatment details: Chemotherapy, with selected cumulative doses, radiotherapy doses and fields, surgical procedures, blood product exposures
- 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 send to survivor and healthcare providers

Research

- Optional participation
- Recognized as a Lance Armstrong Foundation Center Of Excellence
- Collaborative research with other institutions
- Survivorship is an emerging and exciting field of research

Research

- Improving quality of life for cancer survivors addressing physical, social and cognitive functioning as outcome criteria
- Developing and evaluating prevention and treatment strategies for long term and late effects of cancer therapies
- Goal is to prevent ongoing poor health or unnecessary disability among cancer survivors

Summary of MOST

- Treatment Summary
- Evaluate present issues and concerns
- Screening and education for late effects
- Education
- Create a plan for the future (SCP)
- Communicate to PCP and other providers involved in care
- Referrals as necessary
- Follow-up annually or as necessary

Meet other survivors!



Breast Cancer Survivor

- 45 year old female, 3 years out from diagnosis
- **Treatment included** mastectomy, chemotherapy, radiation and hormonal treatment
- **Concerns** included arthralgias, menopausal symptoms (hot flashes, sleep disturbances) sexual dysfunction, fatigue and anxiety about recurrence k1

k1

weight gain?

ksyrjala, 10/6/2008

Breast Cancer Survivor

- **Education** about bone & heart health, lymphedema and risks for genetic and second cancers and menopausal symptoms
- **Referrals and Coordination:** Referred to nutrition, psychologist and PT as well as genetic counselor and several community support resources. Screening included DEXA scans, fasting lipids and CBC.

Outcome

- Return to PCP for routine visits for health maintenance that she had not yet done
- Lost 30 lbs and had ovaries removed. Achiness improved which allowed her to stay on the aromasin. She felt better physically, (taking vitamin D and started stretching though a community class)
- Decreased anxiety. She reduced her risk of recurrence. Slept better, felt better and improved QOL!

Colon Cancer Survivor

- 65yr old, 10 years out from diagnosis
- **Treatment included:** Chemotherapy, radiation and several surgeries
- **Concerns:** Digestive issues, frequent BMs, depression and sexual difficulties
- Off therapy and no longer seeing his oncologist.
- Unsure that his PCP would understand his cancer treatment.. didn't know where to go?

Colon Cancer Survivor

- **Education** about risks for: secondary cancers, digestive and psychological and sexual dysfunction issues.
- **What did we do?** Referrals: to a nutritionist and to a psychologist who specializes in sexuality and intimacy.

Outcomes

- Nutritionist worked on dietary changes and relieved his frequent BMs.
- Therapist improved communication and intimacy with his wife about sexual difficulties.
- He gained confidence with SCP to return to his PCP with ongoing issues.
- QOL improved! Able to work more and volunteer in the community.

Hodgkin's Survivor

- 50 year old female, 1 yr out from diagnosis.
- **Treatment included:** chemotherapy and radiation.
- **Concerns:** Appropriate screening tests? Anxiety about recurrence, fatigue so severe that she had to stop many of her favorite activities and worked only part time. She had complained of intermittent palpitations but not had any work-up.

Hodgkins Survivor

- **Education about risks:** Hypothyroid, secondary cancers and heart disease.
- **What did we do? Education** about secondary cancers, **Screening:** mammogram, echocardiogram and **referral** to cardiologist, as well as community support group.

Outcomes

- Tachycardia found by cardiologist, started on medication. Was able to resume activities, exercise and work again.
- Screening schedule developed for SCP
- Active in a support group and QOL improved substantially!!

Contact us!

- **To schedule a clinic appointment:**
(206) 288-7646 or toll free 1-866-543-4272
- **Fax:** (206) 667-2742
- **E-mail:** survivor@fhcrc.org

Questions?

