

Cancer Survivorship Care Plans

Carolyn Vachani, MSN, RN, AOCN

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I'm a Survivor, Now What?

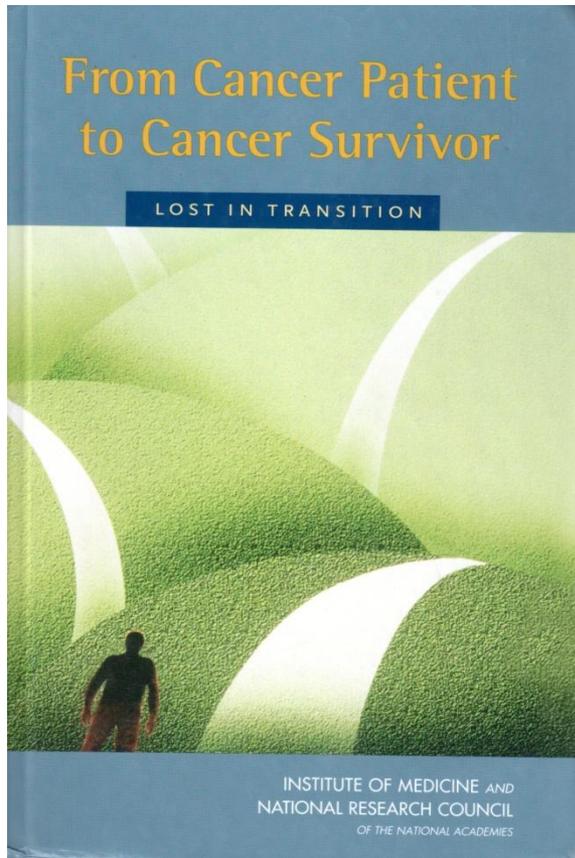


- Leaving the “comfort” of frequent visits with the oncology team can be a very difficult transition
- Lack of knowledge / research in medical community about long term effects
- Historically survivors have not been told about late effects of treatment
- Importance of survivorship care plans and learning about late effects

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Institute of Medicine Report



- Published in 2006 by an expert panel
- PCPs and other HCPs are not aware of late effects related to cancer therapy
- Seldom receive guidance from oncology community
- Recommended:
 - More research initiatives
 - Increase awareness
 - All survivors need to receive a treatment summary and care plan to address medical, psychological, financial and lifestyle issues

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What is a Treatment Summary?



- A document that summarizes the cancer diagnosis & treatments
 - Relevant pathology results
 - Surgery
 - Medical therapies (chemo, biotherapy)
 - Radiation therapy
- No “right way” to do this

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What is a Survivorship Plan?



- A survivorship plan is a document that outlines possible health risks, psychosocial effects, financial effects and genetic risk related to cancer and cancer therapy
- How to reduce the risk, when possible, through healthy lifestyle and preventive therapies
- How to monitor for late effects with your healthcare team
- Referrals for follow up care and resources

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How Do I Get a Survivorship Plan?



- Talk with oncology team
- Visit a Late Effects / Survivorship Clinic
- Research your treatments
- Create a **LIVESTRONG** Care Plan

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- Learning about late effects can be overwhelming, but remember:
- Some survivors will have no long term effects, some will have many, but most will be somewhere in between
- Educating yourself allows you to be your best advocate

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What is OncoLink?

- The first cancer information website, started in 1994, remains one of the largest
- Based at the University of Pennsylvania Cancer Center in Philadelphia
- Average 3.9 million pages served per month
- Information at all levels, free, no registration
- Users are 80% pts/families, 20% HCPs
- 15% Philadelphia area; 25% International; 70% female
- Average length of session 11 minutes
- Updated daily, written by nurses, physicians and other healthcare providers

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What is the **LIVESTRONG** Care Plan?

- Individualized survivorship care plan program based on the Institute of Medicine recommendations, available literature and professional recommendations
- Free and easy to use
- Provides survivors with information about health risks they may face as a result of cancer therapies, how to decrease their risk and monitor for these effects
- Encourages a review of the plan with their healthcare team to “get specific”
- Empowers patients to become participants in their follow up care.

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What do I Need to Create a Plan?



- Type of cancer you were diagnosed with
- What surgery you had for this cancer
- What medications you received (chemotherapy, biotherapy, hormone therapy)
- Did you receive radiation therapy?
- That's it!

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The **LIVESTRONG** Care Plan

- The answers provided generate a plan that addresses:
 - Importance of coordinating your care
 - Risk of second cancers and need for screening
 - Healthy lifestyle tips
 - Potential long term side effects
 - Tips to reduce risk or cope with the issue
 - Ways to monitor / symptoms to look for
 - Divided by treatment cause

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What We Have Learned

- Over 8500 plans have been created since launch in 5/2007
- 89% of those have never been offered survivorship information before
- Takes an average 6-7 minutes to complete the questionnaire
- 91% of those completing it said they had the information needed to do so
- 95% of users describe the information as good to excellent
- Most common primary diagnoses breast, hematologic, and GI malignancies (Prostate cancer under-represented)
- Users are:
 - Survivors: 65%
 - Family / Friends: 11%
 - Healthcare providers: 22% (85% of those are nurses)

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The Future / Evaluation

- Quarterly reviews and updates
 - Improvements based on user feedback, usage statistics
 - Additions as knowledge grows
 - Improvements to improve user experience
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- Most survivors have not received survivorship information and the LIVE**STRONG** Care Plan fills an important need for survivors and their healthcare providers

What keeps us going...

- My prior Oncologist "refused" to see me some years after my cancer treatment, when I developed "after effects"... what you are doing is a great service to all people who have lived thru these illnesses, and are trying to continue as survivors.
- Over the years I have tried to research the potential long term complications of my treatment. My research has always ended with incomplete, fragmented information. The report produced by your tool is comprehensive and clear. Thank you for producing this great tool.
- This site is an answer to prayer..thank you!!! Cancer survivorship has been the forgotten child of healthcare. As a survivor, I know that the scariest part of treatment is it's termination. We ask "Now what?" There have been few places to turn for help. On behalf of all survivors, we thank you.

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