



A Survivorship Care Plan

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OncoLink Background

- <http://www.oncolink.upenn.edu>
- Based at the University of Pennsylvania Cancer Center
- Established in 1994 by Penn cancer specialists
- One of the largest general cancer information resources on the Internet
- Online before Yahoo & Microsoft

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OncoLink Background

- 3.9 million pages served per month to over 385,000 unique IP addresses
- Information at every level
- Free access, no registration
- Users 80% patients/families, 20% healthcare provider
- 15 % PA, NJ, DE
- 25 % International

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OncoLink Background

- 70% Female
- Average Depth of session 6 pages
- Average length of session 11 minutes
- Completely funded through unrestricted educational grants

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OncoLink Background

- Updated Daily
- Information provided by a team of physicians, nurses, social workers
- Contributions from patients, families
- Daily news feed
- Now in Spanish

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Life in the Survivor Lane



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Did You Know???

- Only 50% of PCPs are comfortable being responsible for recurrence surveillance in breast/ CRC survivors
 - 60% uncertain of which tests to order
 - 70% unsure of frequency/ duration of testing
 - 40% unsure of treatment-related side effects
 - [Nissen et al. Family Medicine 2007; 39 \(7\).](#)

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WHAT CAN YOU DO?

❖ Take Charge

- Make a Care Plan
- Bring it to your PCP
- Start a conversation about the rest of your life!

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What is in a Care Plan?

- Summary of your cancer treatments
- Potential side effects of cancer treatment
- Recommendations for cancer screening
- Psychosocial effects (including sexuality/fertility);
- Recommendations for a healthy lifestyle,
- Genetic counseling (if appropriate),
- Effective prevention options;
- Referrals for follow-up care *AND*
- A list of support resources...

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Daunting but Do-Able!



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Seems Overwhelming!

- How can I gather all of that information?

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Let Nurses BE Nurses!

- WE DID THE WORK FOR YOU!
- The nurses at OncoLink® performed an extensive literature review,
- We categorized treatment side effects and linked them with known cancer therapy causes.
- We made a computer based tool called OncoLife™
- To help answer the question...

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Now What?!?...



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What is OncoLife?

- Individualized care plan based on the Institute of Medicine recommendations for cancer survivors
- Free and easy to use
- Provides you with information about long term side effects you might face as a result of cancer therapies

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Sounds Scary...I am Not Sure I Want to Know!

- We are here to help
- Each survivor needs to become an active member of her healthcare team.
- Many survivors suffer from fear and denial of side effects
- If you do not know what is coming you can not fight!
- We have a *common sense approach* to help you
- We took the labor intensive medical records review and streamlined the process.

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How Do I Make a Care Plan?

- Go on Line www.oncolife.org
- Fill out a confidential survey
- It only takes 6 minutes
- The Plan prints instantly
- ***Review of the plan with your healthcare team***
- Knowledge is POWER

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What Do I Need to Fill Out a Survey?

- Type of Cancer
- Therapy particulars including:
 - chemotherapy
 - hormone therapy
 - radiation therapy
 - surgical procedures

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OncoLife Survey



OncoLife Questionnaire

Sex: Female Male

Race:

Age at Diagnosis:

Current Age:

Highest Education Level:

What is your relationship to the patient?

Have you (or the patient) ever been offered survivorship health information before?
 No Yes

Who is currently managing your healthcare needs?
 If Other, Please specify:

What is your geographical location?
 USA
 Canada
 Other Country

OncoLife Questionnaire

1. What type of cancer did you have?

(Select all that apply by holding the control key then selecting)

-- Please Select All that Apply --

- Acute Lymphocytic Leukemia
- Acute Myeloid Leukemia
- Anal Cancer

SURGERY

2. Did you undergo surgery for this cancer?
 No | Yes

2a. IF YES: Which surgical procedure did you have? (check all that apply)

CHEMOTHERAPY AND HORMONE THERAPIES

3. Did you receive medication, IV (administered into your vein) or oral (by mouth), for treatment of this cancer (including chemotherapy, biologic therapy and hormone therapy)?
 No | Yes

3a. IF YES: What chemotherapies did you receive? (check all that apply)

4. Did you receive intrathecal chemotherapy (administered into your spinal fluid)?
 No | Yes

4a. IF YES: What chemotherapies did you receive? (check all that apply)

RADIATION THERAPY

5. Did you receive radiation therapy?
 No | Yes

5a. IF YES: What type of treatment did you receive? (check all that apply)

6. Did you receive radioiodine therapy (I-131)?

No | Yes

7. Have you been told you have a genetic abnormality or syndrome?

No | Yes

Submit

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What Do I Get?

- You get a plan to *bridge the gap* between the end of cancer treatment and the rest of your life!
- Life after cancer can be a precarious position ...

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Between a Rock and a Hard Place!



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What You Get

- Tips for Coordinating your After-Care
- Help with Side Effects of your Chemo
- Help with Side Effects of your Radiation
- Tips for dealing with your “new normal” after your surgery
- Help with Emotional or Sexual problems you may have
- Nutrition Tips
- Recommendations for Cancer Screenings and Prevention
- And Much More!!!

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Collaboration with LAF

- The LAF and OncoLink are collaborating to create a survivorship care plan to be accessed on the Internet by cancer survivors worldwide.
- This will empower patients to take control of their long term care at the completion of cancer therapy
- The survivorship care plan will be data driven by the needs of the survivorship population and healthcare providers

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New Logo

LIVESTRONG CARE PLAN

POWERED BY
Penn Medicine's **OncoLink**

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