

National Coalition for Cancer Survivorship

**Patient-Care Team Communication: How Can the
Survivor Prepare to Manage a Lifetime of Care**

Wednesday, April 29, 2015

3:00pm-4:30pm EDT



NCCS Mission

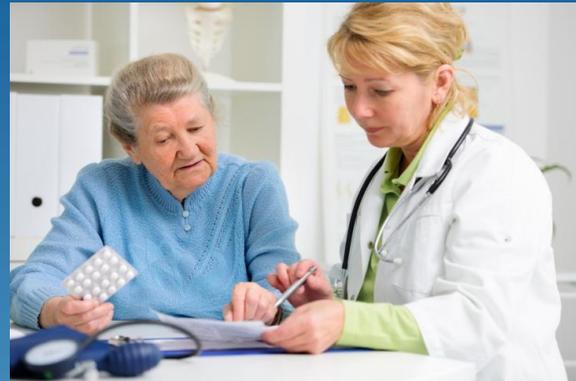


*Advocate for
quality cancer
care for all people
touched by cancer*



NCCS Public Policy Priorities

...ensure that every cancer patient has access to cancer care planning and coordination services



113TH CONGRESS
1st Session **H. R. 2477**

To amend title XVIII of the Social Security Act to provide for coverage of cancer care planning and coordination under the Medicare program.

IN THE HOUSE OF REPRESENTATIVES

JUNE 23, 2013

Mrs. CAPPS (for herself and Mr. BOHART) introduced the following bill, which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned:

A BILL

To amend title XVIII of the Social Security Act to provide for coverage of cancer care planning and coordination under the Medicare program.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 (a) **SHORT TITLE.**—This Act may be cited as the
5 “Planning Actively for Cancer Treatment (FACT) Act of
6 2013”.

7 (b) **FINDINGS.**—Congress makes the following find-
8 ings:

Cancer Policy Advocate Training

- Late and long-term effects – recent research findings
- Survivorship care plans
- Cancer care workforce challenges
- New value-based cancer care payment systems – do they foster better survivorship care
- Disparities in survivorship care

knepote@canceradvocacy.org



June 25-26, 2015
Washington, DC





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Dr. Deborah Mayer



Patient-Care Team Communication: How Can the Survivor Prepare to Manage a Lifetime of Care?

NCCS Cancer Policy Advocate Training

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UNC
LINEBERGER



UNC
CANCER CARE



Objectives

At the completion of this program, the learner will be able to:

- Describe who is a cancer survivor
- Discuss who are the health care team members for survivorship care
- Distinguish key transitions along the cancer continuum
- Consider the role of communication to facilitate survivorship care
- Identify resources about survivorship care

Survivor

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

– *Adapted from the National Coalition for Cancer Survivorship*

Survivorship Defined

- Living cancer free
 - For remainder of life
 - Experiences ≥ 1 treatment complication
 - But dying after a late recurrence
 - But develops another cancer
- Living with cancer
 - Intermittent periods of active disease on/off treatment
 - Continuously without disease free period

Survivorship Definition and Attributes

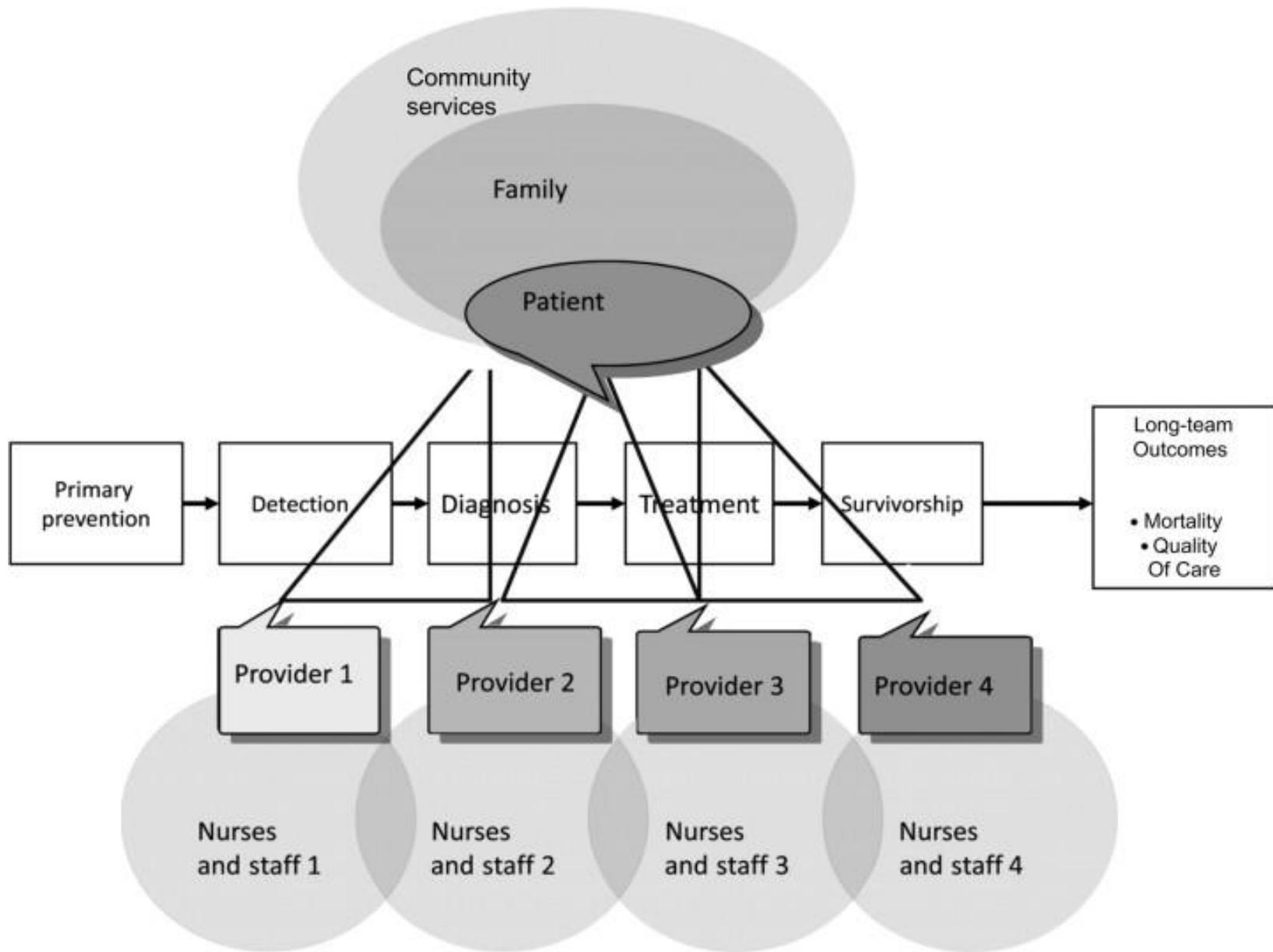
- Defined as those who have lived through a potentially deadly or life altering event.
- It is a dynamic process
- It involves uncertainty
- It is a life changing experience
- It has duality of positive and negative aspects
- It is an individual experience with universality
 - Doyle, N. (2008) Cancer survivorship: evolutionary concept analysis. *J Adv Nursing*, 62(4): 499-509.
 - Peck (2008) Survivorship: A concept analysis. *Nsg. Forum*, 43(2), 91-102.



LIVING WITH CANCER TAKES GUTS

Who is on your health care team?

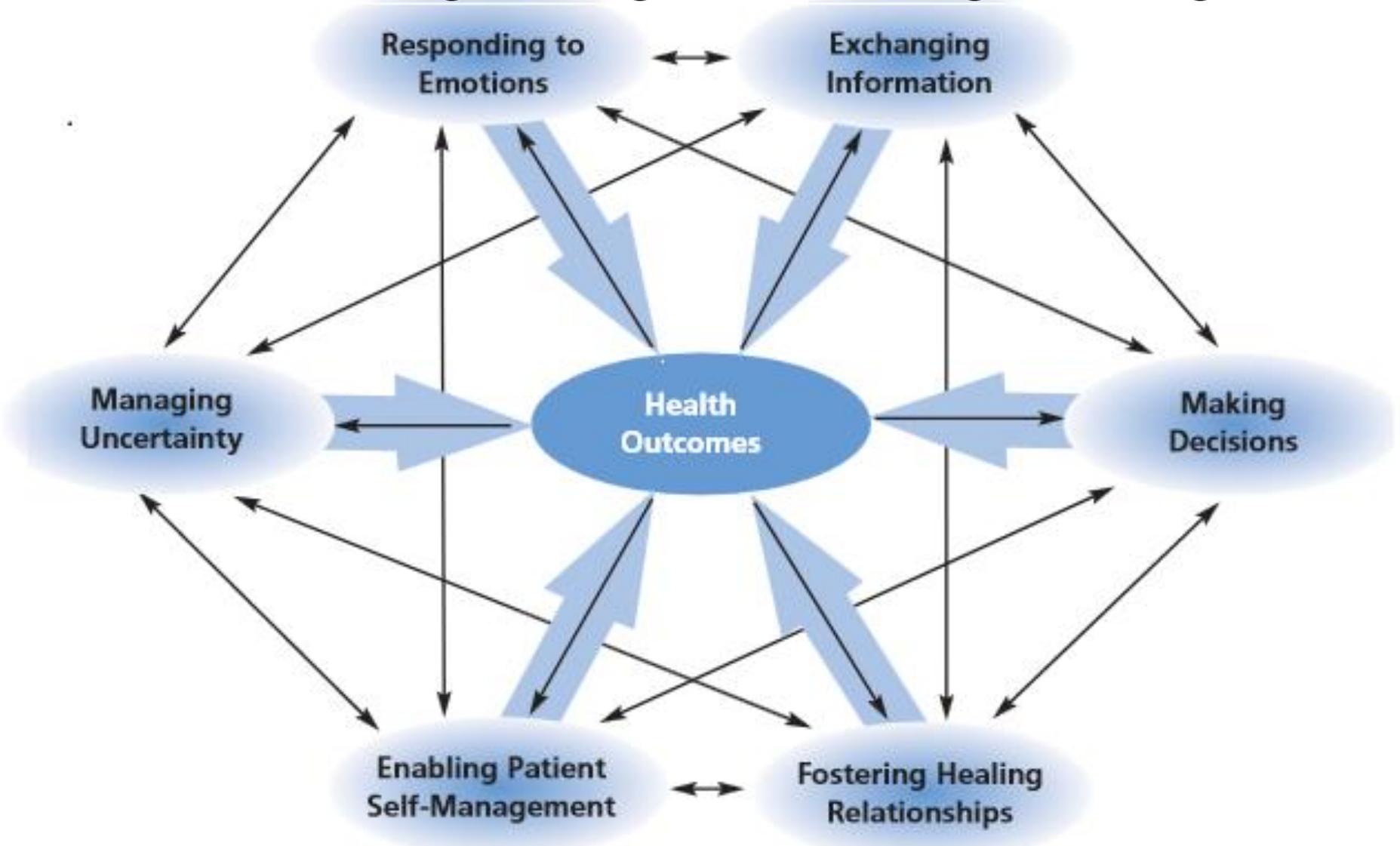
- **You**
- Your family and friends
- Your primary care provider
- Your cancer doctors and nurses
- Any other providers that you may need



Adapted from Taplin et al. 2009 (16)

Taplin; Natl Cancer Inst Monogr (2010) 2010 (40): 3-10.

Patient-Centered Communication in Cancer Care: *Promoting Healing and Reducing Suffering*



Epstein RM, Street RL Jr. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007.

How do you ask questions when you don't know what to ask?



Cancer Care Continuum

Prevention and Risk Reduction

- Tobacco control
- Diet
- Physical activity
- Sun and environmental exposures
- Alcohol use
- Chemoprevention
- Immunization

Screening

- Age and gender specific screening
- Genetic testing

Diagnosis

- Biopsy
- Pathology reporting
- Histological assessment
- Staging
- Biomarker assessment
- Molecular profiling

Treatment

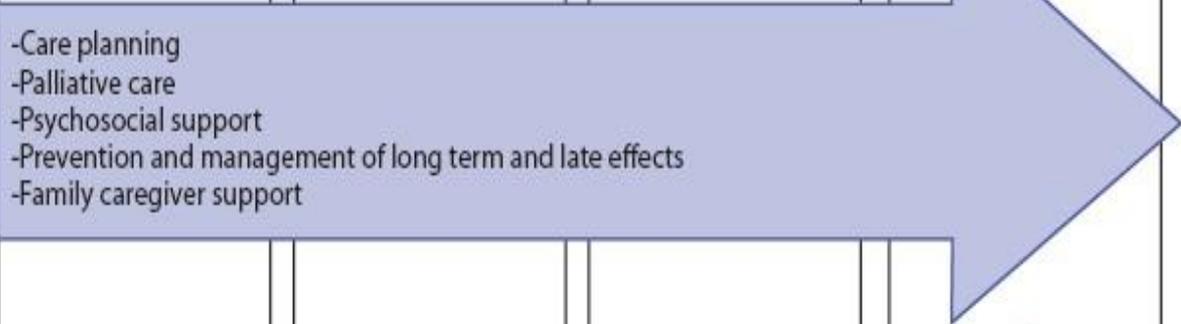
- Systemic therapy
- Surgery
- Radiation

Survivorship

- Surveillance for recurrences
- Screening for related cancers
- Hereditary cancer predisposition/genetics

End-of-life Care

- Implementation of advance care planning
- Hospice care
- Bereavement care

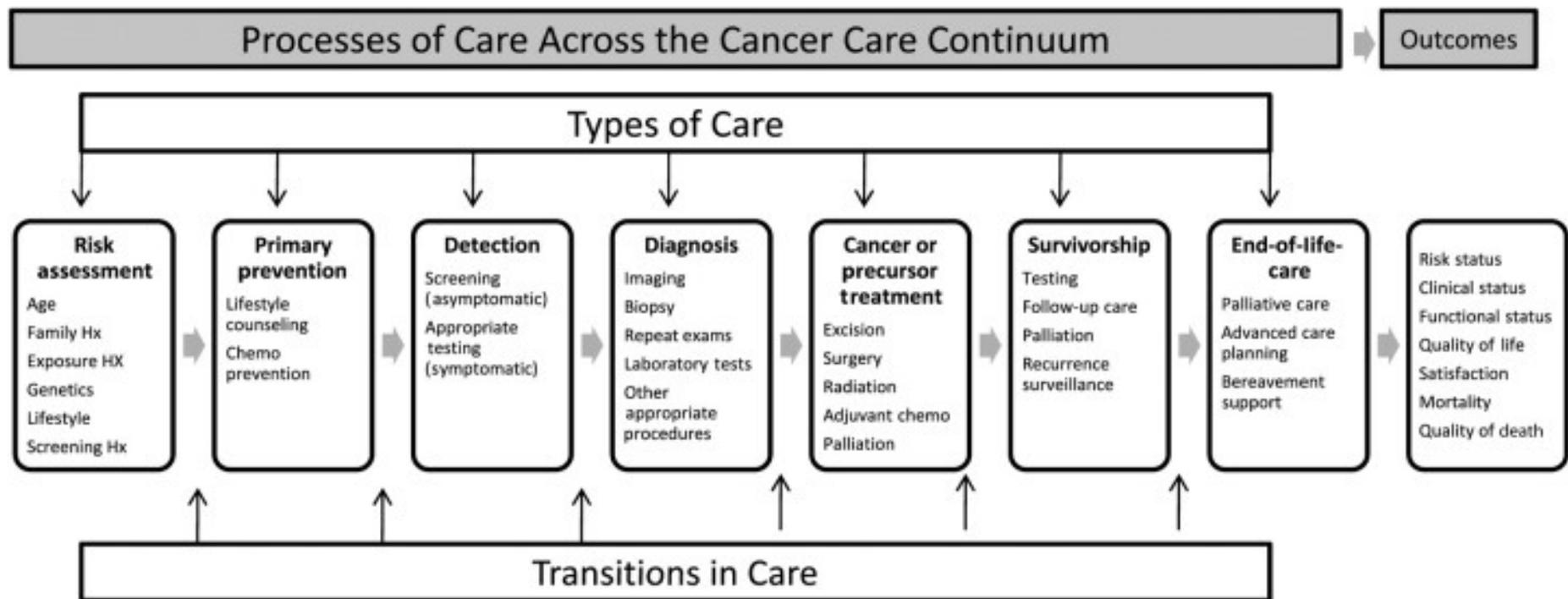
- 
- Care planning
 - Palliative care
 - Psychosocial support
 - Prevention and management of long term and late effects
 - Family caregiver support



Acute Care

Chronic Care

End-of-Life Care



Taplin, Natl Cancer Inst Monogr (2010) 2010 (40): 3-10.



UNCHARTED



Expressions of a Cancer Journey



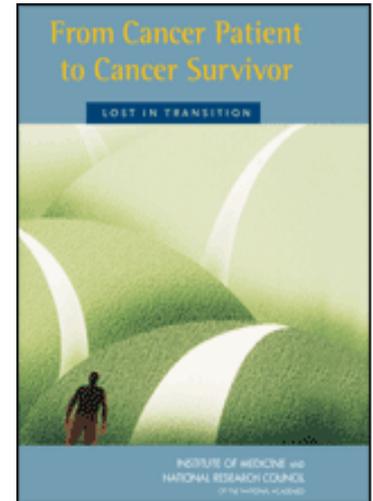
NATIONAL COALITION FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

From Cancer Patient to Cancer Survivor: Lost in Transition

The IOM 2005 recommendations:

- Raising awareness of medical and psychosocial needs of survivors
- Providing survivorship care plans for all patients completing primary treatment
- Developing evidence-based clinical practice guidelines for survivorship care
- Refining quality care measures for cancer survivorship



IOM Essential Components of Survivorship Care

- Surveillance for recurrence
- Screening for new cancers
- Identification and interventions for consequences of cancer and its treatment
- Health promotion strategies
- ‘Shared Care’ coordination between oncology specialists and primary care providers

IOM Essential Components of Survivorship Care

- **Surveillance for cancer coming back (recurrence)**
 - What tests should I have?
 - How often should I have them?
 - Who will order them?
 - When and how will I get the results?

IOM Essential Components of Survivorship Care

- **Screening for new cancers**

- What screening should I have?
- How often should I have them?
- Who will order them?
- When and how will I get the results?

IOM Essential Components of Survivorship Care

- **Identification and interventions for consequences of cancer and its treatment**
 - What will my recovery be like?
 - Will all my side effects go away?
 - If they don't go away, will they get better?
 - What might happen later because I had this cancer and this treatment?
 - Is there anything I can do to prevent them from happening?
 - Who should I talk to if I develop any of these problems?

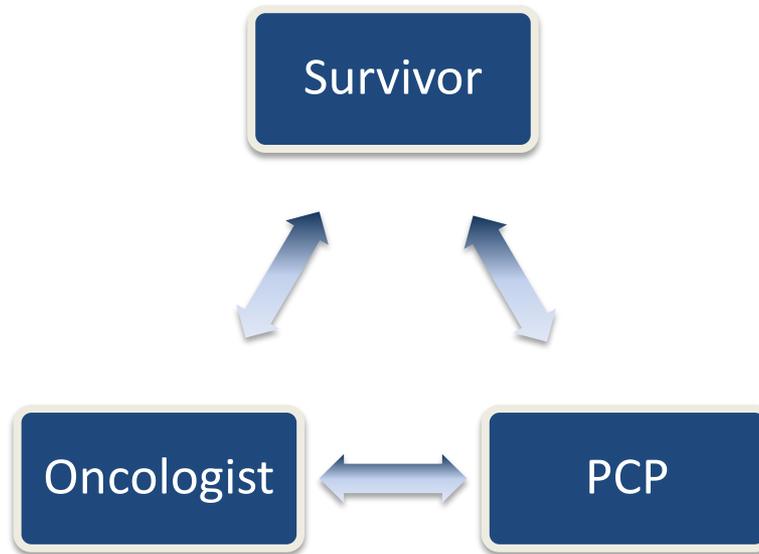
IOM Essential Components of Survivorship Care

- **Health promotion strategies**
 - What can I do to become or stay healthy?
 - Are there things I should avoid?
 - Are there any programs available to help me with this?
- **Lifestyle changes**
 - Stop smoking.
 - Achieve or maintain healthy weight.
 - *Maintain regular exercise.*
 - Moderate alcohol intake.
 - Control sun exposure.
 - Receive appropriate vaccinations.

IOM Essential Components of Survivorship Care

- **‘Shared Care’ coordination between oncology specialists and primary care providers**
 - How will you keep my [primary care provider or cancer doctors] in the loop about how I am doing and about any of my tests?
 - Will I ever stop seeing my cancer doctors? If so, when?
 - How will I know if I need to see my cancer doctors or go to my primary care provider?

Survivorship Care Plans



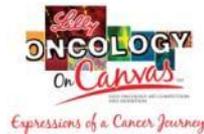
- **Enhance communication**
- **Coordinate care**
- **Increase surveillance**
- **Identify and manage long term/late effects**
- **Encourage health monitoring and promotion**

Hewitt et al., 2006; Ganz & Hahn, 2009; Earle, 2006; Jacobs et al., 2009; Salz et al, 2012.

Cancer Survivors Unmet Needs



SEARCHING: THE ANSWER IS OUT THERE



Unmet Needs of Survivors

- N =1668 from VT Tumor Registry 77% >5 years after diagnosis; 62% had >1 treatment
 - **Most unmet needs were informational and emotional**
 - Greatest unmet needs:
 - Help to address sex life problems (40.7%)
 - Help dealing with impact on partner (35.5%)
 - Help reducing stress (34.4%)
 - Help reducing worrying (29.5%)
 - **More information about side effects *after* treatment (22.9%)**
 - Help with recurrence concerns (21.7%)
- » Geller (2014) *J Fam Prac*

Unmet Needs of Cancer Survivors (ACS Cohort)

- N=1514, 2, 5 and 10 year survivors
- Not associated with time since diagnosis but there were gender and age differences
- Unmet needs included:
 - Physical (38.2%)
 - Financial (20.3%)
 - Information (19.5%)
 - » Burg (2015) Cancer

Survivors' Information Needs

1040 Survivors 2-5 years after diagnosis:

- Tests & treatment 70.8%
- Health promotion 67.8%
- Side effects & symptoms 63.3%
- Interpersonal & emotional 54.4%
- Insurance 42.1%
- Sexual function and fertility 30.9%

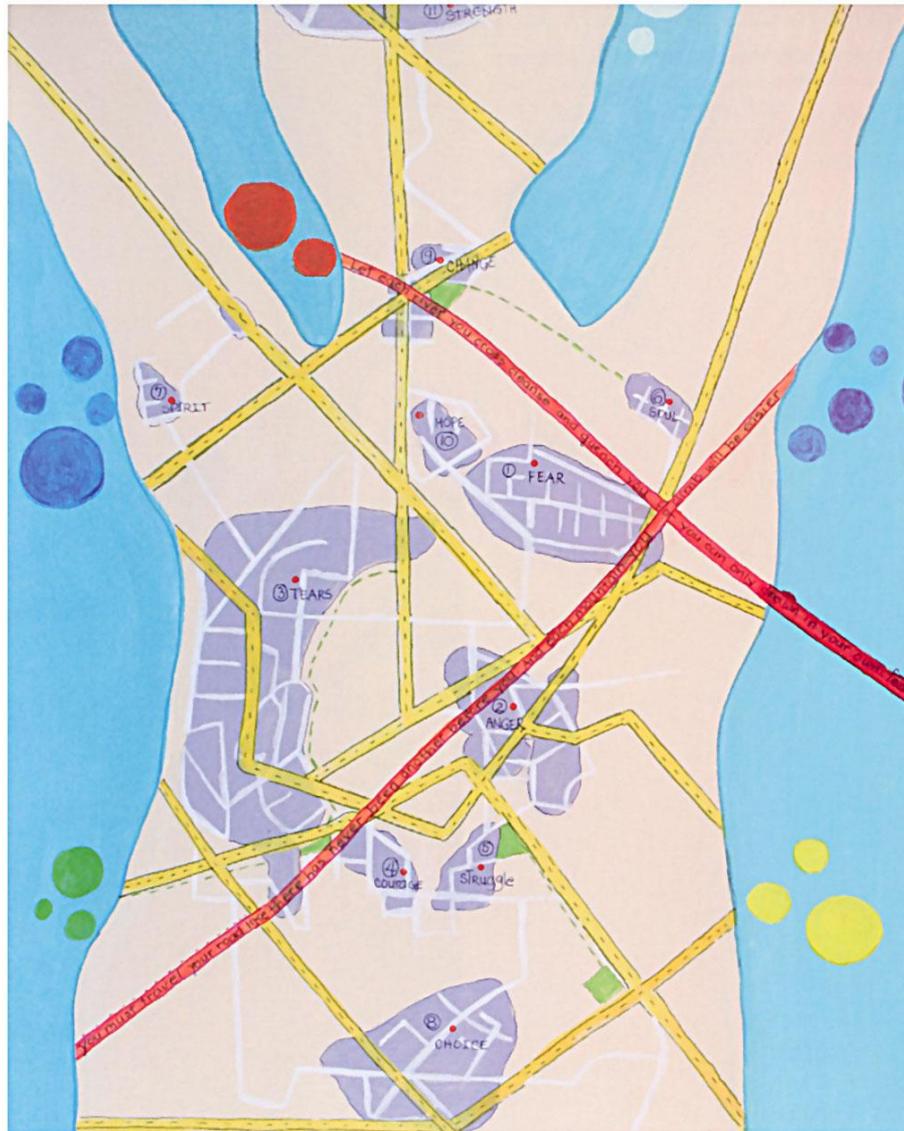
Greater information needs were associated with worse perceived mental and physical health.

» Beckjord et al (2008). *J Cancer Surviv*, 2: 179-189.

Survivors Needs >50%

Need	% reporting need
Access to Care	
To feel like you were managing your health together with your team	68.6%
To screening for recurrence or other cancers	63.8%
Assurance that your doctors talked to each other to coordinate your care	62%
Information	
Provide in understandable way	62.5%
Possible effects <i>after</i> treatment	63.2%
Possible side effects of treatment	61.8%
More about diagnosis	60.7%
Emotional, Social, and Spiritual Issues	
Help managing concerns about cancer returning	54.1%
To talk with others who have had cancer	52%
A group or person with whom you feel safe expressing how you feel?	50.1%
Physical Issues	none

Management of Long Term and Late Sequelae



The Road Home

Long Term and Late Effects

Late effects: unrecognized toxicities that are absent or subclinical at the end of treatment and manifest months or years later

Long term effects: any side effect or complication for which the survivor must compensate

Long Term Issues

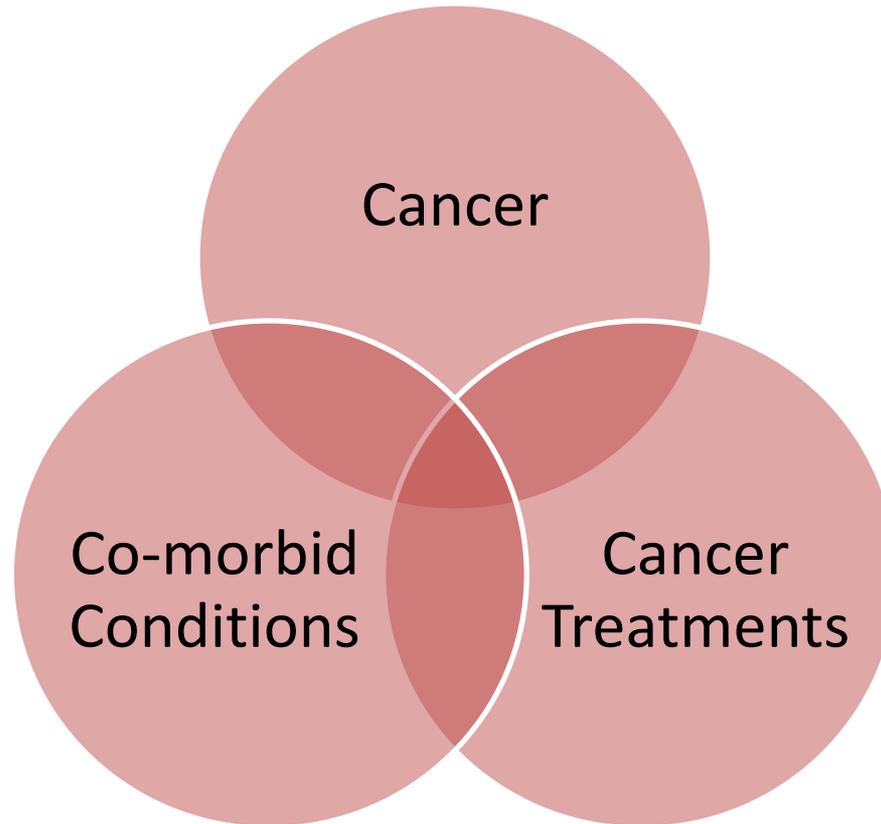
- Fatigue
- Weight changes
- Pain
- Sleep
- Depression
- Cognitive changes
- Osteoporosis
- Sexuality changes
- Lymphedema

<https://www.ons.org/practice-resources/pep>

Comorbidities in Cancer Survivors

- Obesity
- Diabetes
- Dyslipidemia
- Hypertension
- Osteoporosis/osteopenia
- Hypothyroidism
- Depression
- Cognitive changes
- Age related changes

Long-term and Late Effects



Source: *From Cancer Patient to Cancer Survivor: Lost in Transition*; page 24, Box 2-2.

Barriers to Survivorship Care

- Fragmented Delivery System
 - Hampers coordinated care
 - Lack of HCP education/training
 - Lack of standards of care/guidelines
 - Care documentation/sharing/tracking
 - Capacity
- Communication
 - HCP to HCP
 - HCP and Survivor
- Research
 - Lack of data on long term and late effects
 - Few longitudinal studies of adults

Resources



BEFORE...DURING...AFTER (2008)



Navigation: [Home](#) » [Cancer Resources](#) » [Planning Your Care](#)

What is a Cancer Care Plan?

One way to help make sure you and your health care team understand each other is by using cancer care plans. If you were going on a trip, you would likely have a plan of how to get to your destination and what to do when you arrive. In the same way, cancer care plans are roadmaps that make sure you know where you are going and how you will get there. This roadmap should be discussed with your health care team and can be shared with other health professionals you see, such as your primary care doctor, radiologist, and surgeon. Cancer care plans are useful whether you are newly diagnosed, making the transition off of active treatment, or changing your treatment course.

NCCS Resource Menu

+ Cancer Survival Toolbox

- Care Planning

Examples of Care Plans

+ Take Charge of Your Care

Examples of Care Plans

+ Teamwork: Talking with Your Doctor

Journey Forward

Post-Treatment Care Planning

There are currently more than 12 million Americans who are considered cancer survivors, and their ranks are growing rapidly as more than a million new cases of cancer are diagnosed each year. Unfortunately, the current U.S. health care system is failing to deliver the comprehensive and coordinated follow-up care cancer survivors deserve. Too many survivors are lost in transition once they finish treatment.

Every cancer survivor should have a comprehensive care summary and follow-up plan once they complete their primary cancer care that reflects their treatment and addresses a myriad of post-treatment needs to improve their health and quality of life.



eNEWS SIGNUP



SEARCH THE SITE

- Home
- TYPES OF CANCER
- NAVIGATING CANCER CARE
- COPING AND EMOTIONS
- RESEARCH AND ADVOCACY
- SURVIVORSHIP**
- BLOG
- ABOUT US

Home > Survivorship

Survivorship

Today, there are more than 14 million Americans alive with a history of cancer. Cancer.Net's survivorship section provides helpful information for cancer survivors and their friends and family.

About Cancer Survivorship

An introduction to survivorship. Learn about adjusting to various changes in your life following cancer treatment and find information about the Institute of Medicine report on survivorship.

Long-Term Side Effects of Cancer Treatment

Learn about the side effects that can occur months or years after cancer treatment is finished.

Survivor Artwork

View artwork submitted for the American Society of Clinical Oncology (ASCO) annual wall calendar.

Follow-up Care After Cancer Treatment

This section outlines the importance of follow-up care after cancer treatment along with tips for healthier living.

Dealing With Cancer Recurrence

Learn more about diagnosing and treating a cancer recurrence.

Survivorship Resources

Find additional resources about survivorship.

Life After Cancer

This section outlines a wide variety of resources to help with the transition to survivorship once active treatment is completed.

Making a Difference

Learn about volunteer opportunities to help people cope with cancer.

Give Feedback

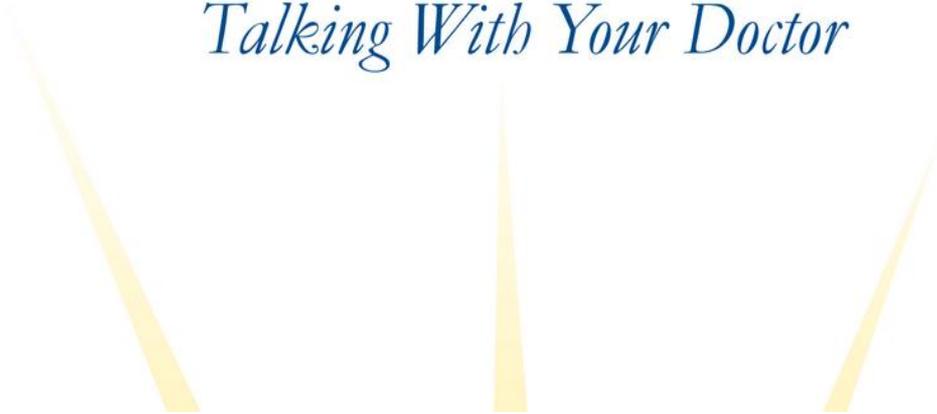




• Elizabeth J. Clark, PhD, Editor •

TEAMWORK

*The Cancer Patient's Guide To
Talking With Your Doctor*



<http://www.canceradvocacy.org/wp-content/uploads/2013/01/Teamwork.pdf>

National Cancer Institute

at the National Institutes of Health

We Can Answer Your Questions
1-800-4-CANCER

 SEARCH

- NCI Home
- Cancer Topics
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Home > Cancer Topics > Coping with Cancer



- Coping with Cancer**
- ▶ Feelings and Cancer
- ▶ Adjusting to Cancer
- ▶ Self Image & Sexuality
- ▶ Day-to-Day Life
- ▶ For Family & Friends
- ▶ **Survivorship**
 - ▶ A New Normal
 - ▶ Follow-Up Medical Care
 - ▶ Physical Changes
 - ▶ Family Issues
- ▶ Managing Physical Effects
- ▶ Preparing for the End of Life
- ▶ Questions to Ask About Cancer

- Popular Resources**
- [NCI Dictionary of Cancer Terms](#)
- [NCI Drug Dictionary](#)
- [Search for Clinical Trials](#)
- [NCI Publications](#)
- [Español](#)

Survivorship

There are millions of people in the United States who are cancer survivors. Many say that they felt they had lots of support during their treatment, but once it ended, it was hard to make a transition to a new way of life. It was like entering a whole new world where they had to adjust to new feelings, new problems and different ways of looking at the world.



[A New Normal](#)

Adjusting to physical and emotional changes after cancer treatment and tips on coping with fear of recurrence.

[Follow-Up Medical Care](#)

Information about follow-up medical care for patients who have completed cancer treatment. Discusses your follow-up care plan, getting a wellness plan, and guidelines for a healthy lifestyle.

[Physical Changes](#)

Information about the physical changes you may experience after you complete cancer treatment.

[Family Issues](#)

Discusses common family problems and issues that often occur after treatment and ways to cope.

As hard as treatment is, many cancer survivors say that the experience led them to make important changes in their lives. It helped them learn the value of being grateful for each day and for the people in their lives.

Related Resources

- [Facing Forward: Life After Cancer Treatment](#)
- [Facing Forward: Making a Difference in Cancer](#)
- [Moving Beyond Breast Cancer Videos](#)
- [Office of Cancer Survivorship](#)

Posted: December 2, 2014

Survivorship: During and After Treatment

In this section you'll find information and tips on staying active and healthy during and after cancer treatment. You can also get information on dealing with the possibility of cancer recurrence, and find inspiration and hope in stories about other people whose lives have been touched by cancer.



Nutrition for People With Cancer

Nutrition is an important part of cancer treatment. Eating the right kinds of foods during and after treatment can help you feel better and stay stronger. Learn more about the importance of good nutrition during and after cancer treatment here.



Staying Active

Find out more about staying active during and after cancer treatment. Learn about the importance of exercise, as well as what you need to know if you are planning on working during treatment or returning to work afterwards.



Survivorship Videos from the American Cancer Society

More people than ever are surviving cancer and thriving after treatment. Watch this video series to learn how to cope with the physical and emotional challenges that come during cancer treatment and beyond, and find inspiration in the experiences of other survivors.



National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaborative effort to shape the future of cancer survivorship care and improve the quality of life of cancer survivors as they transition from treatment to recovery. Learn more about The Survivorship Center and view resources for survivors, health care professionals, and the policy and advocacy community.

Find Support & Treatment Topics

- [Understanding Your Diagnosis](#)
- [Finding and Paying for Treatment](#)
- [Treatments and Side Effects](#)
- [Survivorship: During and After Treatment](#)
- [Children and Cancer](#)
- [Caregivers and Family](#)
- [Nearing the End of Life](#)
- [Find Support Programs and Services in Your Area](#)

Questions?

Chat with an Information Specialist

Monday - Friday
7am - 6:30pm CST

CHAT LIVE »

or call
1-800-227-2345

Cancer Survivors Network

National Resources

- Cancer Care-helps with financial, emotional and supportive needs of cancer patients
www.cancercares.org
- MD Anderson's Life After Cancer Care
www.mdanderson.org/departments/lacc
- George Washington Collection of Resources for Patient Navigators Assisting Cancer Survivors After Treatment (2013)
 - <http://smhs.gwu.edu/gwci/sites/gwci/files/Resource%20Compendium%20Final%20Updated%202013.pdf>

National Resources

- Cancer Survivorship in Primary Care
www.cancersurvivorshipprimarycare.org
- Cancer Survivorship E-Learning Series
<https://cancersurvivorshipcentereducation.org/>
- Lance Armstrong Foundation (**LIVESTRONG**)
www.livestrong.org



WHEN LIFE IS SEWN BACK TOGETHER,
IT HAS CHANGED

Q&A

- **Type your question in the chat box area located on the lower left corner of your screen**
- **If you are dialed in, select *1 on your telephone keypad**



Thank You

WHILE WE HOPE
FOR THE CURE...

WE MUST FOCUS
ON THE CARE

