



Care of Cancer Survivors

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Objectives

- 1. Review the history of the development of the concept of Cancer Survivorship
- 2. Identify the components of Survivorship Care
- 3. Discuss the characteristics of the population of Cancer Survivors in the United States
- 4. Identify the late effects and risks for second malignancies in Cancer Survivors
- 5. Discuss strategies to address the Survivorship Care health domains, and identify barriers

Disclosure of Conflicts of Interest

- M. Alma Rodriguez, MD, MACP, has no relevant financial relationships to disclose.

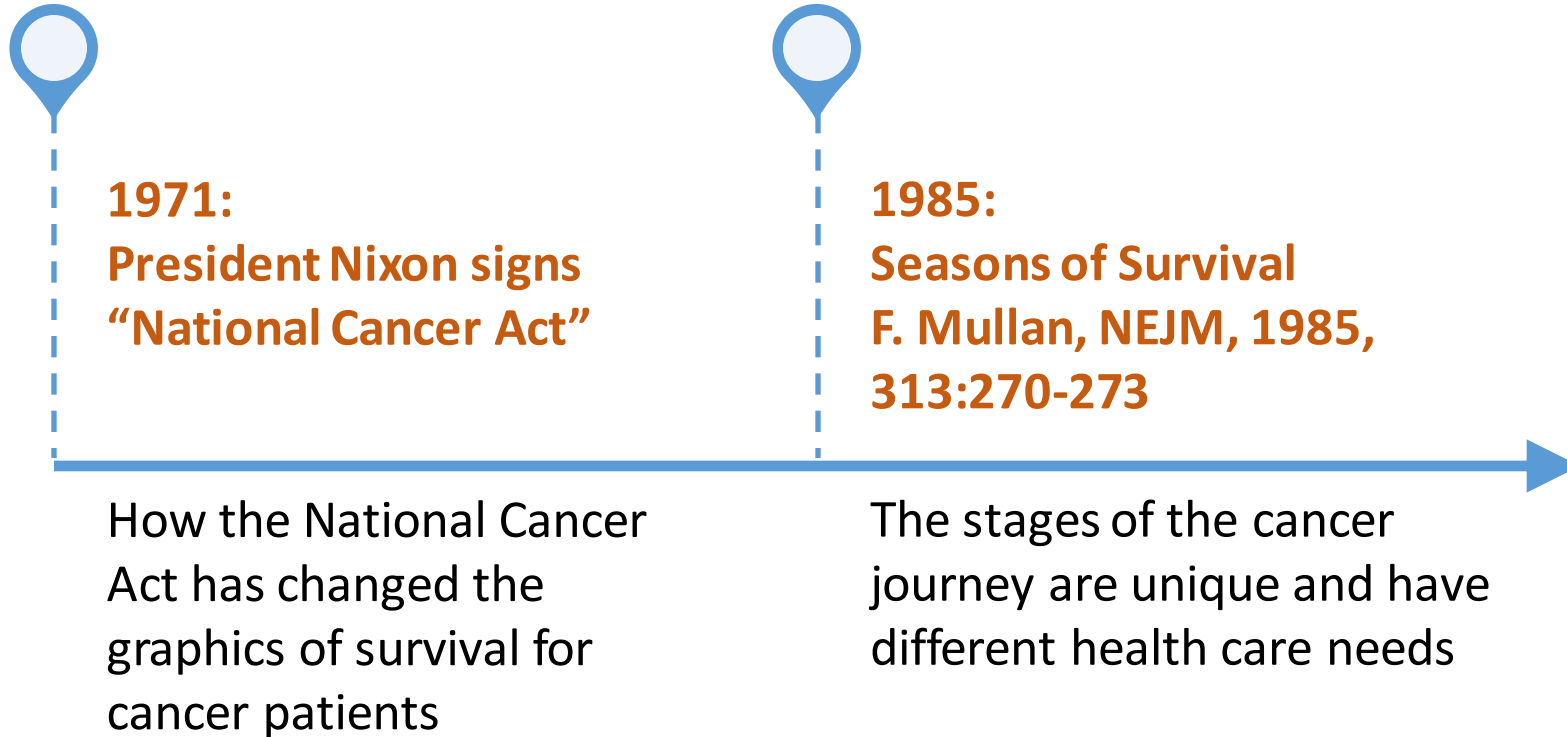
A Brief Guide to the History of Cancer Survivorship



1971:
President Nixon signs
“National Cancer Act”

How the National Cancer
Act has changed the
graphics of survival for
cancer patients

A Brief Guide to the History of Cancer Survivorship



* Phases of Cancer Survivorship: From *Cancer Remission* to *Recovery* and *Wellness*



- **Acute**: Begins with diagnosis of cancer, and includes the period of *testing and treatment* of cancer



- **Extended** (Intermediate): Begins upon reaching remission and concluding the acute treatment; this phase can include *maintenance, consolidation, or watchful monitoring*

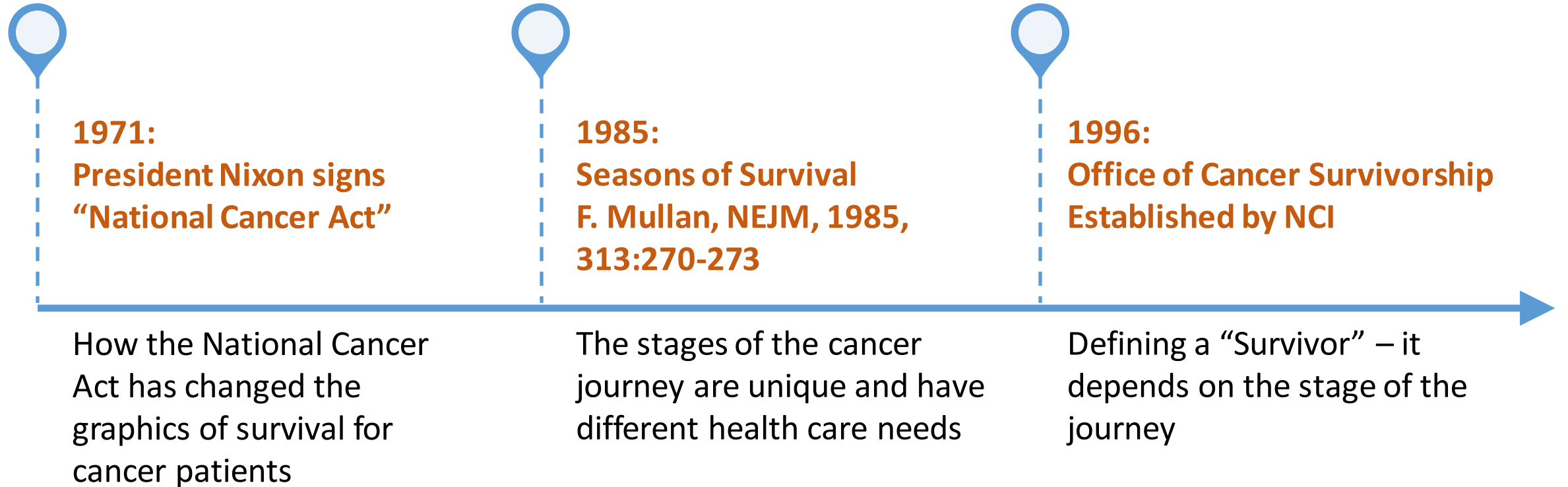


- **Permanent** (Long-Term): Depending on disease type, this is the phase of *low risk of recurrence*, equated with 'cure' in many cases

- *Fitzhugh Mullan. Seasons of Survival: Reflections by a Physician with Cancer. NEJM 1985;313(4):270-3

NOTE: new category of long-term survivors are *patients who live with chronic malignancies*, such as chronic leukemia

A Brief Guide to the History of Cancer Survivorship



Who is a Cancer 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 therefore included in this definition.

NCI Office of Cancer Survivorship, 1996

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The stages of the cancer journey are unique and have different health care needs



1996:
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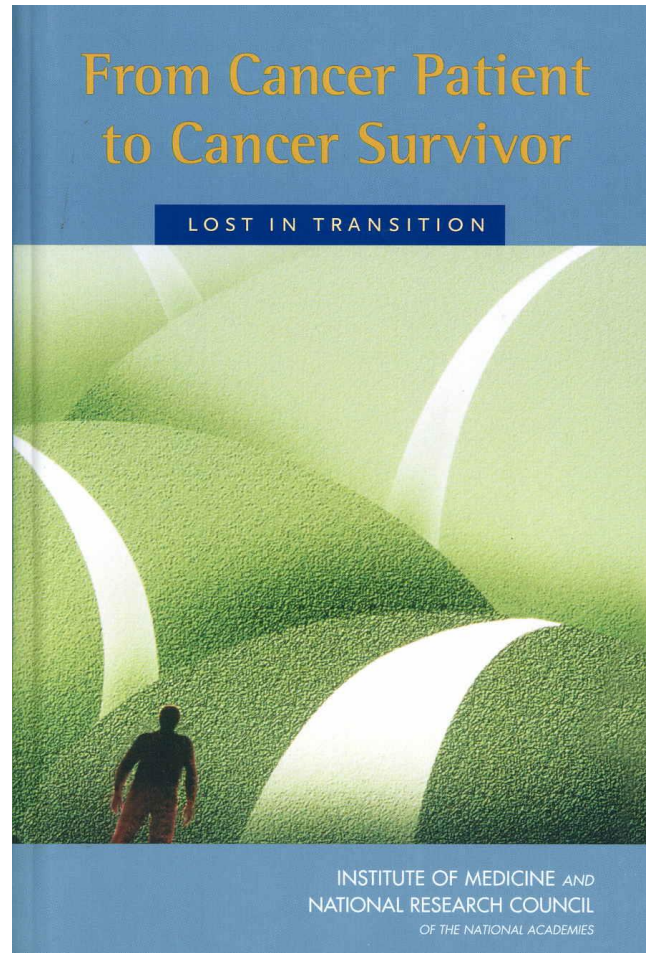
Defining a “Survivor” – it depends on the stage of the journey



2006:
**From Cancer Patient to
Cancer Survivor: Lost in
Transition**

The domains of care necessary in any care model that is designed to address Survivorship Care needs

Survivorship Healthcare Challenges: Lost in Transition



2006, National Academies Press; IOM ,
Wash. D.C.

- **Persistent symptoms after cancer treatment**
- **Health effects new onset years after treatment**
- **Emotional symptoms, loss of relationships, economic distress**
- ***Difficulty finding physicians after cancer treatment***
- ***Lack of communication among physicians***

Key Domains of Survivorship Care

Cancer Surveillance and Screening

- Detection and treatment of late malignancy

Risk Reduction and Cancer Prevention

- Lifestyle changes to prevent cancer and risk

Late Effects / Side Effects Management

- Health maintenance and preservation of vital organ

Psychosocial Functioning

- Psychosocial support services to maintain healthy relationships and restored life

Coordination of care

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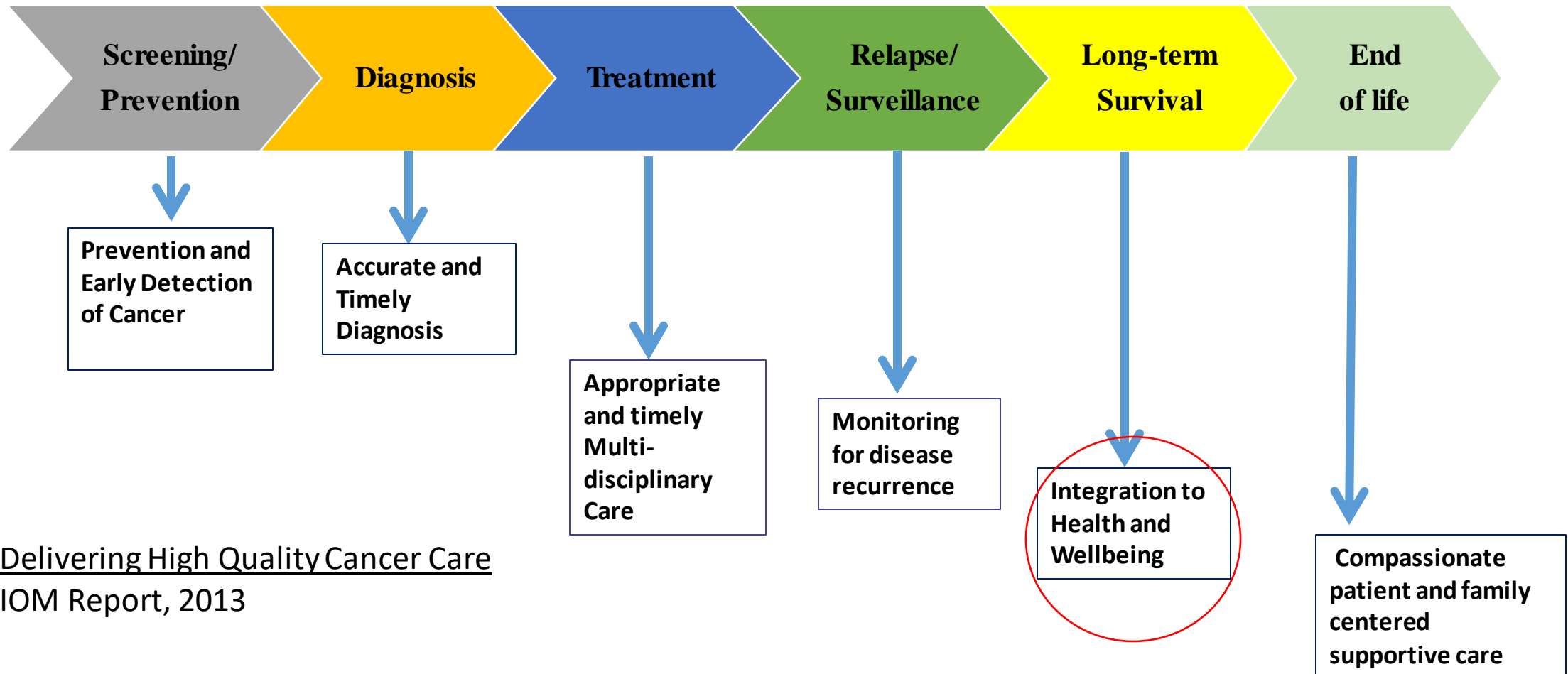
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2013:
Delivering High-Quality
Cancer Care: Charting a
New Course for a System in
Crisis

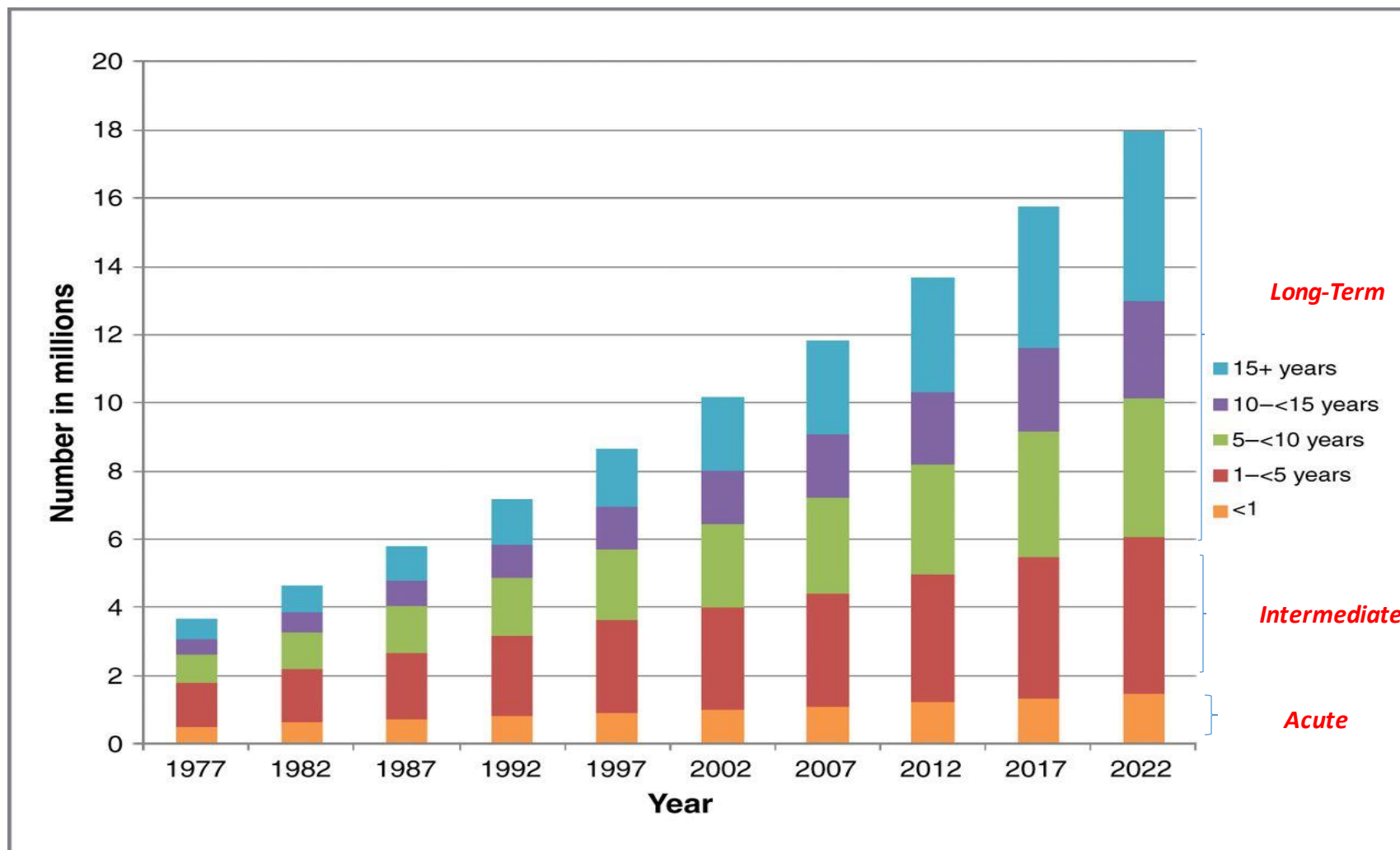
Outline the Components of Cancer Care Cycle

The Cancer Care Cycle



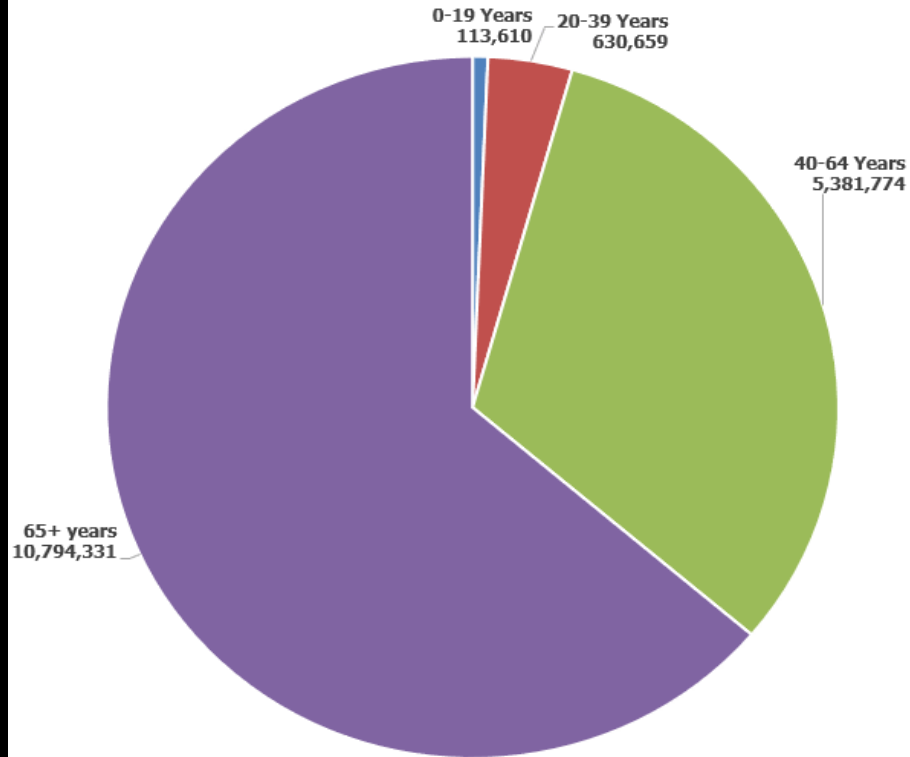
Delivering High Quality Cancer Care
IOM Report, 2013

18 Million Cancer Survivors in 2022



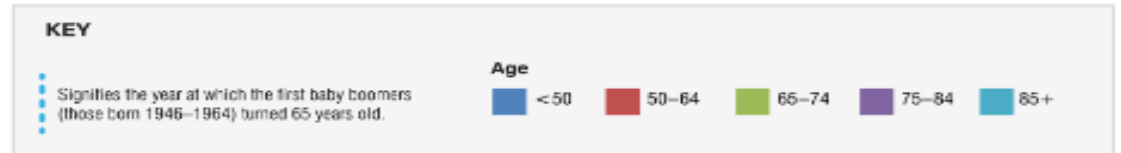
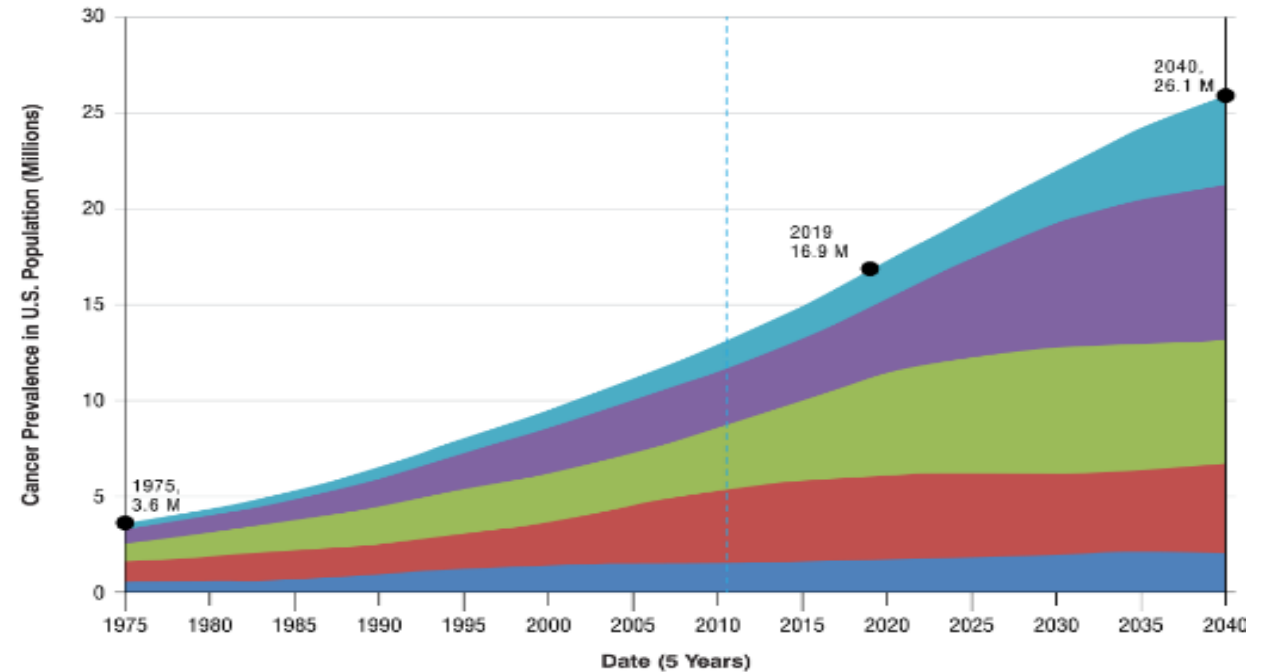
Not All Survivors Are The Same....

Estimated Number of Cancer Survivors in the U.S., by Current Age



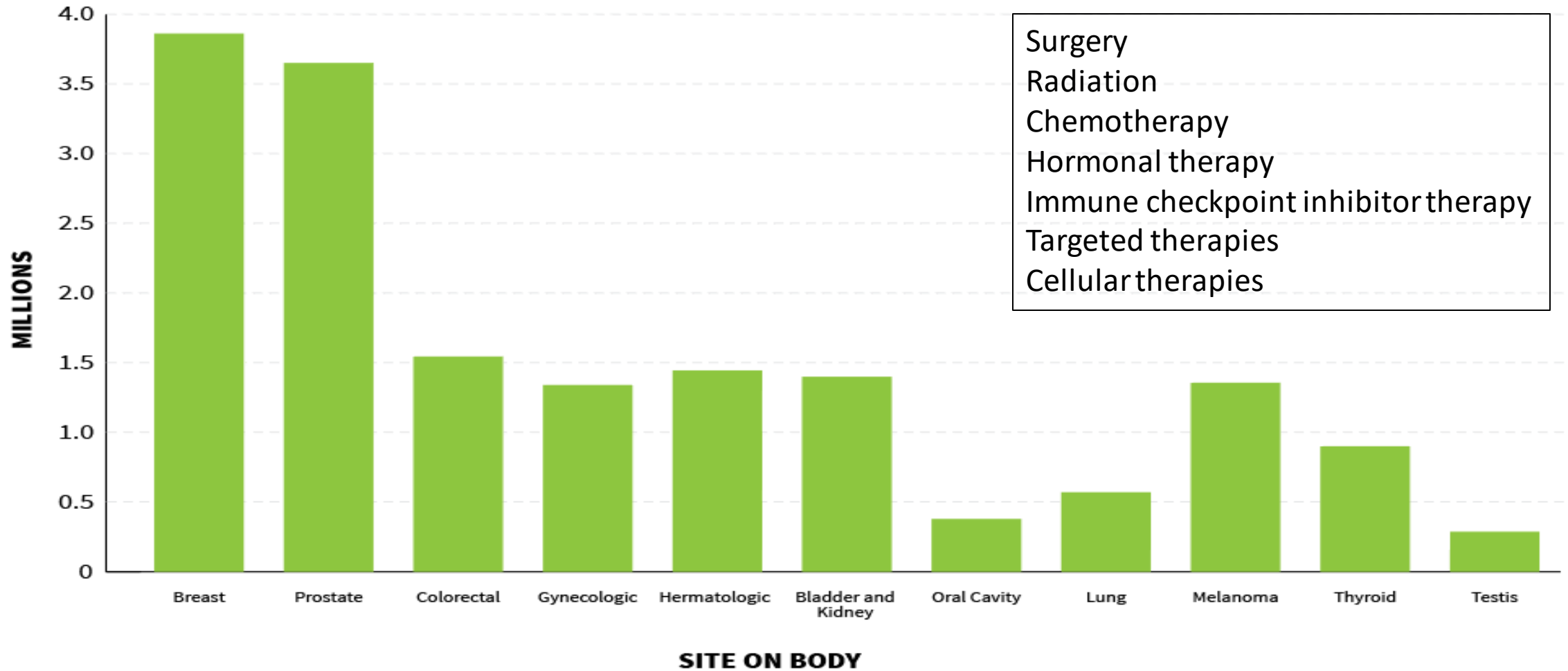
REFERENCE: American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta: American Cancer Society; 2016. Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., Stein, K. D., Alteri, R. and Jemal, A. (2016), Cancer treatment and survivorship statistics, 2016. CA: A Cancer Journal for Clinicians.

Cancer Prevalence and Projections in U.S. Population from 1975-2040



REFERENCE: Bluethmann SM, Mariotto AB, Rowland, JH. Anticipating the "Silver Tsunami": Prevalence Trajectories and Comorbidity Burden among Older Cancer Survivors In the United States. *Cancer Epidemiol Biomarkers Prev*. 2016;25:1029-1036.

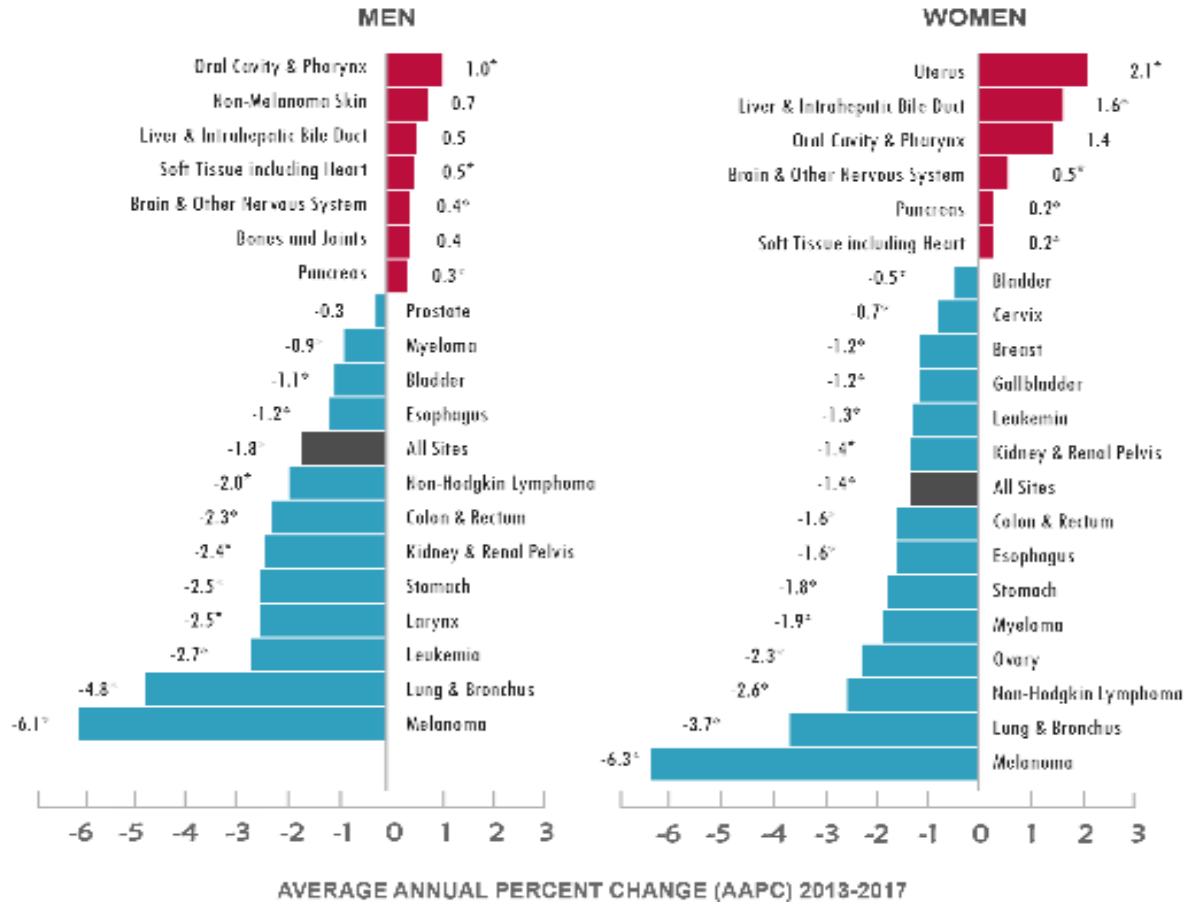
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Declining Mortality Across Multiple Cancers: 2020 National Report

NATIONAL TRENDS IN CANCER DEATH RATES



*AAPC is significantly different from zero (p<.05).

seer.cancer.gov

Source: Annual Report to the Nation

Most significant trends in declining death rates are in Lung & Bronchus and Melanoma thanks to check-point inhibitor immune modulating agents: Nivolumab, Pembrolizumab and Ipilimumab

Not All Survivors Are The Same....

- 1. *Risk of recurrence* depends on the primary malignancy *type and stage at diagnosis*.
- 2. *Risk of secondary late effects of treatment, including subsequent cancers*, depend on the *type of treatment, combinations of treatment*, as well as *the age and health of the patient*.
- 3. Survivorship care plans therefore must be tailored to *each person's tumor, treatment, and health history*.



Complications of cancer therapy

- Anatomic or functional changes secondary to surgery and/or radiation
- Organ toxicity secondary to systemic chemotherapies that lead to premature onset of chronic illnesses
- Immune deficits or autoimmune syndromes secondary to immune system targeted therapies
- Psychological disturbances
- Socioeconomic burdens
- Increased risk of second malignancies
- **In addition, other health co-morbidities can worsen, particularly in older cancer patients**

Risk factors for second malignancies

- Treatment related
 - Radiation, chemotherapy, hormonal
- Hereditary
 - Genetic or familial syndromes
- Environmental
 - Exposure to harmful conditions
- Type of primary cancer
 - Some cancers have risk of other second primary cancers
- Lifestyle
 - **Obesity**
 - Tobacco use: smoking, chewing
 - Alcohol consumption
- Health related
 - Infectious illnesses
 - Autoimmune disorders

Psychological and Socioeconomic Effects

- Anxiety or fear of relapse
- Depression
- Grief over loss of health, lifestyle, relationships, work
- Body image
- Sexuality concerns
- Employment challenges
- Economic losses



Returning to Life Activities



- Gradual integration to normal prior level of activity recommended
- Fatigue is a common complaint – can be improved by exercise
- Special activity considerations for people who have lymphedema, ostomy bags, and lung or limb resections: recommend consult with PM&R
- Impaired immunity post cellular therapies is a concern for travel outside the USA; immunization and precautions per CDC guidelines

Fertility

- Strategies to preserve fertility prior to treatment should have been discussed
- Counseling regarding risk of infertility and possible fetal genetic risks related to specific treatments also pre-treatment
- Post treatment evaluation for fertility:
 - Sperm counts at least 6 months after treatment
 - Return of menses may not always relate to fertility
- Options for in-vitro fertilization, surrogacy or adoption to be discussed with Fertility experts and Family Counselors, if cannot conceive post treatment.



Survivorship Care Models

Oncology Clinic

Patient continues care in an Oncology clinic setting

Surveillance for late recurrences and second malignancies

Survivorship Clinic

Dedicated personnel to survivorship care (APPs, Prevention specialists)

Multidisciplinary care based on IOM domains of care

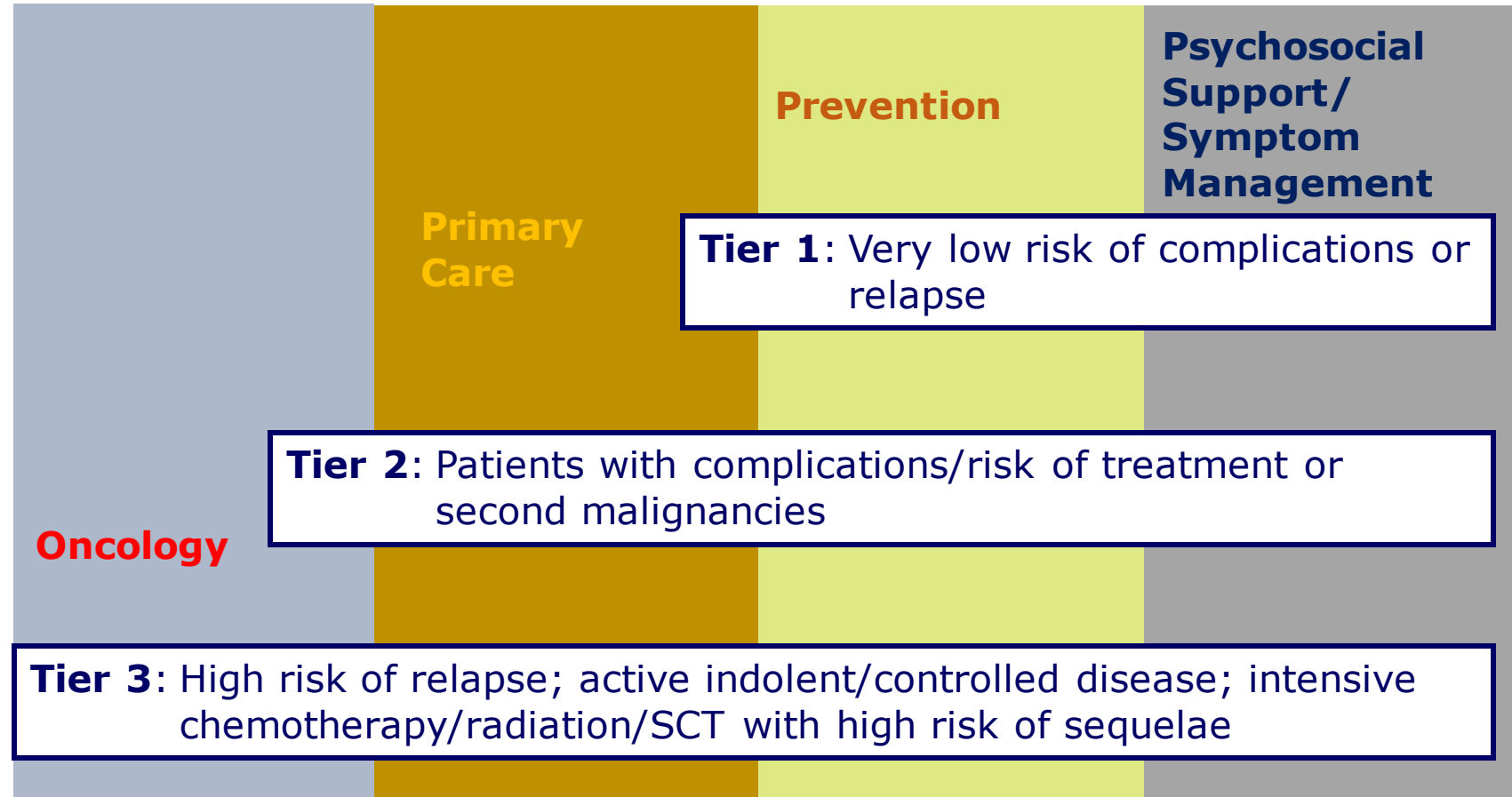
Primary Care Transition

Patients return to their PCP

Recommendations for Survivorship care given to the patient and PCP to follow (Survivorship Care Plan)

MD Anderson Survivorship Model: Tiers of Risk

Rodriguez MA, Zandstra F. *Models of Survivorship Care*. In Advances in Cancer Survivorship Management. Foxhall L, Rodriguez M A, eds. 2015; 7-25. Springer, New York, NY.

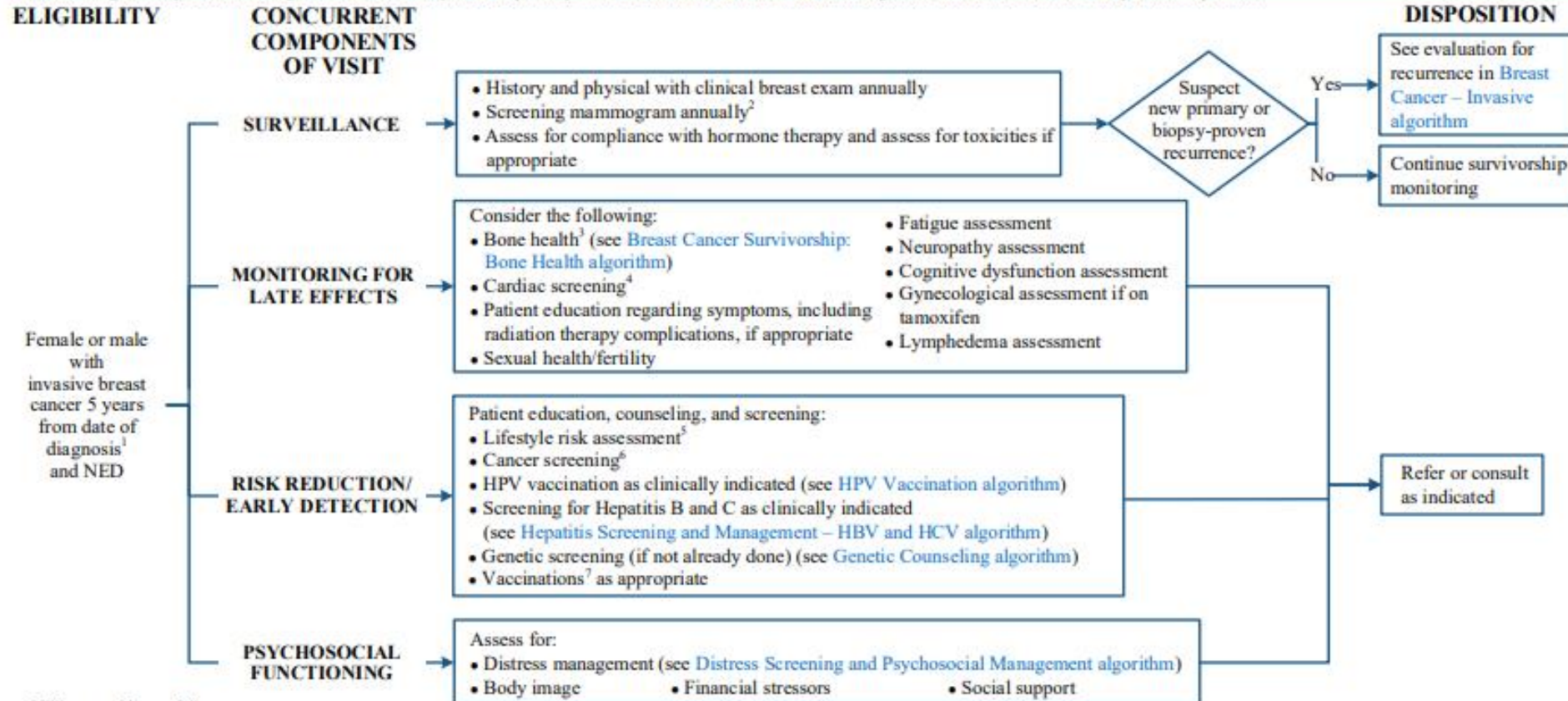


Key Domains of Survivorship Care

Survivorship – Invasive Breast Cancer

Disclaimer: This algorithm has been developed for MD Anderson using a multidisciplinary approach considering circumstances particular to MD Anderson's specific patient population, services and structure, and clinical information. This is not intended to replace the independent medical or professional judgment of physicians or other health care providers in the context of individual clinical circumstances to determine a patient's care. This algorithm should not be used to treat pregnant women.

Note: Mammograms may continue as long as a woman has a 10-year life expectancy and no co-morbidities that would limit the diagnostic evaluation or treatment of any identified problem.



NED = no evidence of disease

¹ Completion of all treatment with the exception of hormonal agents

² Consider tomosynthesis

³ All postmenopausal women (especially those on aromatase inhibitors) and premenopausal women on ovarian suppression

⁴ Consider use of Vanderbilt's ABCDE's approach to cardiovascular health

⁵ See Physical Activity, Nutrition, and Tobacco Cessation algorithms; ongoing reassessment of lifestyle risks should be a part of routine clinical practice

⁶ Includes cervical (if appropriate), colorectal, liver, lung, pancreatic, prostate (if appropriate), and skin cancer screening

⁷ Based on Centers for Disease Control and Prevention (CDC) guidelines

Support tools: Practice Algorithms Available Online

Clinical Tools & Resources > Clinical Practice Algorithms > Cancer Survivorship Algorithms

Clinical Practice Algorithms

Cancer Survivorship Algorithms

Clinical Management Algorithms

Cancer Screening & Risk Reduction Algorithms

Cancer Treatment Algorithms



Cancer Survivorship Algorithms

Survivorship algorithms depict best practices for care delivery by providing patient management tools to patients under surveillance for cancer recurrence and secondary cancers. Patients are transitioned to Survivorship once there is no evidence of disease for a specific time period dependent on the patient's cancer site. These algorithms are not intended to replace the independent medical judgment of the physician in the context of individual clinical circumstances to determine a patient's care.

Breast Cancer

- [Bone Health](#)
- [Invasive](#)
- [Noninvasive](#)

Gastrointestinal Cancer

- [Anal Cancer](#)
- [Colon Cancer](#)
- [Esophageal Cancer](#)
- [Rectal Cancer](#)

Genitourinary Cancer

- [Bladder Cancer](#)
- [Kidney Cancer](#)
- [Penile Cancer](#)

Head and Neck Cancer

- [Larynx/Hypopharynx Cancer](#)
- [Nasopharynx Cancer](#)
- [Oral Cavity Cancer](#)
- [Oropharynx Cancer](#)
- [Salivary Cancer](#)
- [Unknown Primary](#)

Leukemia

- [Acute Lymphoblastic Leukemia \(ALL\)](#)
- [Acute Myelogenous Leukemia \(AML\)](#)

Lung

- [Non-Small Cell Lung Cancer \(NSCLC\)](#)

- www.mdanderson.org/algorithms

Support tools: Practice Algorithms App

[Clinical Tools & Resources](#) > [Clinical Practice Algorithms](#) > [Cancer Survivorship Algorithms](#)

This app contains the same up-to-date algorithms developed and used at MD Anderson Cancer Center.

Apple App Store



Google Play Store



Technology development and support are provided by Assessment, Intervention and Measurement (AIM) Shared Resource through a Cancer Center Support Grant (CA16672, PI: P. Pisters, MD Anderson Cancer Center), from the National Institutes of Health.

Survivorship Care Plans: Coordinating Care

Treatment Summary

1. Cancer diagnosis
2. Stage of the cancer
3. Unique risk characteristics by molecular or tumor marker reports
4. Treatments received
5. Anticipated potential late effects

Survivorship Care Plan

1. Surveillance exams/tests recommended
2. Prevention/screening evaluations based on guidelines
3. Monitoring for late effects, as described in treatment summary
4. Recommendations for life style changes
5. Follow-up plan

Survivorship Care Plans: Coordinating Care

Treatment Summary and Survivorship Care Plan

1. Cancer diagnosis
 2. Stage and molecular or marker characteristics
 3. Treatments received
 4. Anticipated potential late effects
-
1. Surveillance exams/tests recommended
 2. Prevention/screening evaluations based on guidelines
 3. Monitoring for late effects, as described in treatment summary
 4. Recommendations for life style changes
 5. Follow-up plan

www.asco.org/sites/new-www.asco.org/files/content-files/practice-and-guideline

<https://www.livestrong.org/we-can-help/healthy-living-after-treatment/your-survivorship-care-plan>

ASCO Treatment Summary and Survivorship Care Plan		
General Information		
Patient Name:		Patient DOB:
Patient phone:		Email:
Health Care Providers (Including Names, Institution)		
Primary Care Provider:		
Surgeon:		
Radiation Oncologist:		
Medical Oncologist:		
Other Providers:		
Treatment Summary		
Diagnosis		
Cancer Type/Location/Histology Subtype:		Diagnosis Date (year):
Stage: <input type="checkbox"/> I <input type="checkbox"/> II <input type="checkbox"/> III <input type="checkbox"/> Not applicable		
Treatment		
Surgery <input type="checkbox"/> Yes <input type="checkbox"/> No		Surgery Date(s) (year):
Surgical procedure/location/findings:		
Radiation <input type="checkbox"/> Yes <input type="checkbox"/> No		Body area treated: End Date (year):
Systemic Therapy (chemotherapy, hormonal therapy, other) <input type="checkbox"/> Yes <input type="checkbox"/> No		
Names of Agents Used		End Dates (year)
Persistent symptoms or side effects at completion of treatment: <input type="checkbox"/> No <input type="checkbox"/> Yes (enter type(s)) :		
Familial Cancer Risk Assessment		
Genetic/hereditary risk factor(s) or predisposing conditions:		
Genetic counseling: <input type="checkbox"/> Yes <input type="checkbox"/> No		Genetic testing results:
Follow-up Care Plan		
Need for ongoing (adjuvant) treatment for cancer <input type="checkbox"/> Yes <input type="checkbox"/> No		
Additional treatment name	Planned duration	Possible Side effects
Schedule of clinical visits		
Coordinating Provider	When/How often	

ASCO Survivorship Care Plan	
<small>Updated based on a consensus conference held on 9.27.13 and the ASCO Survivorship Committee</small>	
Cancer surveillance or other recommended related tests	
Coordinating Provider	What/When/How Often
Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:	
<ol style="list-style-type: none"> 1. Anything that represents a brand new symptom; 2. Anything that represents a persistent symptom; 3. Anything you are worried about that might be related to the cancer coming back. 	
Possible late- and long-term effects that someone with this type of cancer and treatment may experience:	
Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.	
<input type="checkbox"/> Emotional and mental health <input type="checkbox"/> Fatigue <input type="checkbox"/> Weight changes <input type="checkbox"/> Stopping smoking <input type="checkbox"/> Physical Functioning <input type="checkbox"/> Insurance <input type="checkbox"/> School/Work <input type="checkbox"/> Financial advice or assistance <input type="checkbox"/> Memory or concentration loss <input type="checkbox"/> Parenting <input type="checkbox"/> Fertility <input type="checkbox"/> Sexual functioning <input type="checkbox"/> Other	
A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:	
<input type="checkbox"/> Tobacco use/cessation <input type="checkbox"/> Diet <input type="checkbox"/> Alcohol use <input type="checkbox"/> Sun screen use <input type="checkbox"/> Weight management (loss/gain) <input type="checkbox"/> Physical activity	
Resources you may be interested in:	
Other comments:	
Prepared by:	Delivered on:

- This Survivorship Care Plan is a cancer treatment summary and follow-up plan is provided to you to keep with your health care records and to share with your primary care provider.
- This summary is a brief record of major aspects of your cancer treatment. You can share your copy with any of your doctors or nurses. However, this is not a detailed or comprehensive record of your care.

Electronic Health Record Example

Cancer Treatment Summary	
Provided on 09/16/16	
General Information	
Patient name	Our Patient
Patient ID	2001245
Date of birth	9/9/1970
Age	46 y.o.
Sex	female
Allergies	Review of patient's allergies indicates not on file.
Provider(s)	
Medical Oncologist	Dr. Smith
Surgeon	Dr. Jones
Radiation Oncologist	N/A
Cancer Diagnosis Information	
Cancer Diagnosis	Breast cancer
Stage	Breast cancer Staging form: Breast, AJCC 7th Edition Clinical stage from 9/1/2016: Stage IA (T1, N0, M0) - Unsigned
Histology	Left: N/A Right: Invasive Ductal Carcinoma
Estrogen Receptor	Positive
Progesterone Receptor	Positive
Her2/neu	Negative
Hereditary Genetic Findings	BRCA1+ (Hereditary Breast and Ovarian Cancer syndrome)
Additional Cancer Diagnosis	No additional cancer diagnosis
Background Information	
Past medical history	No past medical history on file.
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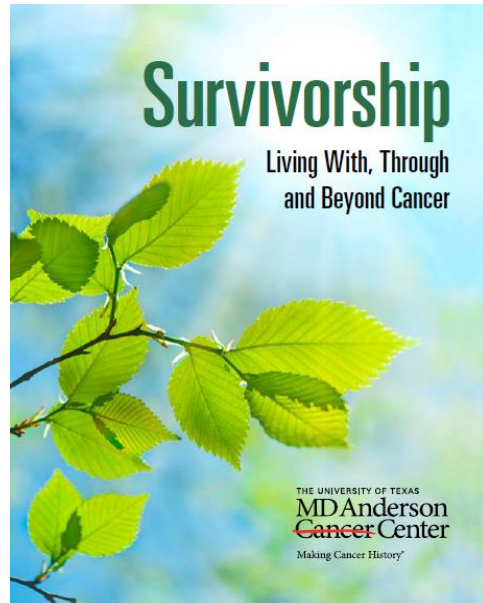
Coordination of Care for Survivors

- Identified challenges:
 - Preparation of the Summary Treatment and Care Plans requires significant amount of time
 - Treatment data may be housed in different record systems or separate treatment facilities
 - Because care is multidisciplinary, responsibility for this document is not clearly explicit
 - The primary care clinician(s) are not identified and updated in the health record by the patient
 - The health records are not visible or transparent across practices

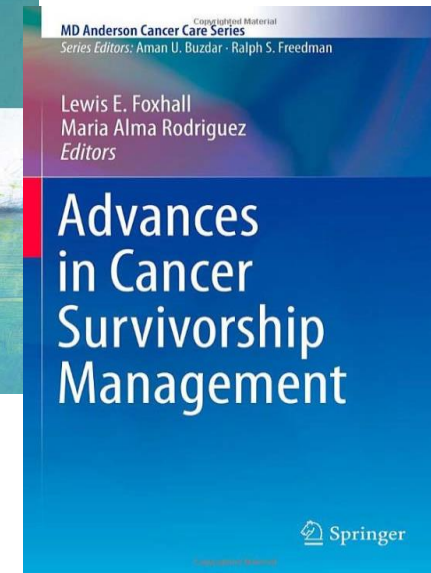
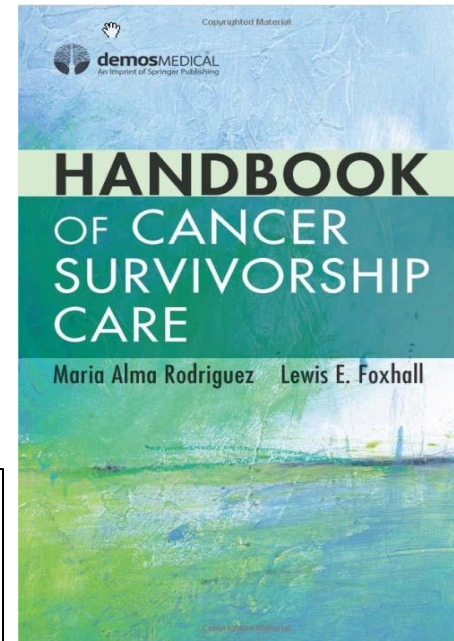
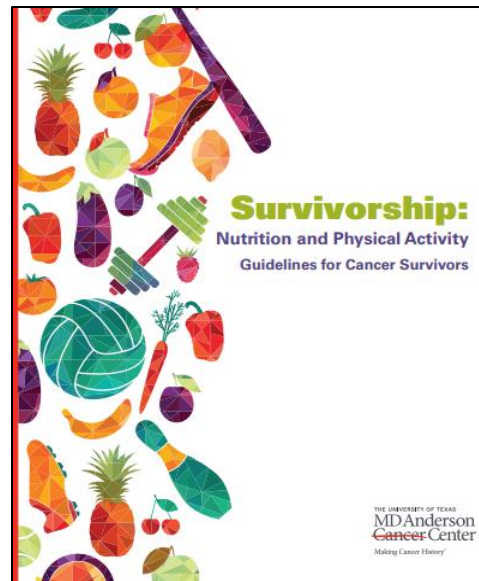
Survivorship Resources

- NCCN Guidelines for Patients – Cancer-related Late and Long-Term Effects
<https://www.nccn.org/patients/guidelines/content/PDF/survivorship-crl-patient.pdf>
- NCCN Guidelines for Patients – Healthy Living
<https://www.nccn.org/patients/guidelines/content/PDF/survivorship-hl-patient.pdf>
- National Cancer Institute – Cancer Survivorship:
<https://www.cancer.gov/about-cancer/coping/survivorship>
- CDC – Cancer Survivors: Guidelines to Healthy Living:
<https://www.cdc.gov/cancer/survivors/>
- National Coalition for Cancer Survivorship: <https://canceradvocacy.org/>
- CancerCare: www.CancerCare.org
- American Cancer Society – Survivorship: During and After Treatment
<https://www.cancer.org/treatment/survivorship-during-and-after-treatment.html>
- MD Anderson Cancer Center – Life After Cancer:
<https://www.mdanderson.org/patients-family/life-after-cancer.html>

Clinical Tools and Resources



Patient Education



Professional Education

Summary

1. Long term cancer survivors (5 years or longer) constitute the majority of cancer survivors in the USA today
2. More than 2/3 of long term survivors are older adults (65 years and older), and that number will significantly increase over the next 20 years, as predicted by SEER statistics based on the aging US population
3. The needs of survivors are driven not only by their age and health conditions, but also by the prior cancer diagnosis and the cancer treatment received
4. While breast and prostate cancer survivors constitute nearly half of the total survivor population, the dropping mortality rates in lung and other solid tumors is increasingly diversifying the groups of survivors
5. The key components of survivorship care as supported by the 2006 IOM report are intended to address the issues faced by survivors after their treatment ends, and these domains include surveillance, prevention/screening for second primary cancers, management of late effects, and psychosocial health
6. The primary care clinical community increasingly will be caring for cancer survivors in their practice, and coordinated information exchange with and from the oncology providers is very important to the seamless transition of the patients' care

The Challenge of Survivorship

- The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly, but also to map the middle ground of survivorship and minimize its medical and social hazards

- Fitzhugh Mullan. Seasons of Survival: Reflections by a Physician with Cancer. NEJM 1985;313(4):270-3.

