

# Survivorship Care is Palliative Care

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### My Personal Story

- I finished hematology-oncology fellowship training in 1978 at UCLA
- Kubler-Ross, Cicely Saunders, Balfour Mount were leading the movement towards hospice care
- Recruited to the VAMC-Sepulveda to develop a hospice and palliative care unit; founding member of the NCCS in 1986
- Chief of Hematology-Oncology at the VAMC and in 1992 I moved back to UCLA full time
- Leader in cancer survivorship research and care for the past 35 years

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#### A few words about Ellen Stovall...

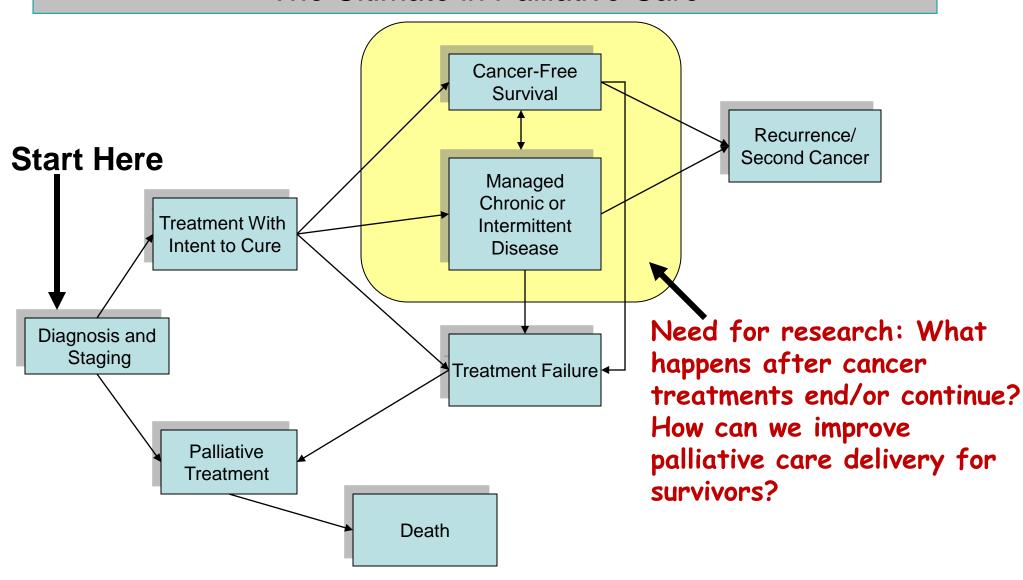
- An extraordinary human being...
- A wonderful colleague...
- ■A tenacious advocate...
- ■A quality of care maven...
- ■A cancer survivor...



1946-2016

- + Statements attributed to Ellen Stovall (Mullan, 2016)
  - "Survivorship is a condition of its own."
  - "We need to change the system to achieve the goals of survivorship."
  - "Getting doctors to change is like moving a battleship."
  - "Every survivor needs a survivorship care plan."
  - "Survivorship research should put more focus on delivery models and payment reform."
  - "The system falsely denies death."

# Strategies to Prevent the Late Effects of Cancer Treatment The Ultimate in Palliative Care



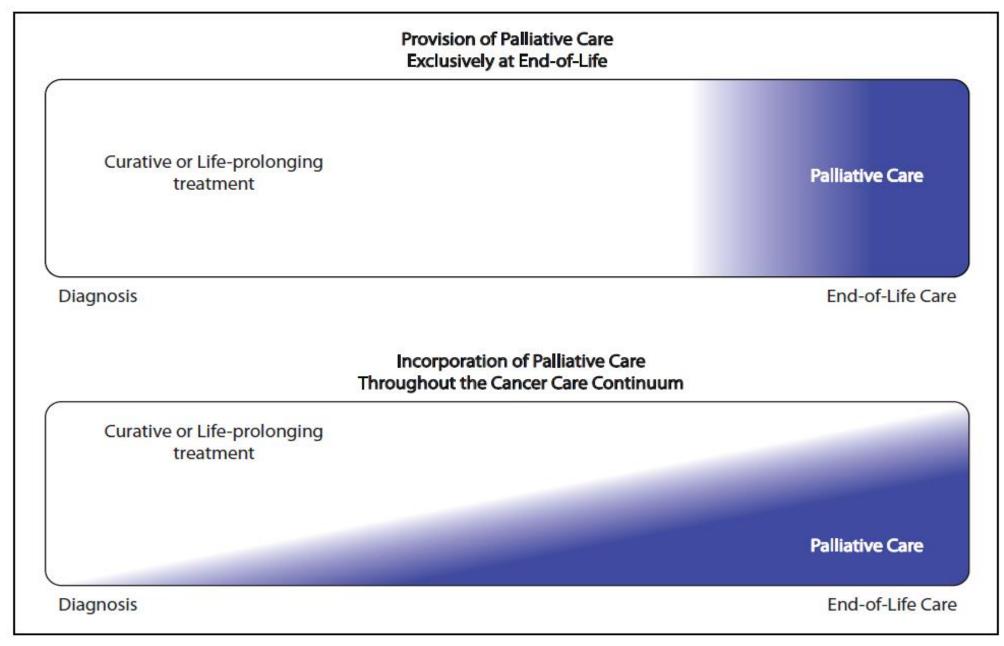
# **Definitions**

- Long-term effect: a symptom or problem that begins during cancer treatment and persists when treatment ends e.g., fatigue, cognitive complaints, pain
- <u>Late effect</u>: a symptom or problem that occurs months to years after treatment ends, e.g. a second cancer, congestive heart failure, lymphedema
- Some symptoms or problems can either be long-term or late effects---confusing!

# **Cancer Care Continuum**

Screening	Diagnosis	Treatment	Survivorship	End-of-life Care
-Age and gender specific screening -Genetic testing	-Biopsy -Pathology reporting -Histological assessment -Staging -Biomarker assessment -Molecular profiling	-Systemic therapy -Surgery -Radiation	-Surveillance for recurrences -Screening for related cancers -Hereditary cancer predisposition/ genetics	-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 Chro	onic Care	End-of-Life Care
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#### Incorporation of palliative care across the care continuum



# **Survivorship Health Care Delivery**

- The Three P's of Survivor Care
  - Palliation
  - Prevention
  - Health Promotion

# Symptom Management/Palliative Care: An Integral Part of Survivorship Care

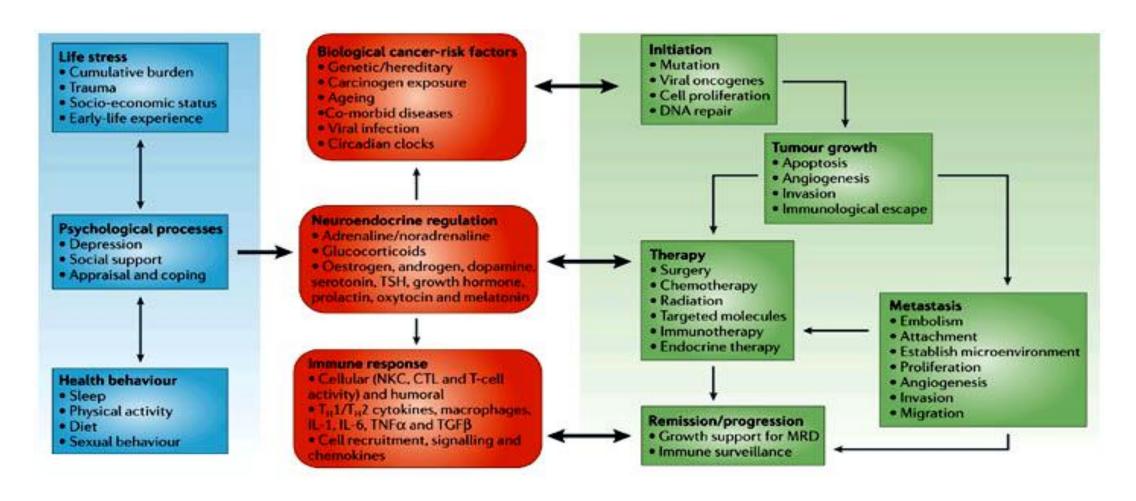
- Definition of Palliative Care:
  - Medical care or treatment that concentrates on reducing the severity of disease symptoms (particularly if there is not a curative medical treatment)
  - Goal is to prevent and relieve suffering and to improve quality of life for people facing complex illness

 Focus on the most severe symptoms that the survivor wants help with

# Why is it important to understand biological mechanisms of symptoms?

- Identification of underlying biology provides support/validity for complaints
- Leads to possible interventions (pharmacological or behavioral)
- Potential for prevention, if at-risk individuals identified
- Possible relationship to tumor biology and progression

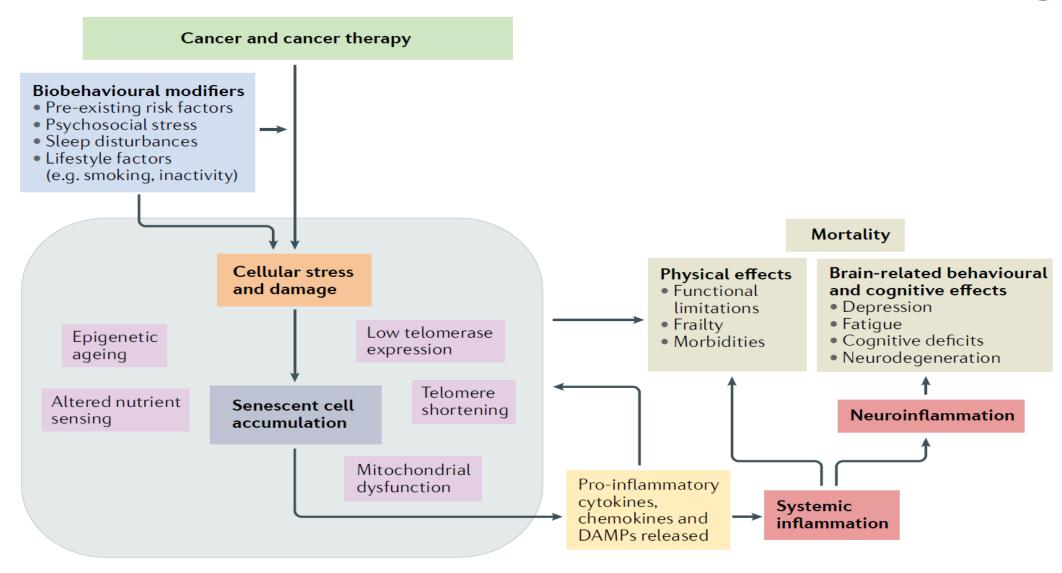
#### A Biobehavioral Model of Cancer



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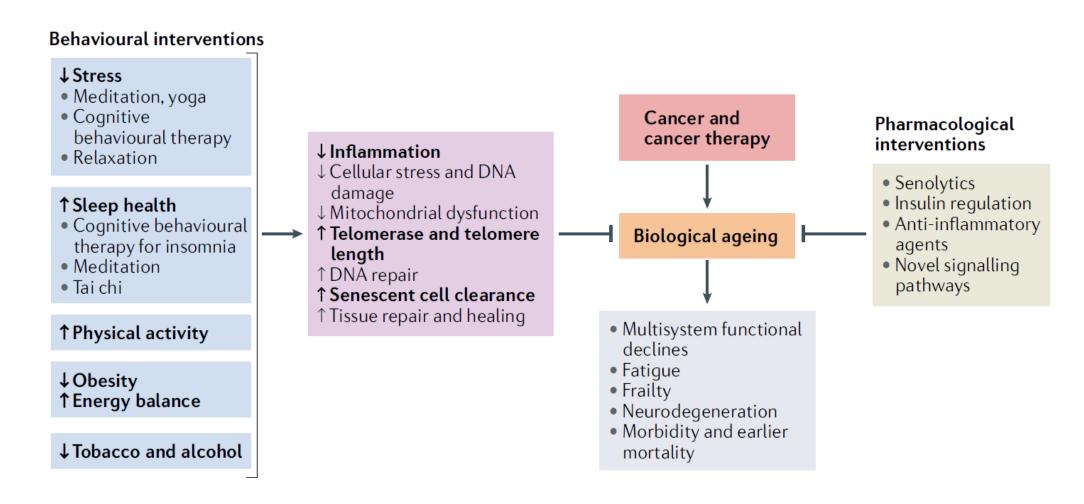


### Model of Behavioral Modifiers of Cancer-Related Accelerated Aging



Carroll, Bower, Ganz, Nat Rev Clin Oncol, 2021

# Behavioral Interventions May Reduce Effects of Cancer Treatment on Biological Aging and Minimize Physical and Cognitive Decline



# Common Palliative Care Concerns in Cancer Survivors

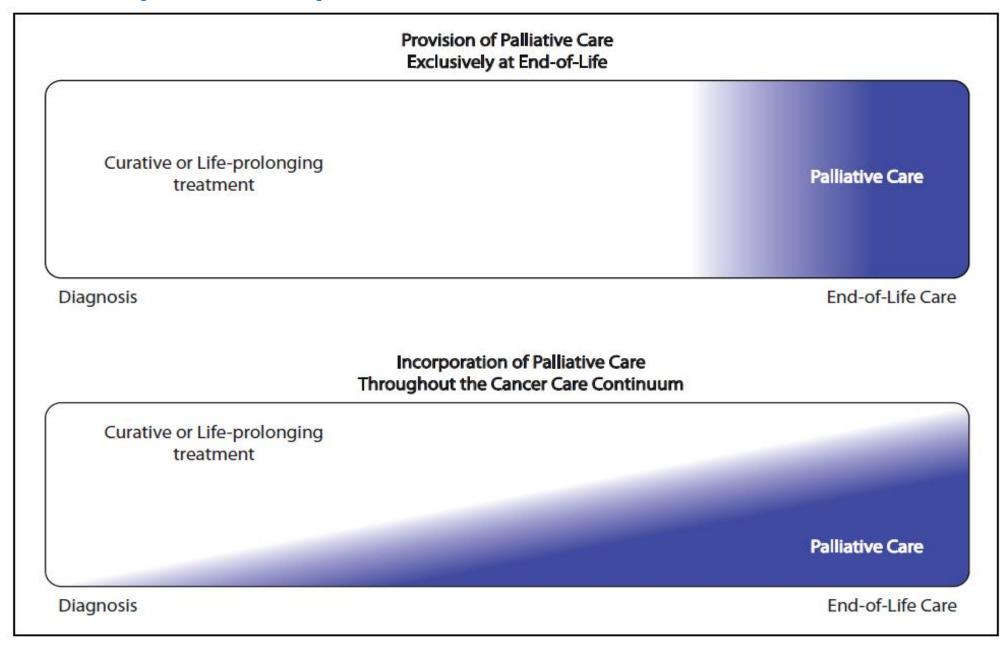
- Pain
- Fatigue
- Depression
- Insomnia
- Physical limitations
- Cognitive changes

- Neuropathy
- Lymphedema
- Sexual dysfunction
- Menopause related symptoms
- Body image changes

# Consultant Specialists Required

- Mental health
- Pain management
- Physical medicine/vocational rehab
- Endocrinology
- Cardiology
- Gynecology/fertility
- Pulmonary
- Neurology/neuropsychology

#### Incorporation of palliative care across the care continuum



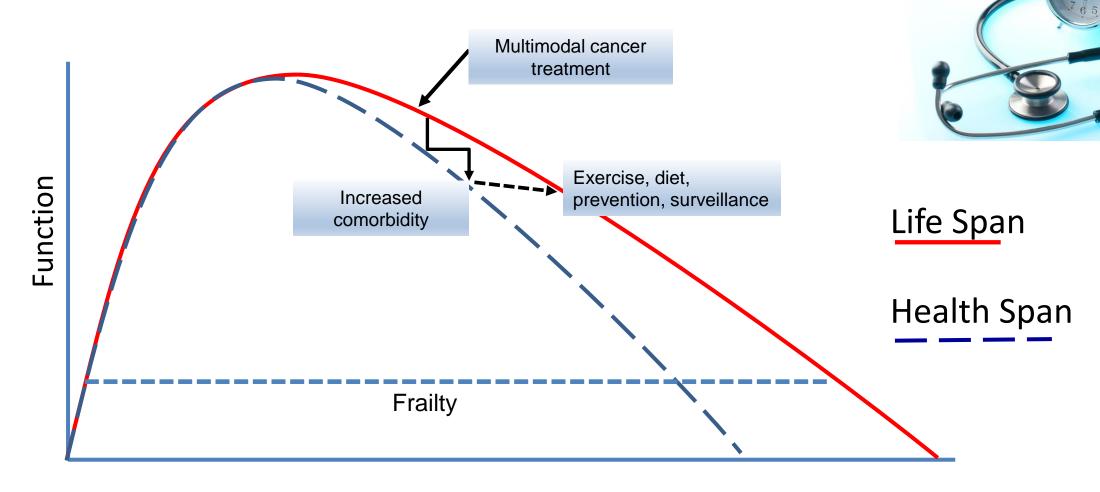
## **Prevention**

- Systematic ongoing follow-up required for screening
  - Goal: early detection and early intervention for potentially serious late-onset complications e.g., cataracts, osteoporosis, cardiac disease
  - Chemoprevention when available
  - Genetic counseling for hereditary cancers
- Life style modification to prevent second cancers

## **Health Promotion**

- Health promotion counseling
  - Goal: promote risk reduction for health problems that commonly present during adulthood (esp. for childhood cancer survivors)
  - Avoid weight gain
  - Increase physical activity
  - Avoidance of exposures that are harmful
  - Decrease risk of other chronic diseases, e.g. diabetes, heart disease

### **Health Span and Life Span**



Age in Years

# How to deliver the 3 P's?

- New research is needed on models of care delivery
- One size will not fit all; different settings and different patients will have different requirements
- What is right for UCLA may not be right in other settings
- Treatment plans and shared decision-making can help to reduce potential long-term or late effects
- Survivorship care plans can educate patients about how they can enhance their recovery

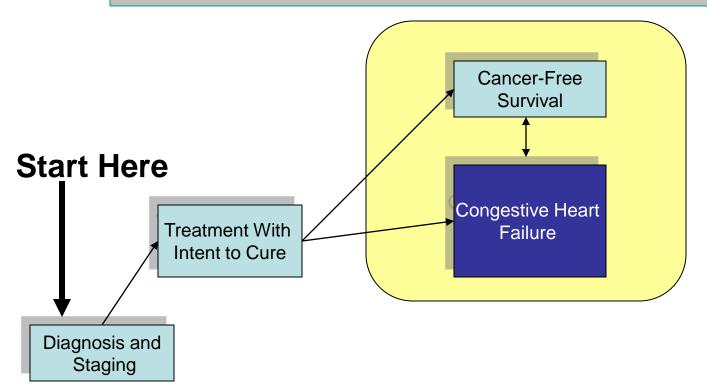
## Communication and Cancer Survivors

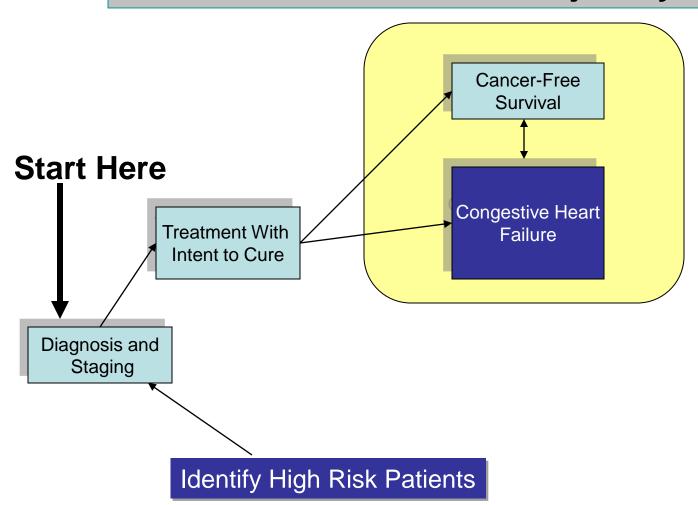


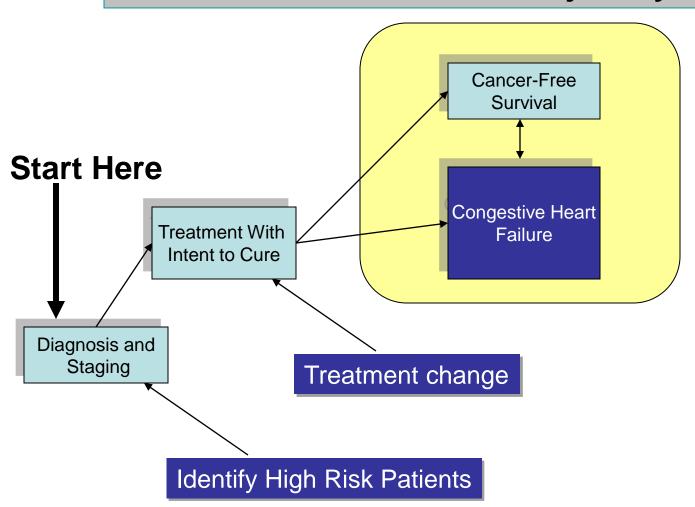
Jessie Gruman 1953-2014

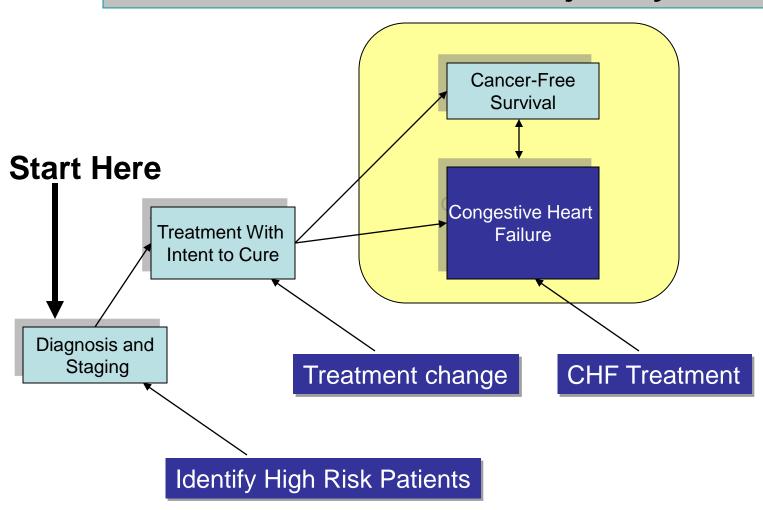
"Those of us with multiple chronic conditions may consult many physicians in the course of a year. Last year, I saw 11. Not one of my doctors has ever communicated directly with another, despite the fact that some of them work in the same health system and have offices in the same building. I am the sole arbiter of who gets what information in what format and when."\*

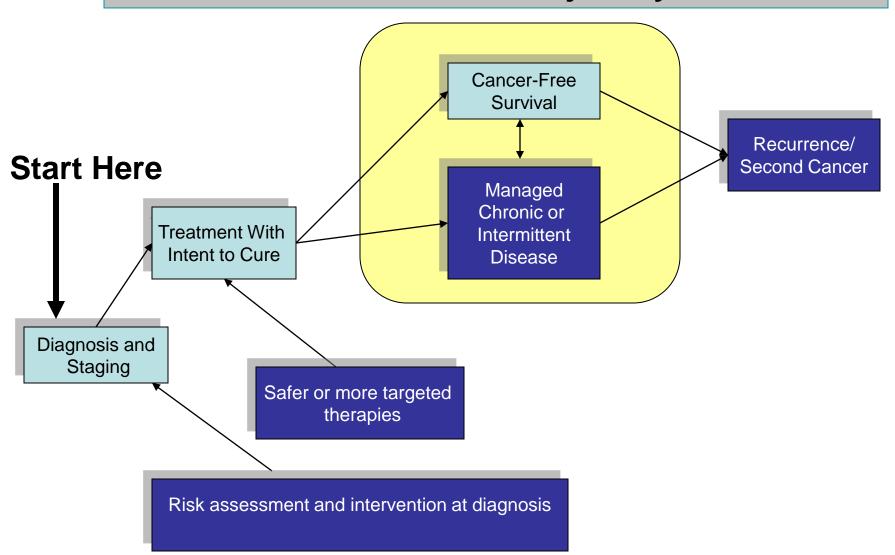
<sup>\*</sup> Gruman, J.C., Making health information technology sing for people with chronic conditions. Am J Prev Med, 2011. 40(5 Suppl 2): p. S238-40.

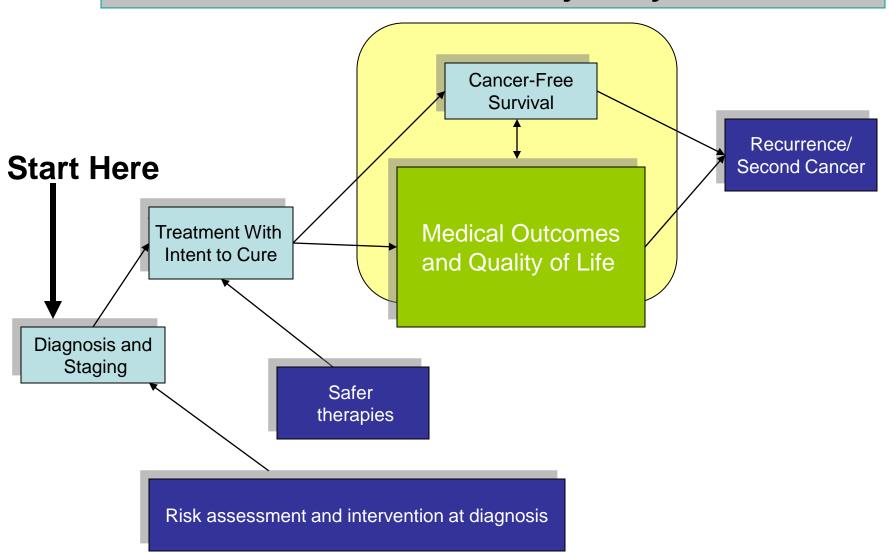


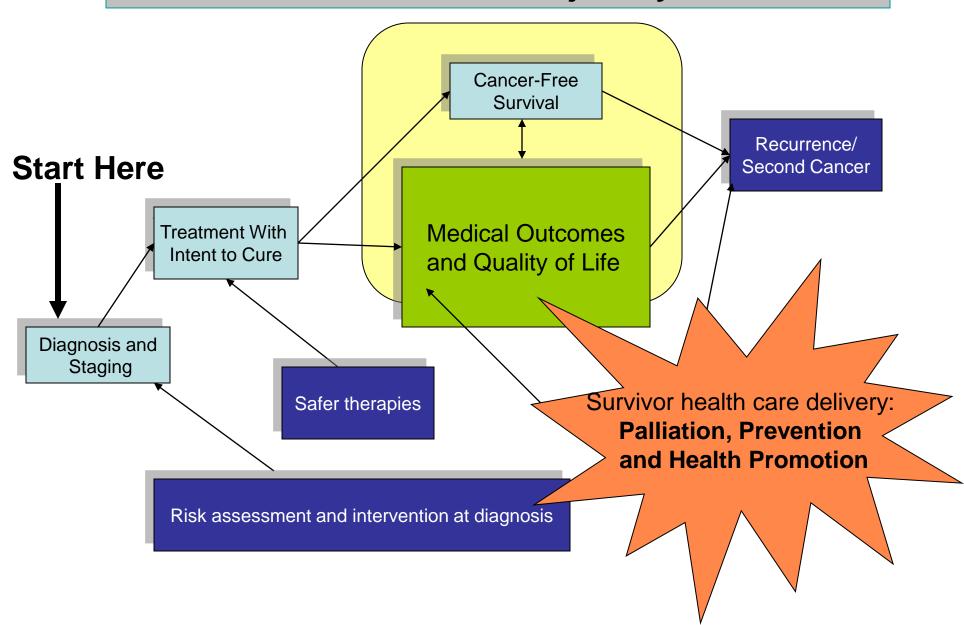


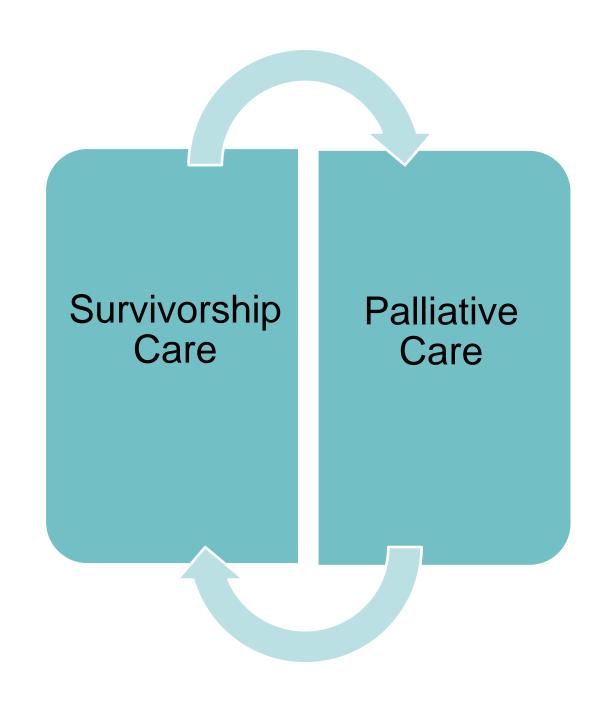












With attention to survivorship needs, there can still be a good life after cancer!





