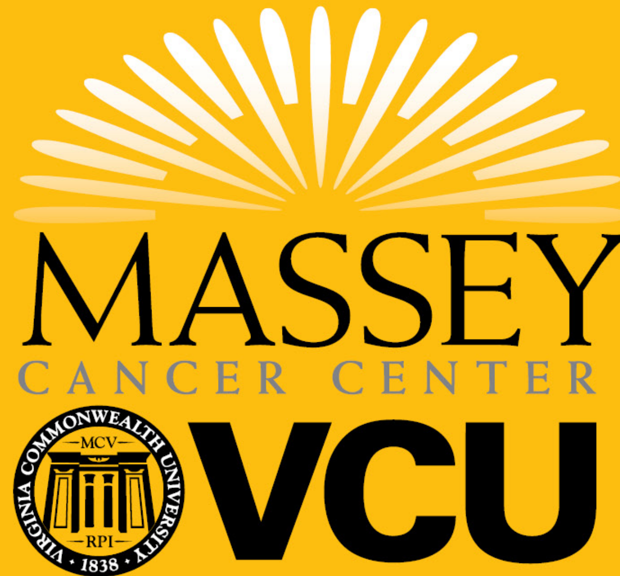

Survivorship Begins at Diagnosis

Mary Helen Hackney, MD MS FACP
VCU Massey Cancer Center

November 2015

Who is a cancer survivor?

- Definition 1:
  - Person who was diagnosed, treated and has no evidence of disease
- Definition 2:
  - Person who has a diagnosis and is in the process of going through and beyond treatment. This person could be living with cancer.
    - » Adapted, ACS, 2012

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The Facts

- One of two men and one of three women will have a personal history of cancer
- Over 12 million people in the U.S. with history of cancer
- 68% with a cancer diagnosis live >5 years
- 15% were diagnosed with cancer > 20 years ago
- Most survivors are 65 and older

  » ACS, 2012

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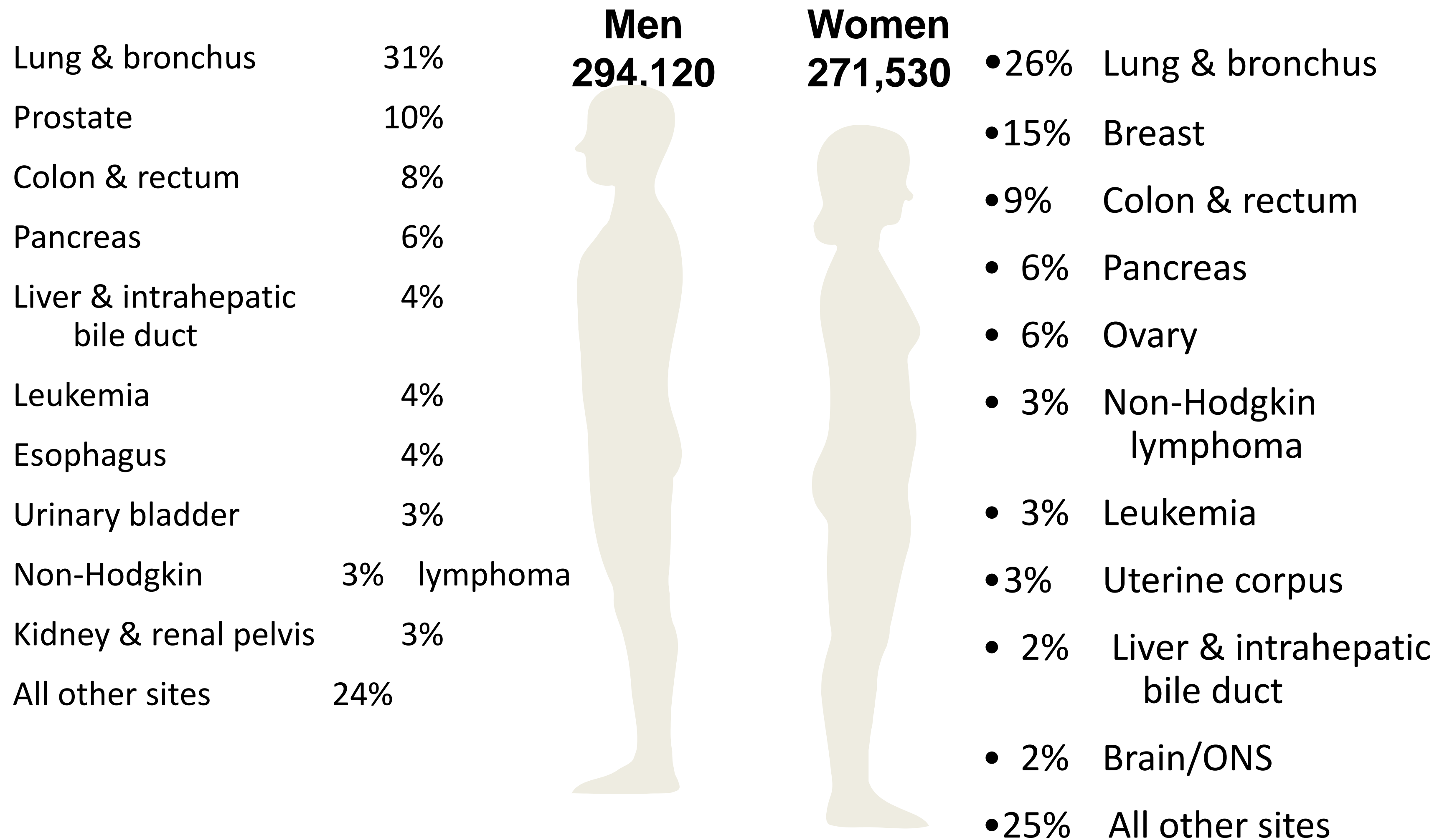
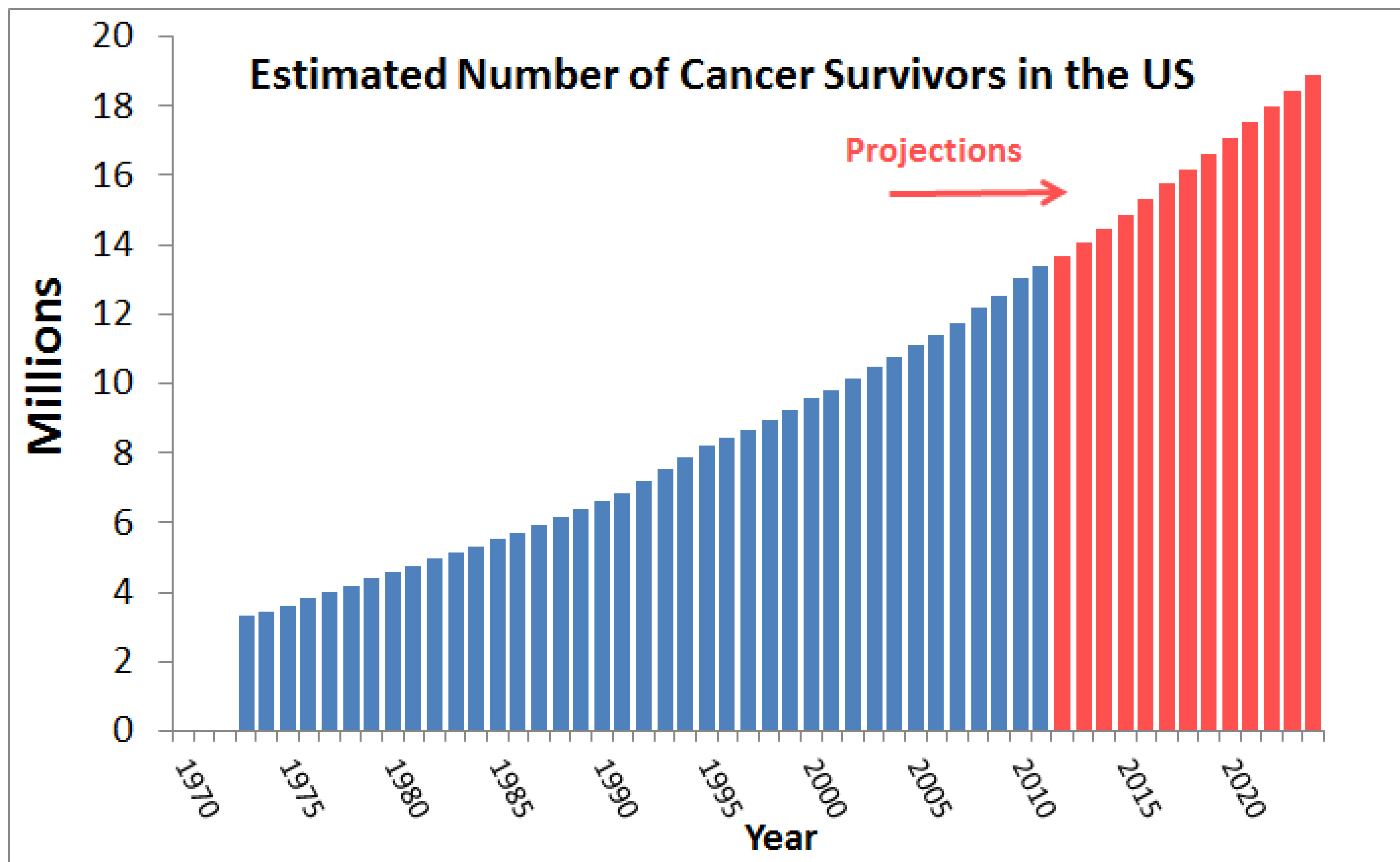
2008 Estimated US Cancer Deaths*



ONS=Other nervous system.
Source: American Cancer Society, 2008.



[1] DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press.

Treating Cancer: It Requires Multiple Disciplines

- Primary Care Physicians
- Medical Oncologist
- Surgical Oncologist
- Radiation Oncologist
- Special surgeons: ENT, urology, gynecology, plastics, neurosurg.
- Radiologist
- Pathologist
- Genetic counselors
- Other specialties: dermatology, GI, pulmonary,cardiology
- Oncology nurses
- Clinical trial/research team
- Chaplain/spiritual
- Physical/occupational therapy
- Psychologist/Psych.
- Social worker
- Navigators/educators
- Nutritionist
- Palliative Care team

Institute of Medicine Update

- September 2013 published an updated report on the state of cancer care in the U.S.
- 322 page document but good summary slides are available for free on the website www.iom.edu/qualitycancercare
- Among the key points:
  - Teamwork among physicians
  - Adequate information for patients before, during and after treatment to include prognosis, short and long term side effects

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Treatment Summaries and Follow Up Care Plans

Several groups have now mandated that treatment summaries and follow up care plans be provided to all patients (with long term survival or curable cancer)

The best supported care plans are for breast , colon/rectal, non small lung, large cell lymphoma

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Do post treatment guidelines and care plans make a difference?

- Hope to use the best evidence for when and when not to perform tests
- Provide security for patients
- Provide security for primary care physicians and others
- Provides a comprehensive care plan for all disciplines
- Does it improve survival? Quality of life?

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The Challenges

- Education of patients, oncologists and primary care providers
- Diversity of treatments thus the diversity of side effects
- Increasing age of patients with additional comorbid conditions
- Lack of good information on many long term consequences of treatment

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The Challenges of Care Plans

- Finding evidence based guidelines for how to follow up patients after treatment
  - Best documentation thus far for breast and colorectal cancers
- How to put the information into a user and electronic medical record friendly format
- Who is responsible for filling out the forms since cancer care is usually multidisciplinary

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[Insert Practice Name/Info Here]

The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.

Treatment Plan (Continued)			**Treatment Summary (Continued)**
Non-chemotheraputic Agents	**Route**	**Purpose/Goal**	**Comments**

Reason for stopping treatment: ☐ Completion ☐ Toxicity ☐ Progression ☐ Other

Response to treatment: ☐ Complete ☐ Partial ☐ No response ☐ Progression ☐ Not measurable

Treatment-related hospitalization required: ☐ Yes ☐ No

Serious toxicities during treatment (list all):

Ongoing toxicity at completion of treatment:
☐ Yes (enter type(s) and grade(s))
☐ No

Additional Therapies Planned		
Drug name	**Comments**	**Date started (or to start)**
		(/ /)
		(/ /)
		(/ /)

Radiation therapy: ☐ Not planned
☐ Planned
☐ Administered Region treated: Radiation dose:
Date initiated: (/ /) Date completed: (/ /)

	Survivorship Care Provider Contacts
Provider:	**Provider:**
Name:	Name:
Contact Info:	Contact Info:
Provider:	**Provider:**
Name:	Name:
Contact Info:	Contact Info:
Provider:	**Provider:**
Name:	Name:
Contact Info:	Contact Info:
Provider:	**Provider:**
Name:	Name:
Contact Info:	Contact Info:

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Important caution: this is a summary document whose purpose is to review the highlights of the cancer treatment for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and cancer therapies in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

Colon Cancer Survivorship Care Plan v3 10/09

Patient Name:

Name and role of person completing this form:			Completion date:	
FOLLOW-UP CARE RECOMMENDATION	YEAR 1	YEAR 2	YEAR 3	YEARS 4 AND 5*
Doctor's Visit	Every 3 to 6months	Every 3 to 6 months	Every 3 to 6 months	Every 6 months
CEA Test	Every 3 months	Every 3 months	Every 3 months	As determined by your doctor
CT Scanning	Every year, if recommended by your doctor	Every year, if recommended by your doctor	Every year, if recommended by your doctor	As determined by your doctor
Colonoscopy	Once†		At 3 years	

* After 5 years, the need for future tests and visits are decided by the patient and doctor.
† A colonoscopy should be done around the time of surgery. If the examination shows no signs of a recurrent tumor or polyps, a colonoscopy should be done at 3 years, and if normal, every 5 years thereafter.

Scientific evidence for the routine use of the following tests is lacking and they are not recommended for follow-up care:

- A complete blood count (CBC) test or liver function tests
- A fecal occult blood test to look for blood in the stool

COLON CANCER FOLLOW – UP SHEET

Date of Surgery (DOS):

ESTIMATED TARGET DATES		DATES COMPLETED			
DOS plus	Actual Dates	CEA[1] (Date/Value)	Counseling Visit[2]	CT Scanning	Colonoscopy[3]
+ 0y/3m →					
+ 0y/6m →					
+ 0y/9m →					
+ 1y/0m →					
+ 1y/3m →					
+ 1y/6m →					
+ 1y/9m →					
+ 2y/0m →					
+ 2y/3m →					
+ 2y/6m →					
+ 2y/9m →					
+ 3y/0m →					
+ 3y/6m →					
+ 4y/0m →					
+ 4y/6m →					
+ 5y/0m →					

Comments/Evidence of Recurrence:

[1] Carcinoembryonic antigen (CEA) testing is not recommended *during* the administration of adjuvant chemotherapy.
[2] As guidelines suggest 3 to 6 months for counseling visits, optional dates are marked with (opt)
[3] Acceptable to wait 3 years for follow-up if the pre-or perioperative colonoscopy examined the *entire colon*.

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The Survivorship Care Plan recommendations are derived from the 2005 Update of the American Society of Clinical Oncology Practice Guideline. This plan is a practice tool based on ASCO® practice guidelines and is not intended to substitute for the independent professional judgment of the treating physician. Practice guidelines do not account for individual variation among patients. This tool does not purport to suggest any particular course of medical treatment. Use of the practice guidelines and this plan is voluntary. The practice guidelines and additional information are available at http://www.asco.org/guidelines/crcfollowup.

Where to find the plans?

- www.cancer.net
  - Website for patients and non-oncologists
  - Part of the American Society of Clinical Oncology
  - Guidelines are available for breast cancer, colon cancer and rectal cancer follow up
    - Others always being added
  - Generic care plans are also available
- Other sites for care plans
  - Livestrong

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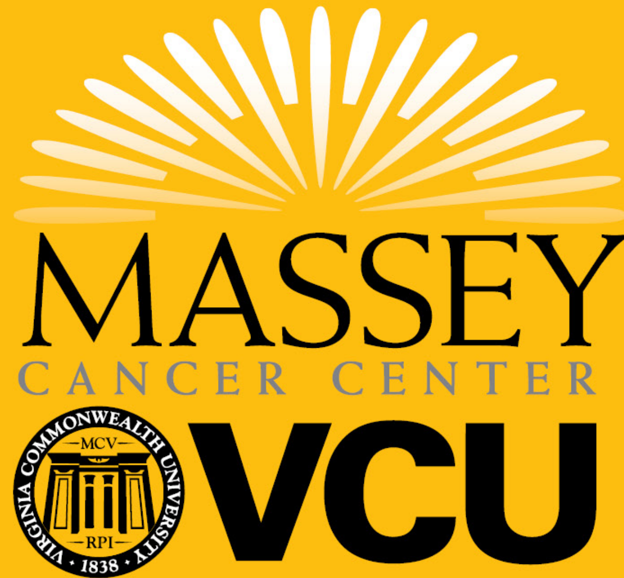

Health after Cancer Treatment

Systems Affected by Cancer Treatment

- Cardiac
- Pulmonary
- Renal
- Emotional , psychiatric and cognitive
- Endocrine
- Gastrointestinal
- Gynecologic and fertility
- Dermatologic
- Musculoskeletal
- Neurologic

Survivor Topics

- Recurrence fears
- Fertility/Sexuality
- Cognitive dysfunction
- Fatigue
- Self image/esteem
- Weight control
- Bone Health
- Stress/Depression
- Cardiac complications
- Bone marrow complications
- Pain
  - Neuropathy
  - Pain at surgical sites
- Menopause/premature aging

Emotional/Psychiatric/Cognitive

- Recognition that many patients and families need support and counseling
- The Losses:
  - Hair, body parts, breasts, limbs
  - Normal body functions (ostomies, erectile dysfunction)
  - Memory
  - Job, self worth, family, friends, finances
  - Loss of family and social role

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Cognitive Changes

- Increased recognition that chemotherapy and radiation therapy can impact cognitive function
- “Chemo Brain” or “Chemo Fog”
- Changes may last for months after treatment
  – Word finding problems
  – Difficulty learning new tasks
  – Directional challenges

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Cognitive Changes

- Recent publication looked at multiple studies in breast cancer patients
  - Significant difference seen with word finding visual spatial skills
  - Most difficulties resolved within one year of completing therapy
    - JCO (2012:30)
- There is a clear need for more research
  - Who is most affected
  - Are changes a function of : drugs, age, sex, previous level of functioning
  - Is there an intervention?

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Radiation Therapy and Cognitive Function

- Short term memory loss not uncommon
- Early onset dementia and its complications
  - In patients who have had aggressive brain irradiation; the brain can now be treated multiple times leading to cumulative toxicity
  - In most the systemic disease is well controlled with new treatment modalities
  - Patients now potentially live years after brain radiation treatment

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Cognitive…

- How to improve cognitive function:
  - Adequate rest
  - Limit multitasking
  - Limit mind altering drugs
  - Time heals many
  - No proof yet for medical interventions although several have been tried eg gingko

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Stress

- Employment, finances
  - Many resources for support and counseling
  - LINC
  - Often cannot qualify for disability
- Fatigue
  - May take months to recover from treatment
  - Check thryoid, blood sugars, etc.
- Physical appearance changes
  - Hair loss (may fail to regrow)
  - Limb removal
  - Facial and neck disfiguration
  - Loss of ability to speak or swallow easily
  - Ostomies
  - Breast removal with/without reconstruction

Stress and Relationships

- Caregiver fatigue
  - Friends and family members may grow weary
  - Patient may be the caregiver for others thus adding stress
- Stress on relationships
  - A few small surveys report increased divorce rate particularly with breast cancer patients
  - Partner may fear they will hurt patient with intimacy
  - Children may have stress reactions
  - May need marital counseling during time

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Emotional Challenges

- Fear of recurrence or mortality leading to increased stress
- Partner fearful of hurting the patient and is reluctant to engage, thus more stress and anxiety
- Single women worry that they will be unattractive or rejected as they enter the dating field with body changes
- Several small studies report increase in divorce rate among breast cancer survivors
- Depression and anxiety are not uncommon
  - Medications can diminish libido

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Sexual Health and Cancer

- First: ask the questions
  - Fertility concerns
  - Dyspareunia and vaginal dryness
  - Lack of interest, lack of libido
  - Depression
  - Self esteem about body-surgical disfiguration, hair loss
  - Issues with partner; issues with finding a partner

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Sexuality and Fertility

- Fertility discussions should happen **before** treatment starts
  - There is usually time before treatment starts
- Refer to a fertility expert
- It is not possible to preserve fertility in all women
  - Impact of aging
  - Impact of chemotherapy/radiation therapy/surgery on gynecologic function

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Atrophic Vaginitis

- Non hormonal therapies preferred
- Systemic estrogens not recommended
- Topical hormonal therapies
  - Continued discussion as safety is uncertain
    - Topical estrogen e.g. cream, tablet insert, ring insert
    - DHEA-clinical trial
    - Testosterone cream
    - Ph specific gels-under study
  - Unknown risks vs quality of life: discussion

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Sexuality and Fertility After Cancer

- Erectile dysfunction
  - Both drugs and surgical techniques may help
- Impotence
- Libido loss
  - Particularly difficult for women who cannot take estrogen
- Recurrent cystitis
- Self esteem issues
  - Particularly if disfiguring surgery, ostomy, etc.

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Contd.

- Refer to specialist for urological or gynecologic issues
- May need counseling to reaffirm self worth and/or to support relationships
- Those who desire children may have other challenges
  - Many adoption agencies will not consider cancer survivors as parent for several years after diagnosis, if at all.

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Risk Factors for Bone Health

- **Early menopause**
  - Oophorectomies
  - Chemotherapy induced
- Sex- **female more than male**
- Age
- Race
- Low body mass
- Genetics

- **Medications**
  - Aromatase inhibitors
  - Drugs that inhibit testosterone
  - Steroids

- Decreased calcium
- Decreased vitamin D
- Sedentary
- Alcohol
- Tobacco use

Bone Health Management

- Bone density test at the beginning of medications and every 1-2 years depending on risks
- Maintain Vitamin D levels >35
  - May also reduce arthralgias of aromatase inhibitors
    - » Breast J. 2014, March-April
- Bisphosphonates and RANK Ligand Inhibitor
  - Indicated if high risk or osteoporosis
  - IV bisphosphonate (zoledronic acid) may reduce skeletal recurrence in post menopausal women. Role of oral bisphosphonates uncertain. Who benefits is unknown so not standard of care as an anticancer medication
    - » Cancer Treat Rev 2014, April

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Pulmonary Toxicity

- Chemotherapy culprits
  - Bleomycin and BCNU: diminished diffusing capacity and pulmonary fibrosis
    - Limit oxygen exposure if patient has had bleomycin
  - Taxanes: pulmonary fibrosis
  - Everolimus
- Radiation to lungs, breast, chest wall, or mediastinum
  - Pulmonary fibrosis

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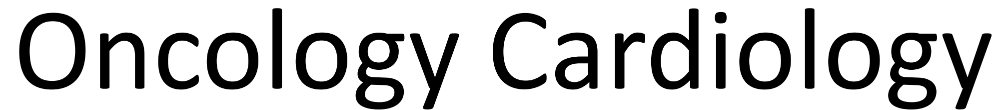

- A new specialty
- Developed from the recognition that many of the newer cancer treatment drugs have cardiac toxicities
- Toxicity can be immediate or delayed even for years
- Most common cardiac effects are heart failure, hypertension and ekg changes

Oncology Cardiology

- New specialty recognizing both acute and chronic complications of treatment
- Recognized complications:
  - Heart failure-sometimes irreversible
  - Arrhythmias
  - Accelerated coronary artery disease
  - Difficult to manage hypertension
  - Pericarditis/pericardial effusions

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Cardiac Issues

The Drugs

- Anthracycline: doxorubicin,, daunorubicin,
- Bevacizumab
- Radiation Therapy
  - Esp. to Chest Wall
- Trastuzumab, pertuzumab
- 5 flurouracil

The Cancers

Breast

Sarcoma

Lymphoma

Acute leukemia

Bone Marrow Transplant

(Lung)

(Colorectal)

(Liver)

Cardiac Problems

- Problems can be acute or delayed
- It is not uncommon that the cardiac issues do not become apparent until years after treatment
  - Ex. Heart failure with the stress of pregnancy
  - Ex. Benign pericardial effusion post radiation

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Fatigue

- Most common long term complaint
- Multifactorial and often hard to solve
- Look for fixable
  - Thyroid issues
  - Anemia
  - Sleep disturbance
  - Medications

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Secondary Cancers

- Acute leukemia or myelodysplasia
  - Due to chemotherapy esp. alkylating agents
  - Due to radiation therapy esp. to major marrow
  - Original cancers: breast, prostate, lymphoma, others
- Breast Cancer
  - Due to radiation therapy to mediastinum for childhood or adolescent lymphoma
- Soft tissue Sarcoma
  - Due to radiation therapy (usually for breast ca)
- Endometrial Cancer
  - Due to tamoxifen used to treat breast cancer

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Secondary Cancers

- Bladder cancer: due to cyclophosphamide
- Basal cell skin cancers: radiation therapy
- Thyroid cancer: radiation therapy
- Meningiomas: radiation therapy

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Other Complications

- Thyroid problems: after radiation therapy to mediastinum or neck
  - Check thyroid function; may develop years later
- Dental problems from radiation or chemotherapy
  - Gingivitis: good hygiene, see dentist
  - Xerostomia: several saliva substitutes
  - Osteonecrosis: limit bisphosphanates
- Cataracts: from steroids, tamoxifen
  - Ophthalmology

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Lymphedema

- Risk increases with extent of lymph node dissection, obesity and radiation therapy
- Breast ca., lymphoma, gynecologic ca.
- Refer to therapist who has had specialized training
- Early intervention is best
  - Often patient feels the difference before it is visible
  - Rough guide: refer if 2 cm or more difference between arms circumference

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Complementary and Alternative Medicine

- The internet and the media are full of information and claims
- Some things make sense
  - Yoga, massage, meditation for stress relief
- Some things are concerning
  - Bioidentical hormones
  - Drastic dietary changes
  - Supplements of unknown risk/benefit

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What are the best suggestions after a cancer diagnosis?

- Not too fat, not too thin—good body weight
- No tobacco products
- Limit or eliminate alcohol
- Regular exercise---minimum 3 hours per week
  - More is better
- Follow up on health maintenance
  - Colonoscopy, mammogram, appropriate blood work

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Celebrate Life!

Not cancer

Thank You!

Questions?

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