

Cancer Survivorship



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Stories of Survivorship

- The history of cancer survivorship in the US
- Seminal events in cancer survivorship
- Common and rare cancers: what's the difference?
- Cancer survivorship among Waldenstrom's Macroglobulinemia survivors

The Dream of Yesterday

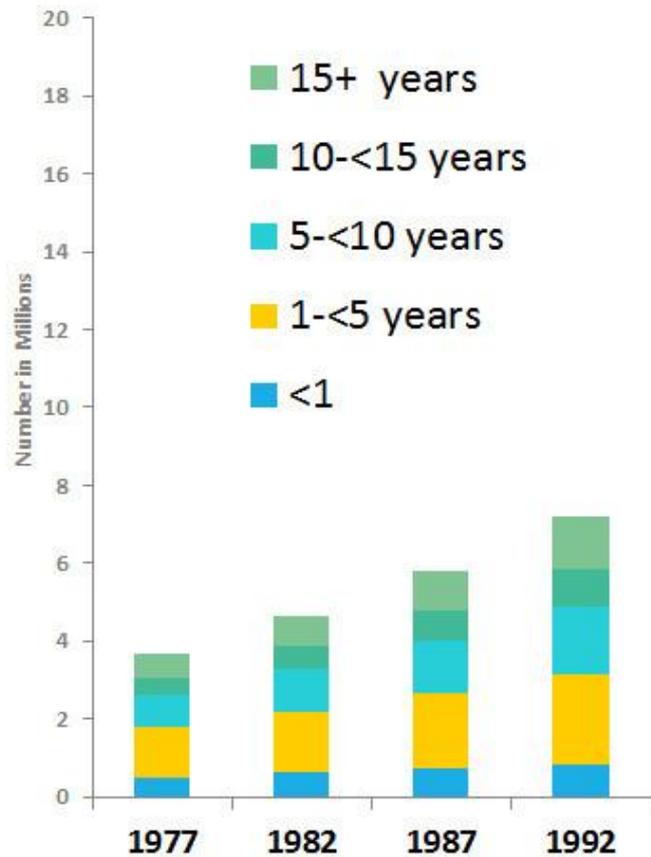
National Cancer Act of 1971



Overall cancer survival was dismal

Cancer survivors were defined as the families of cancer patients

Estimated Number of Cancer Survivors in the US



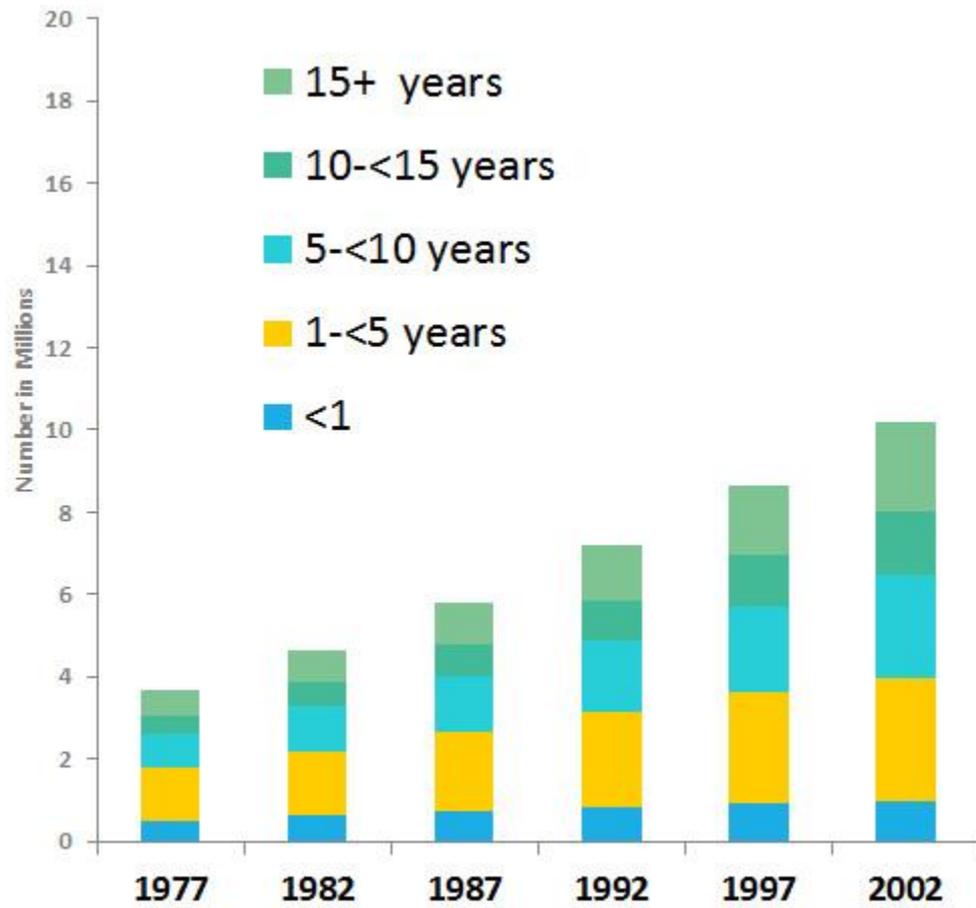
Source: de Moor et al, *CEBP* 2013

Seminal Event: NCCS Established (1986)

- *“Anyone diagnosed with cancer is a survivor - from the time of diagnosis to the end of life. Caregivers and family members are also cancer survivors.”*

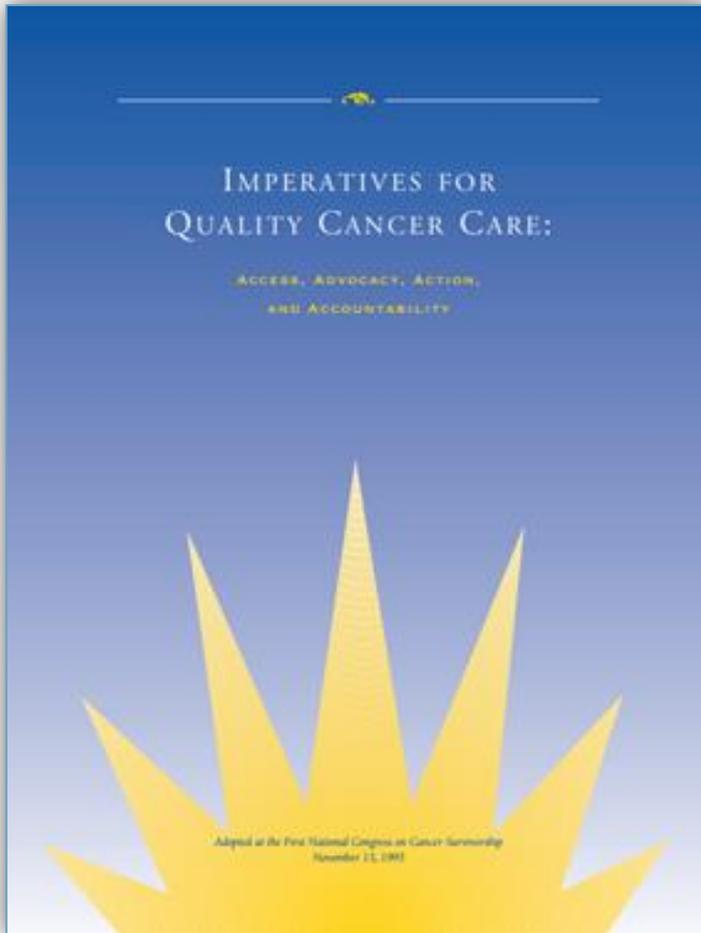


Estimated Number of Cancer Survivors in the US



Source: de Moor et al, *CEBP* 2013

Seminal Event: Office of Cancer Survivorship



NCI Office of Cancer Survivorship (OCS) established in 1996

Defined quality cancer care from the patient's perspective

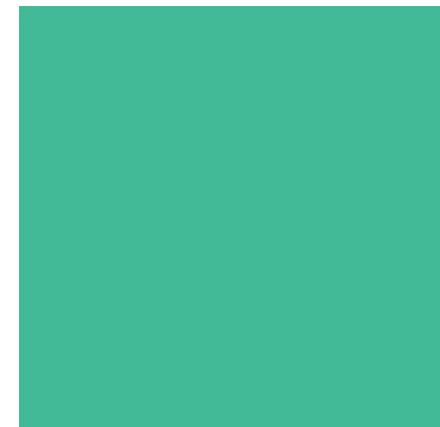
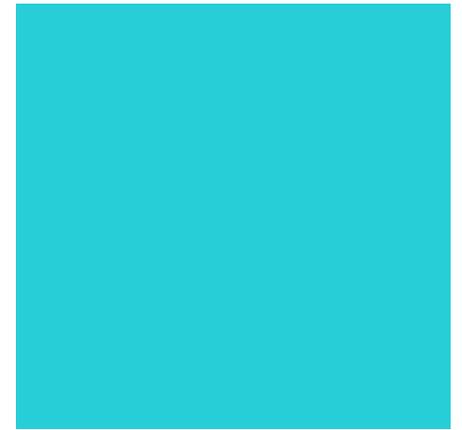


From WMSG to IWWMF

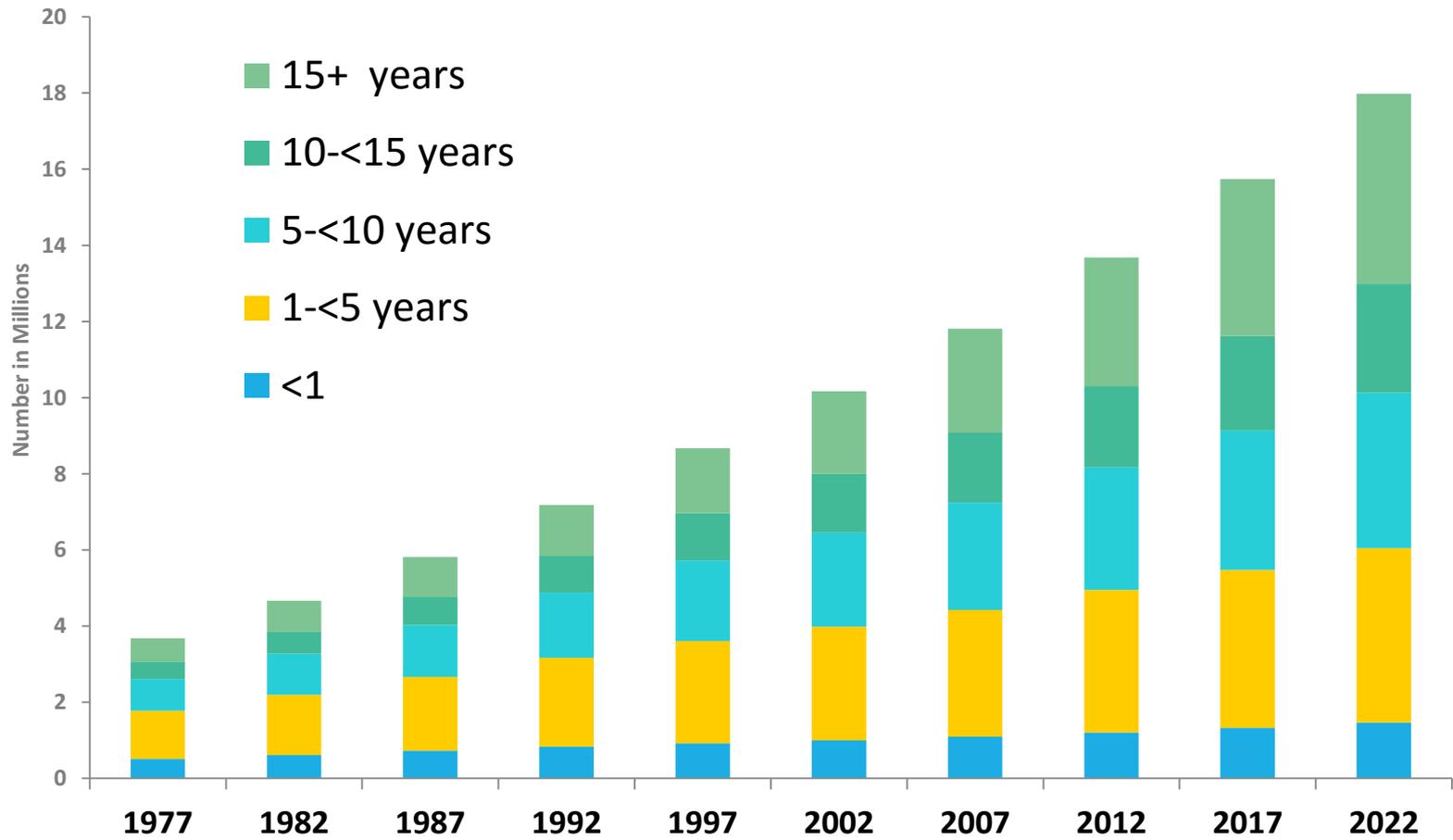
Founded in 1994 by Arnold Smokler

*WMSG began with
21 survivors*

*995 newsletter sent to 125 survivors;
website started
1996 first WMSG conference*

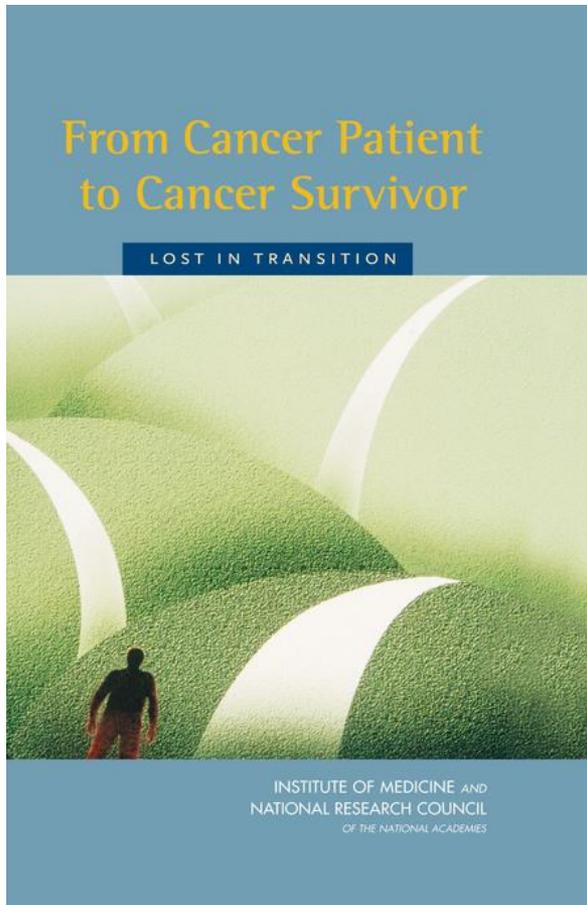


Projected Number of Cancer Survivors in the US



Source: de Moor et al, *CEBP* 2013

Seminal Event: IOM Report (2005)



- Raise awareness of the needs of cancer survivors
- Provide comprehensive care summary and follow up plan – The Survivorship Care Plan
- Use evidence-based clinical practice guidelines
- Test models of coordinated interdisciplinary care
- Support CDC and other initiatives in developing comprehensive cancer control
- Provide educational opportunities to equip providers to address health and QoL among survivors
- Minimize effects of cancer on employment

IWMF Today



- Provides support to patients and their caregivers
- Enables patients to communicate with one another
- Sponsors WM educational forums featuring prominent physicians and researchers
- Publishes booklets on WM and its treatment
- Supports research aimed at ultimately finding a cure for WM
- Invested over \$8.1 million dollars in research since 1999.

IWMF Progress



- Increase in research proposals from Strategic Research Roadmap Initiative
 - Stronger research collaboration
- IWMF Booklet on Treatment Options based on Consensus Panel outcomes
- International research collaboration and international workshops

Common & Rare Cancers: What's the Difference?

Lung, breast, prostate & colorectal cancers

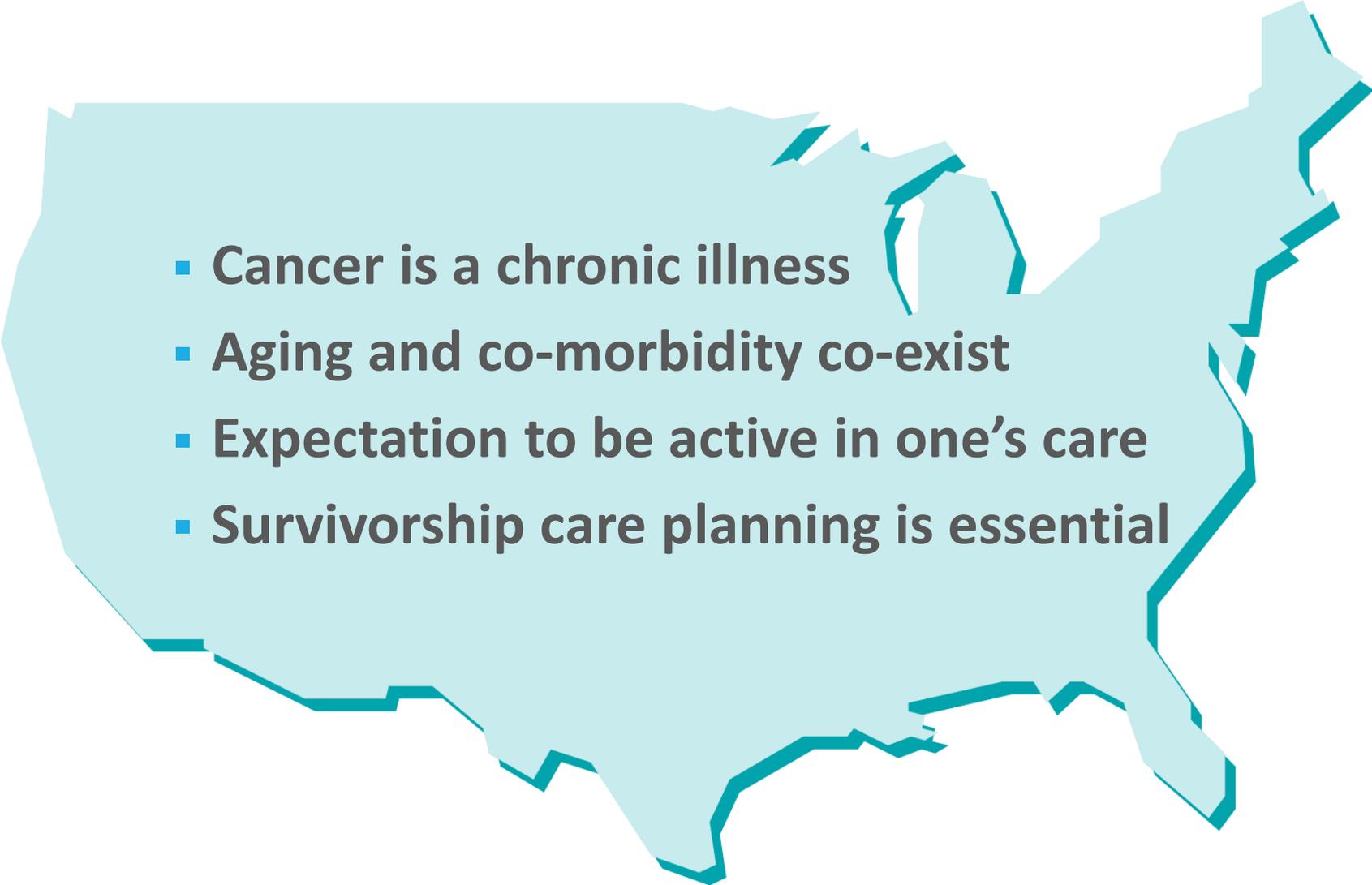
- 50% of all cancers
- Variable growth
- Manage as a chronic disease

WM is a rare disease

- 1,500 individuals diagnosed each year
- Generally slow growing
- Managed as a chronic disease
- Not yet curable



The Changing Demographics of Cancer Survivorship (Rowland, 2015)

- 
- **Cancer is a chronic illness**
 - **Aging and co-morbidity co-exist**
 - **Expectation to be active in one's care**
 - **Survivorship care planning is essential**

Cancer Survivors at Increased Risk for Late Effects

(Rowland, 2015)

Disease recurrence/ new cancers

Cardiovascular disease

Obesity and Diabetes

Functional Decline

Poor quality of life

Changes in Quality of Life (Ferrell & Hassey-Dow, 1999)

Physical: pain, fatigue, memory and attention problems, chemobrain, sexual dysfunction

Psychological: depression, anxiety, uncertainty, isolation

Social: changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, financial burden

Existential and Spiritual: sense of purpose or meaning, appreciation of life



General Tips on Survivorship

- How to approach life after diagnosis and treatment
- Survivorship care plan is essential
- Living with after-effects of treatment
- Nutrition and physical activity recommendations
- To tell or not to tell others about your disease
- Diagnosis at young age versus old age
- Living with threat of relapse
- Dealing with relapse
- Vigilance tips

Survivorship care planning

(NCCN version 2016)

What to expect from your team

Planning for life after cancer
treatment

- Written summary of cancer treatment
- Written summary of intermediate and long-term effects of treatment
- Who you will see in follow up after treatment ends (oncologist and/or primary care provider)
- What is my follow up schedule?
- What tests and procedures will I have?
- Why do I need the tests and procedures?
- How much will these tests and procedures costs?
- What should I be on the look out for?
- What usual psychosocial and physical effects should I expect?
- What can I do to help me get better after cancer treatment?

- Maintain a healthy weight for the rest of your life
- Get physical activity regularly throughout the week
- If you smoke, stop smoking. If you don't smoke, don't start

Nutrition Guidelines for Cancer Survivors



(Rock, et al. 2012)

- **Achieve and maintain a healthy weight throughout life**
 - Be as lean as possible without being overweight
 - Avoid excess weight gain at all ages
 - If you are overweight or obese, even a small amount of weight loss has health benefits
 - Limit consumption of high calorie foods and beverages
- **Consume a healthy diet with emphasis on plant foods**
 - Eat at least 2.5 cups of vegetables and fruits each day
 - Limit consumption of processed meat and red meat
 - Choose foods and beverages in amounts that help achieve and maintain a healthy weight



Quotes from our Survivors



"I know I am obese. My Wii Fit tells me every time I step on it."



"Every time I drink a Pepsi Cola I hear you say that water would be better for me."



"Because of your suggestions, I now read labels. All yogurts are not the same."



"I changed my dinner plates to smaller plates so that the portions I serve my family are smaller."

ACS Physical Activity Guidelines (Rock, 2012)

■ Weekly Activity

- ≥ 150 minutes of **moderate** intensity
- ≥ 75 minutes of **vigorous** intensity activity each week
- or a **combination** of moderate and vigorous activity
- Take the stairs, ride a bike, wear a pedometer, walk the dog, get a workout buddy



■ Limit sedentary behavior such as:

- sitting, lying down, watching TV, and other forms of screen-based entertainment.

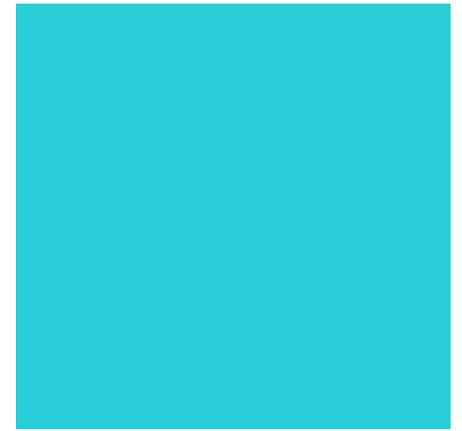
Smoking Cessation

Stop smoking

Don't start smoking

- Health benefits to smoking cessation regardless of cancer stage or prognosis
- Improvement in cancer treatment outcomes
- Reduced risk of disease recurrence and secondary cancers
- It is never too late to stop smoking cigarettes

- **Recommended treatment:**
 - Evidence-based pharmacotherapy (NRT)
 - Behavior therapy counseling
 - Close follow-up with retreatment



Distress, Anxiety,
and Depression

Distress after Cancer Treatment

- Distress, anxiety, depression, and fear of recurrence are common emotions after treatment and for a period of time during survivorship
- Fear of recurrence is most often increased when you have follow up appointments and/or testing procedures
- Recurrent worry, fear, repetitive thoughts are to be expected.

In the past two weeks, have you?

- Had worries or fears related to your cancer?
- Felt nervous or worried about other things?
- Had trouble controlling your worry?
- Had difficulty with your usual daily activities?
- Had trouble sleeping? Staying asleep? Falling asleep? Too much sleep?
- Had less interest or enjoyment in activities than usual?
- Felt sad or depressed?
- Difficulty concentrating?



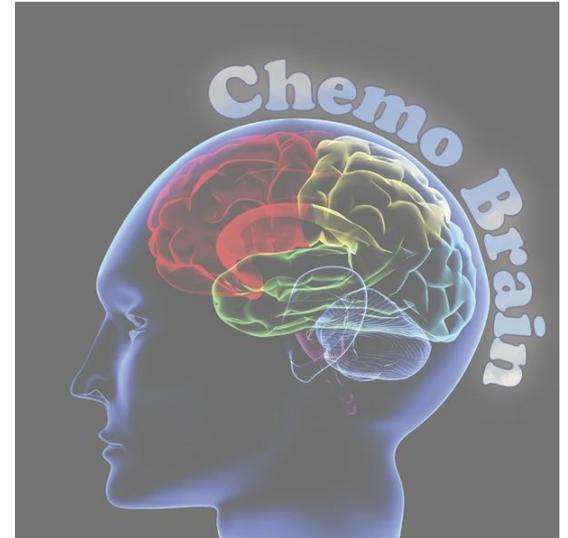
Cognitive Function after Cancer (NCCN 2016)

- Growing evidence supporting patient-reported experience
- Patients benefit from validation of their symptoms
- Modest association between patient report and objective neurologic testing and imaging
- Imaging studies are not generally indicated
- Screen for potentially reversible factors such as depression, sleep disturbance and fatigue
- No screening tools are available
- Limited evidence to guide management for cancers other than breast

Chemobrain or Chemo-Fog (Harrington 2010; Player 2014)

Changes in:

- Memory: *Do you have difficulties with remembering things?*
- Attention/concentration: *Do you have difficulties with multitasking or paying attention?*
- Language (word finding, articulation): *Does your thinking seem slow?*



Symptoms may range from annoying to deeply troubling

Changes in Memory

(Von Ah et al., 2011)

- Most common complaint among those who work
- Changes in remembering and using information
 - Misplacing items: *'Where are my keys?'*
 - Forgetting appointments : *' Do I have a hair appointment today?'*
 - Difficulty retaining new information: *'What's her name again?'*
 - Difficulty remembering why: *'Why did I come here?'*

Changes in Attention & Concentration

(Vecera & Rizzo, 2004)

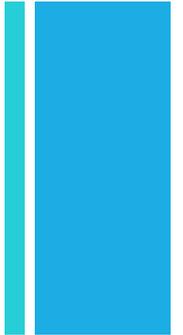
- Ability to focus while ignoring other aspects of environment
- Affects functioning at work, home, and community

Difficulty with:

- paying bills
- multitasking
- concentrating
- driving: 'Did I see a stop sign?'



Relaxation and Stress Reduction



- Prayer
- Meditation
- Relaxation
- Yoga
- Socialize
- Join a support group
- Laugh a lot



Economic Hardship (Financial Toxicity)



“My COBRA ends next month. How can I have my 6 month mammogram?”



“I will buy my breast cancer pills even if it means I won't eat.”



“I can't afford over the counter vitamins or other tests like a bone density.”



“I didn't know I needed a pelvic exam. I haven't had one since I went through menopause.”

Diagnosis at a Young Age: Breast Cancer Survivors



YBCSN
YOUNG BREAST CANCER
SURVIVORSHIP NETWORK
Initiative in the UAB School of Nursing



YBCSN

YOUNG BREAST CANCER SURVIVORSHIP NETWORK

Initiative in the UAB School of Nursing

EDUCATE

- Annual Workshop
- One-on-One education
- Monthly Lunch & Learn
- Website: Tip Sheets

SUPPORT

- One-on-One support
- Referrals to partners
- Monthly Lunch & Learn
- Website: Blog
- Social media: Facebook

NETWORK

- Identify services
- Engage partners (referrals)
- Website
- Annual Workshop

NETWORK & PARTNERSHIP

Interprofessional collaborative partnership among health disciplines, advocates and organizations that care for and about young breast cancer survivors

Web Presence and Social Networking



- Vital way to communicate
- Announce programs, partnerships and available resources
- Maintain a family-centered survivorship approach

<http://www.youngsurvivorsbhm.org>

To disclose or not to disclose

- Americans with Disabilities Act (ADA) is a federal law that prohibits discrimination against qualified individuals with disabilities.
- Equal Employment Opportunity Commission enforces employment provisions of the ADA.

- **Cancer survivors:**
 - Do not need to voluntarily disclose diagnosis
 - May need reasonable accommodations in the workplace
 - May consider safety concerns in the workplace
 - Should never be harassed because of cancer or other disability

Survivorship Resources

- National Coalition for Cancer Survivorship: www.canceradvocacy.org
- American Cancer Society: [www.cancer.org/Survivorship Center](http://www.cancer.org/SurvivorshipCenter)
- American Association for Cancer Research: www.aacr.org
- American Society of Clinical Oncology: www.cancer.net/survivorship
- CDC Survivorship: www.cdc.gov/cancer/survivorship/index.htm
- National Comprehensive Cancer Network: www.nccn.org/
- IWWMF website: <http://iwmf.com>

Questions or Comments?





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