



University of Pittsburgh

Cancer Survivorship:

Management, role of repeated follow-ups, and self-management/rehabilitation

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| <input checked="" type="checkbox"/> | No, nothing to disclose |
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Overview

- Definition of cancer “survivor” & “survivorship”
- Brief history of the movement in survivorship care since 2005
- Key principles/standards of survivorship care
- Current guidelines for survivorship care with a focus on gynecologic cancers
- Progress made in the past 5 years
- Future challenges



Who is a cancer survivor?

**Any patient with a history of cancer
“from the time of its discovery and
for the balance of life”.**

- IOM
- ASCO
- NCCN
- ESGO
- CanCon

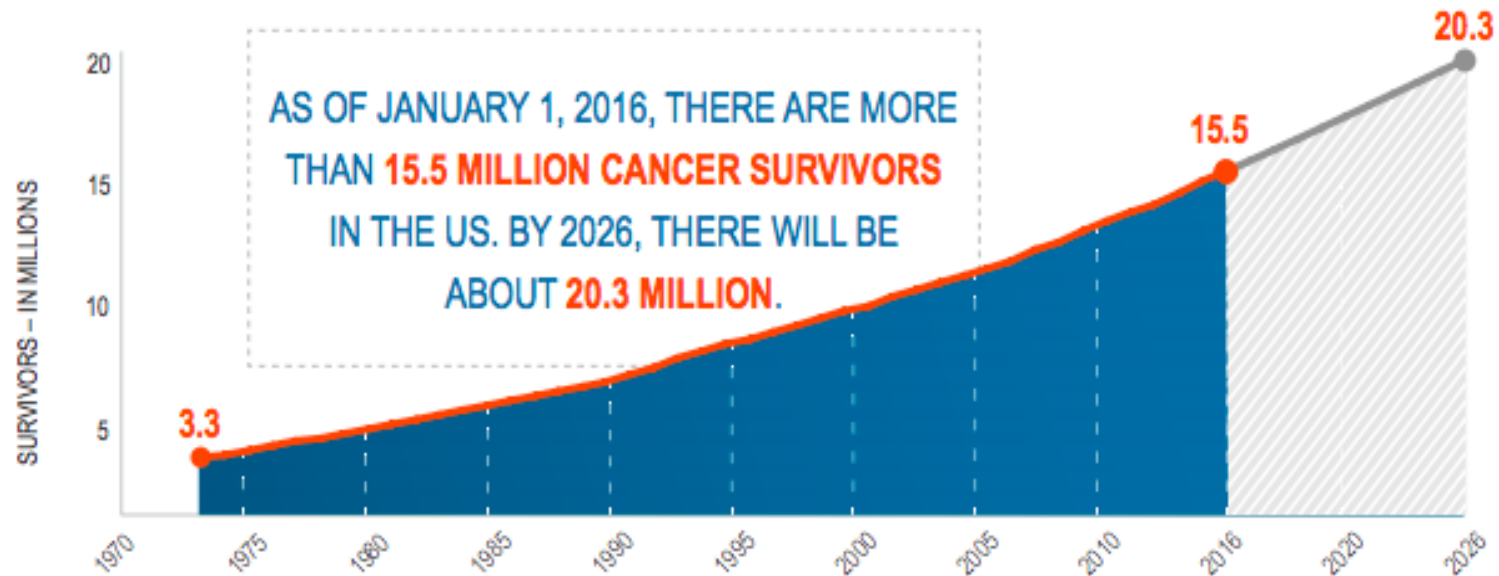


The number of cancer survivors is expanding dramatically

LIFE AFTER CANCER: SURVIVORSHIP BY THE NUMBERS

American Cancer Society // Infographics // 2017

The number of cancer survivors in the United States is increasing, and is expected to grow to about 20.3 million by 2026 according to *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Even though cancer incidence rates are declining in men and stable in women, the number of cancer survivors is rising due to a growing and aging population, as well as earlier detection and better treatments. As this population continues to increase, it will be more important than ever to address this group's unique needs.



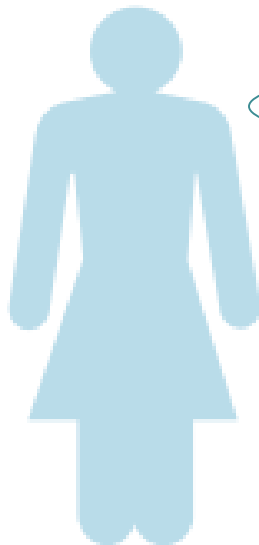


Who are female cancer survivors? (U.S.)

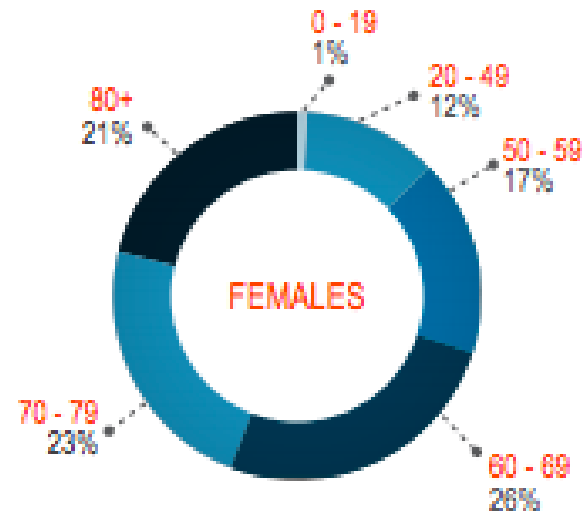
American Cancer Society

FEMALES

January 1, 2016



| | |
|-----------------------|-----------|
| Breast | 3,560,570 |
| Uterine corpus | 757,190 |
| Colon & rectum | 727,350 |
| Thyroid | 630,660 |
| Melanoma | 612,790 |
| Non-Hodgkin lymphoma | 324,890 |
| Lung & bronchus | 288,210 |
| Uterine cervix | 282,780 |
| Ovary | 235,200 |
| Kidney & renal pelvis | 204,040 |
| Total survivors | 8,156,120 |



3 gynecologic cancers are
in top 10 prevalence of
survivors

70% \geq 60 years old



European picture (CanCon 2017)

- 9.17 million in 2012
- Increasing number of survivors due to:
 - Aging population
 - Progress in early diagnosis
 - Effectiveness of therapies
- Disparities in Survival
 - Lower in Eastern countries vs Western and Nordic



Cancer Survivor's Bill of Rights

- Assurance of lifelong medical care
- The right to the pursuit of happiness
- The right to talk with their families and friends about their cancer experience
- The right to freedom from stigma,
- The fight to equal job opportunities
- The right to adequate health insurance

Evidence suggests that these needs are not yet being adequately met

- National Coalition for Cancer Survivorship



WHAT DO WE MEAN BY SURVIVORSHIP?

“Living with, through, and beyond a cancer diagnosis.”

- National Center for Cancer Survivorship 1986



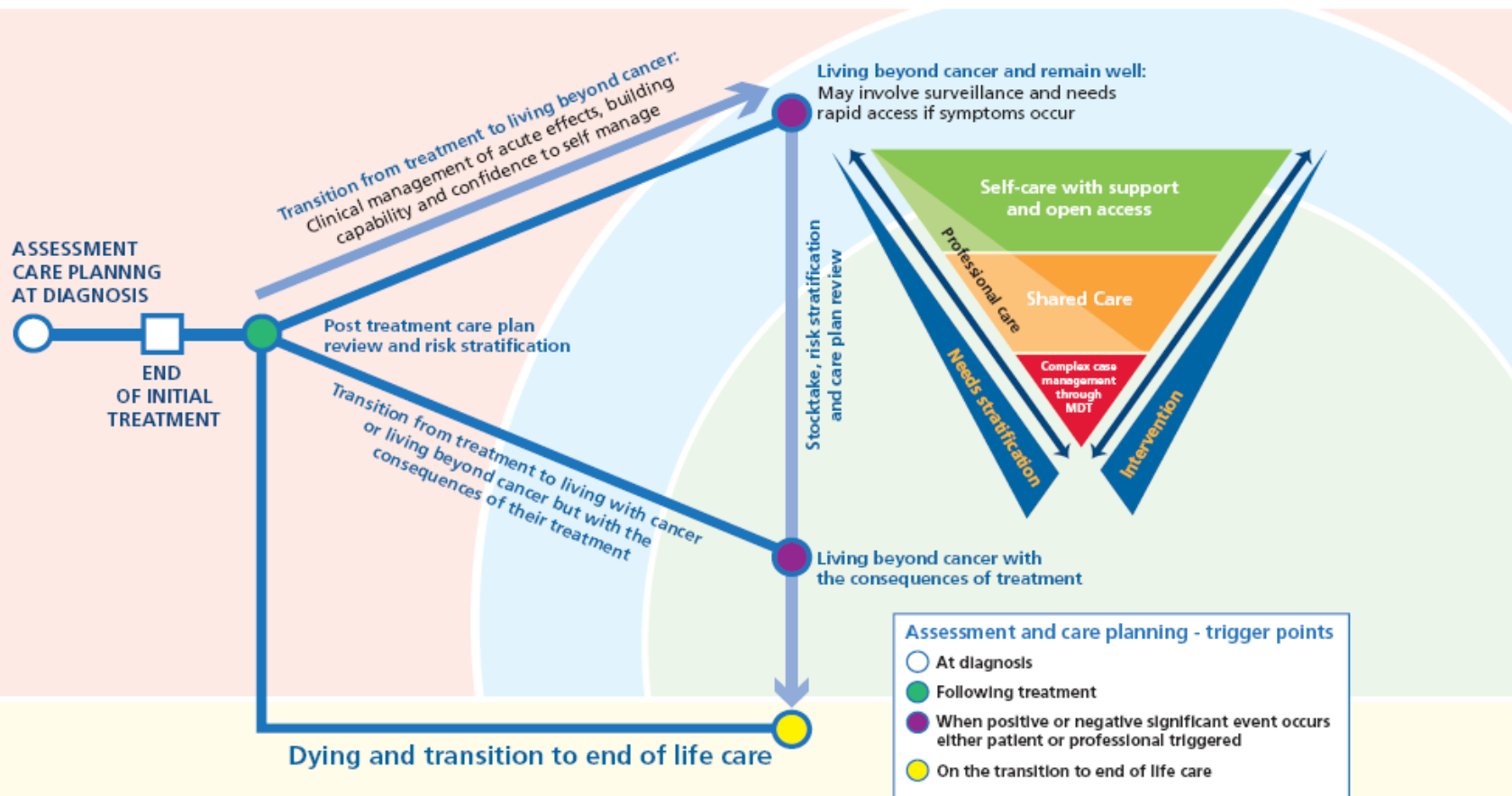
Why is Survivorship Care Important?

- 58% with functional limitations (walking 1/4 mile; standing or sitting for 2 hours)
- Depression/anxiety/PTSD and their consequences
 - Poor social functioning, more disability, functional impairment, sleep problems, fatigue, pain, poor illness monitoring & management, and poor health promotion.
 - “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs” IOM, 2007
- Cancer has a serious impact on income/employment..... And mortality:
 - Two years after the diagnosis, 25.1% of people living with a cancer were below the poverty threshold compared with 14.3% of the general population
 - (data from the French National Institute for Statistics and Economic Studies).
 - Cancer survivors more likely to be in debt (14%) and to file for bankruptcy (3%) than the general population
 - Survivors who file for bankruptcy are almost 2x as likely die compared to non-bankrupt survivors
 - Ramsey et al., JCO 2016



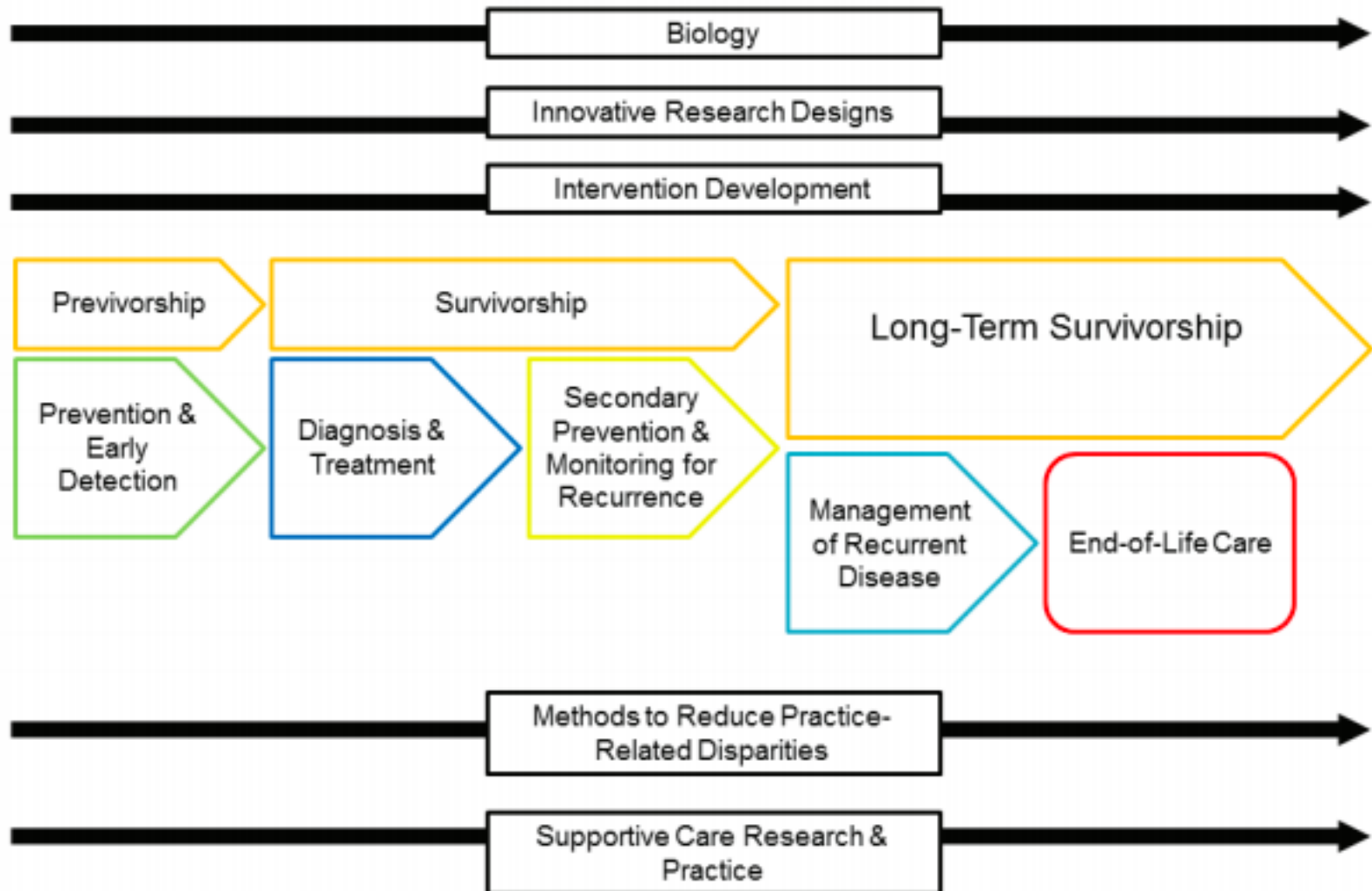
MODELS OF SURVIVORSHIP CARE

Model of Care: Living With and Beyond Cancer





Ovarian Cancers: Evolving Paradigms in Research and Care (NAS, 2016)





KEY PROGRESS IN SURVIVORSHIP CARE

- Initiation of tumor registries
- Development of National/multi-national research cooperatives
- Cancer, psycho-oncology, palliative care, and survivorship associations developed

Europe

United States

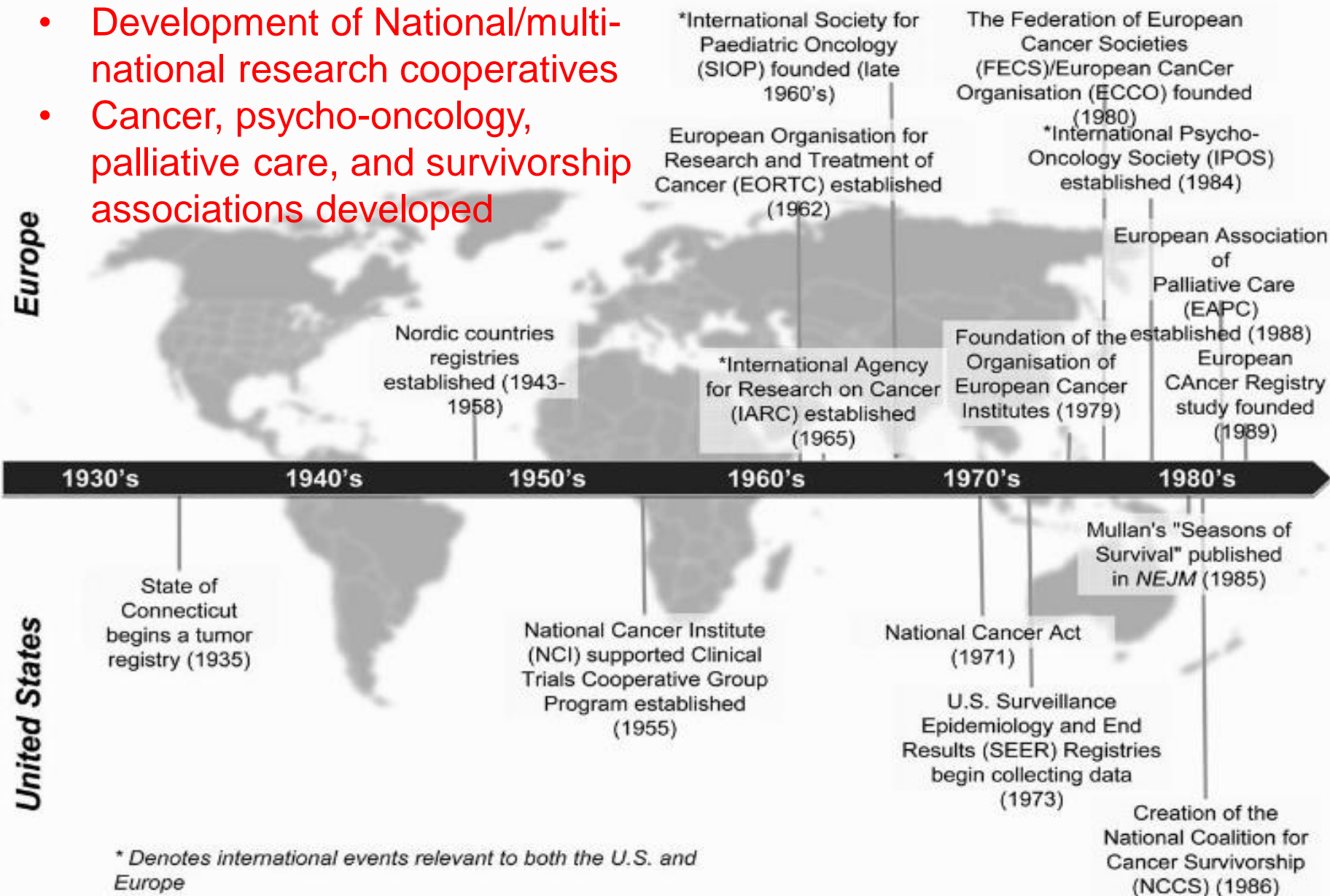


Figure 1. Timeline of important events in the evolution of the field of cancer survivorship.

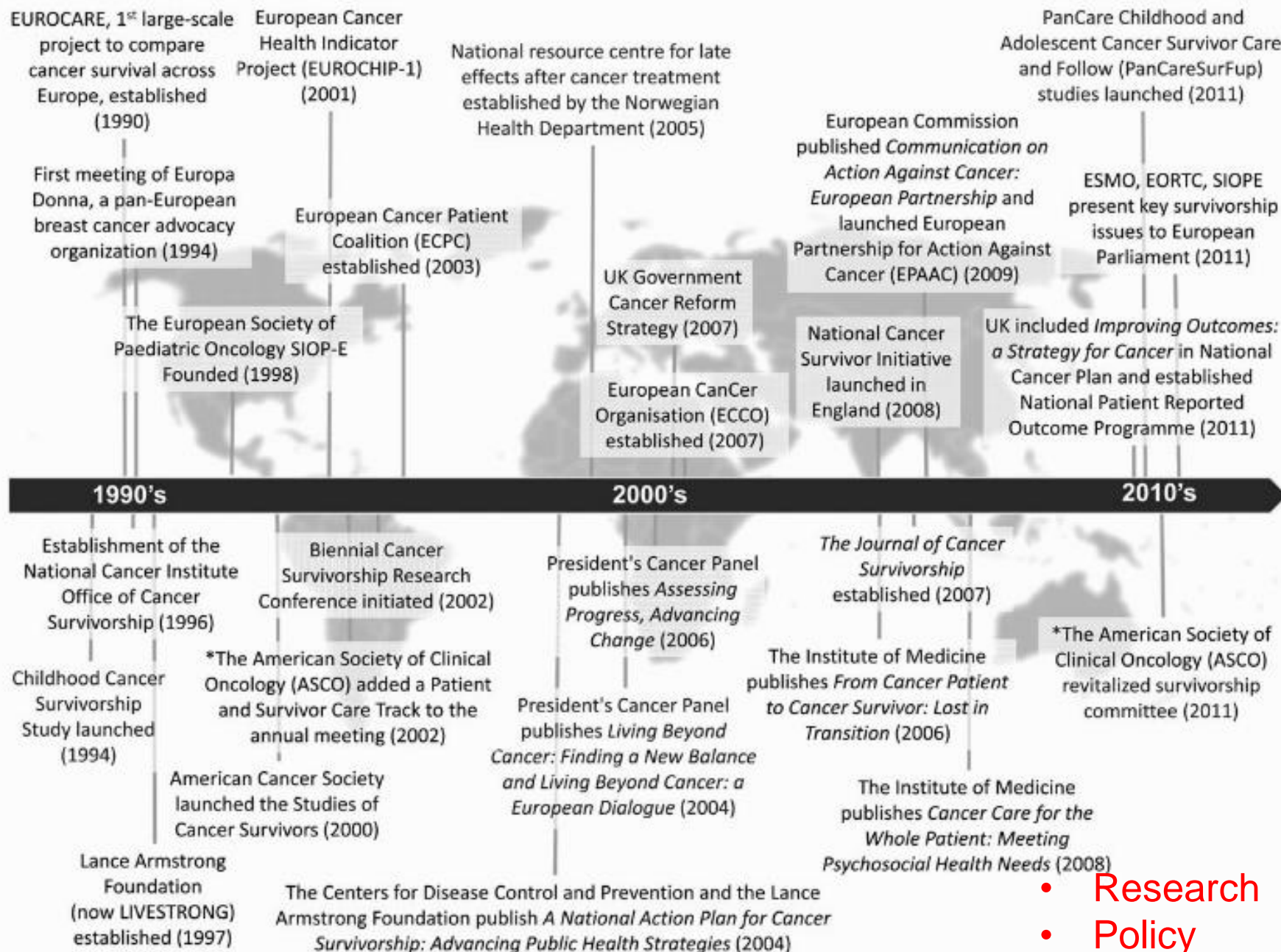


Figure 1. Continued.

- Research
- Policy
- Action Plans



From Cancer Patient to Cancer Survivor: Lost in Transition (IOM, 2006)

- How to optimize survivors' health and maintain QOL after active treatment?
- How to anticipate long-term/late effects of treatment?
- Cancer as a chronic disease? What does that mean?
- Tension between celebration of "completing cancer care" and feelings of isolation/abandonment by trusted providers
- How to support the "Warrior without a war"?



Key IOM Recommendations

1. Recognition of survivorship as a distinct phase of the cancer care continuum.
2. Development and dissemination of survivorship care plans
3. Development of evidence-based guidelines for survivorship care
4. Development of Quality Measures of Survivorship Care & QA programs



5. Creation of demonstration projects to test models of care
6. Development, implementation, & evaluation of comprehensive cancer control plans that include survivorship
7. Provide education to health care providers and survivors
8. Eliminate discrimination & minimize untoward effects of cancer on employment



9. Ensure access to affordable health insurance & reimburse for survivorship care
10. Increase support for survivorship research



Key principles/standards of survivorship care

- Prevention of new and recurrent cancers
- Surveillance for recurrence; screening for 2nd cancers
- Assessment and intervention for late and long-term effects of cancer & treatment
- Coordination of Care
- Survivorship Care Plans



Special Needs: Why is a Survivorship Care Plan Necessary?

- Current method characterized by fragmented care.

By default: cancer survivors are high risk patients, but:

- Too many cancer survivors are lost to follow-up.
- Primary Care Providers lack knowledge regarding guidelines for monitoring for new or recurrent cancers.
- Default is that no one is truly coordinating cancer survivorship plan of care.



Goals of Survivorship Care Planning

- Return cancer patients to as normal a life as possible
- Ensure optimal care
- Focus on patient needs
- Create standards: (What to expect; F/U care; Insurance; Fair employment practices; Hope for healthy future; Communication among HCPs)



Care Plan: Key Components (IOM/ASCO)

Brief summary of cancer diagnosis and treatment

What is recommended for the future? Diagnostic tests? F/U? Special care

Stage; age; date; specific treatments

Late toxicity monitoring

Who is responsible for what

Psychosocial issues

Preventive behaviors and interventions necessary



The Treatment Summary: Essential Components

- Diagnosis (pathology and stage)
- Surgical procedures and dates
- Radiation treatment and dates
- Chemotherapy treatments and dates
- Endocrine therapy and dates
- Other therapies and dates
- Any complications experienced
- Relevant pathology and biomarker data
- Additional planned treatments
- Contact info for key treating physicians

Example of a Survivorship Care Plans (IOM, 2007)

| |
|--|
| <p>Risk of cancer recurrence and second cancer: Patient has high stage cancer with increased risk of recurrence.</p> <p>Patient should report these signs and symptoms if persistent: Blood in stool, abdominal pain, change in bowel habits, cough that doesn't go away, bone pain, new lumps, nausea, vomiting, loss of appetite, weight loss, fatigue</p> <p>Recommended surveillance to detect recurrence/second cancer (specify frequency):</p> <ul style="list-style-type: none">▪ Clinical assessments: Every 3-6 months for the first three years after primary treatment, then every 6 months for years 4 and 5, and subsequently to be determined (ASCO, 2005)▪ Tests: Serum CEA every 3 months for at least 3 years after diagnosis, if the patient is a candidate for surgery or systemic therapy (ASCO, 2005); data not sufficient to recommend other tests such as CBC, LFT's, and stool for occult blood (ASCO, 2005)▪ Imaging: -Annual CT of the chest and abdomen for 3 years after primary therapy (for patients who are at higher risk of recurrence and who could be candidates for surgery with curative intent).▪ Other: -Colonoscopy at 3 years after operative treatment; if results normal, every 5 years thereafter (ASCO, 2005); -Genetic counseling for those who are high risk (colorectal cancer or polyps in a parent, sibling, or child younger than 60 or in two such relatives of any age or colorectal cancer syndromes in family) This patient needs genetic testing due to young age and family history. |
| <p>Potential late effects of treatment (e.g., cardiovascular, skeletal): Surgery: Bowel problems, such as diarrhea, fecal leakage/incontinence, constipation, bowel obstruction, hernia, pain, psychological distress</p> <p>Chemo/Biotherapy: fatigue, peripheral neuropathy</p> <p>Patient should report these signs and symptoms if persistent: Diarrhea, constipation, pain with urination, erectile dysfunction, painful intercourse, infertility, numbness or tingling in hands or feet</p> <p>Recommended surveillance for late effects of treatment(s): monitor for recovery of peripheral neuropathy</p> |
| <p>Preventive care recommendations (e.g., osteoporosis prevention, weight management, smoking cessation, diet): This patient needs counseling about smoking cessation and weight loss.</p> |
| <p>Physician(s) who will monitor recurrence/second cancer, late effects, and preventive care:</p> <p>Dr. Adams will monitor for late effects and preventive care recommendations. Dr. Adams will monitor CEA and do endoscopy and imaging studies at prescribed intervals</p> |



Beyond Treatment Summaries and Medical f/u:

Financial/Social /Employment Worries

- Job loss
- Disability – loss of purpose/identity/social contact
- Obtaining insurance after cancer
 - Insurance coverage drives so many decisions
- Debt – even for the well-insured
- Guilt for the patient



Key guidelines in Survivorship Care released in the past 5 years

- Practice Guidelines
 - 2013 - National Comprehensive Cancer Network (NCCN) guidelines for survivorship care
- Policy Guidelines
 - 2017 – CanCon *European Guide on Quality Improvement in Comprehensive Cancer Control*, including:
 - CanCon WP-8: [Survivorship and rehabilitation](#)



GUIDELINES FOR SURVIVORSHIP CARE WITH A FOCUS ON THE NEEDS OF GYN CANCER SURVIVORS

(NCCN, 2017)



POST-TREATMENT SURVEILLANCE FOR RECURRENT DISEASE

Based on established guidelines for each cancer type



Cervical

- Follow up exam (with Pap)
 - Every 3-6 months for 2 years
 - Every 6-12 months for 3-5 years
- Imaging and labs as needed based on symptoms or exam
- Patient education re:
 - Symptoms of recurrence
 - Health promotion behaviors
 - Sexual health (e.g. dilators)
 - Potential long-term and late effects

Ovarian

- Follow up exam (with pelvic exam and Ca-125)
 - Every 2-4 months for 2 years
 - Every 3-6 months for 3 years
 - Annually after 5 years
- Imaging and labs as needed based on symptoms or exam
- Refer for genetic risk evaluation if not already done
- Patient education re: long-term wellness care



Screening for 2nd cancers

- Based on screening guidelines for cancer prevention in general population
 - » e.g. U.S. Preventive Services Task Force guidelines
<https://www.uspreventiveservicestaskforce.org/>
- Special guidelines for those with known germline mutations (e.g. BRCA; Lynch syndrome)



Assessment at regular intervals

- Ensure Care Coordination
- Weight & Health Behaviors
- Reversible or contributing causes of symptoms
 - Current disease status
 - Functional/performance status
 - Medications
 - Comorbidities
 - Prior cancer treatments
 - Family history
 - Psychosocial factors



MANAGEMENT OF LATE & LONG-TERM PSYCHOSOCIAL AND PHYSICAL PROBLEMS

Focus on those most salient to Gynecologic
Cancers



Anxiety, Depression & Distress

- Routine Screening at regular intervals
 - In the past 2 weeks on more days than not, have you :
 - Had worries or fears related to your cancer?
 - Felt worried or nervous about other things?
 - Had less enjoyment or interest in activities than usual?
 - Felt sad or depressed?
 - Had difficulty performing daily activities because of these feelings?
 - Had trouble sleeping?
 - Had difficulty concentrating?
- Further evaluation and referral for PTSD/Safety if indicated



Anxiety, Depression Distress

- Non-pharmacologic interventions for all survivors:
 - Address treatable contributing factors
 - Sleep, pain, fatigue, comorbidities, substance use
 - Provide reassurance that these feelings are common and can be treated
 - Support and education to survivor and family regarding normal recovery phases after treatment, common worries/stressors and strategies for coping
 - Provide resources for social support networks and specific social, emotional, spiritual, intimacy resources
 - Develop a plan for regular physical activity and health nutrition



Pharmacologic Interventions

- Selective Serotonin Reuptake Inhibitors (SSRI's)
- Serotonin Norepinephrine Reuptake Inhibitors (SNRI's) (if also have pain and/or hot flashes)
- Monitor for side-effects
- Patient education:
 - 2-6 weeks time to take effect
 - Potential for withdrawal if stop suddenly
- Referral to mental health provider if no response to initial treatment



Cognitive Function

COGNITIVE FUNCTION ASSESSMENT

Focused history:

- Focal neurologic deficits
- High risk or known metastatic disease/brain primary
- Onset, temporality
- Age (a risk factor for developing cognitive deficiency)
- Trajectory over time
- Cancer treatment history
- Prescription medications/OTC medications and supplements
- Education attainment
- Caregiver assessment of cognitive function
- Nature of impairments per patient; clarifying questions may include:
 - › Do you have difficulty paying attention? Multitasking?
 - › Do you frequently leave tasks incomplete?
 - › Do you have difficulty finding words?
 - › Do you have difficulty remembering things?
 - › Do you need to use more prompts like notes or reminders than you used to?
 - › Does it take you longer to think through problems; does your thinking seem slower?
 - › Do you notice an impact on functional performance? Job performance?
- Assessment of medical history that may impact cognitive function

Assessment of contributing factors:

- Medications/side effects
- Emotional distress
 - › Depression/anxiety ([See SANXDE-1](#) and [NCCN Guidelines for Distress Management](#))
- Symptom burden
 - › Pain ([See SPAIN-1](#))
 - › Fatigue ([See SFAT-1](#))
 - › Sleep disturbance ([See SSD-1](#))
- Comorbidities
- Use of alcohol and other agents that alter cognition

SPECIALIZED EVALUATION

Neuroimaging

[See Cancer-associated Cognitive Dysfunction Interventions \(SCF-3\)](#)



Cognitive Function Interventions

- Patient/Family Education: validation, reassurance that it is not generally progressive, self-management strategies
- General strategies:
 - Organizational strategies
 - Timing of high-demand tasks with high energy times
 - Relaxation and stress management; yoga; meditation
 - Physical activity
 - Limit use of alcohol
 - Good management of pain, fatigue, sleep, depression, comorbidities



Cognitive Function Interventions-2

- Neuropsychiatric evaluation
- Cognitive Rehabilitation:
 - Occupational Therapy
 - Speech Therapy
 - Neuropsychology
- Physical Activity Program
- Consider psychostimulants



Fatigue

- Routine screening on a 0-10 scale
- Full evaluation for those with moderate to severe fatigue (>4).
 - Goal is to identify treatable, contributing factors:
 - Medication side effects, pain, emotional distress, anemia, sleep problems, nutritional problems, comorbidities



Fatigue Interventions for survivors

- Patient/Family education re:
 - Monitoring of fatigue
 - Energy Conservation:
 - The 4 P's: Planning, Prioritizing, Pacing, Positioning
 - Physical Activity
 - Others:
 - Psychosocial interventions (CBT, expression)
 - Nutrition
 - CBT for sleep
 - Accupuncture
 - Consider psychostimulants after failure of all others



Menopause-related symptoms

- Screening for
 - signs and symptoms of menopause
 - related health risks (osteoporosis, cardiovascular disease)



Treatment of menopausal symptoms

Vasomotor symptoms
(ie, hot flashes/night
sweats) disruptive to
quality of life in females



- Non-hormonal pharmacologic treatments^h
 - › Categories include low-dose antidepressants, anti-convulsants, neuropathic pain relievers, and certain anti-hypertensives
- Non-pharmacologic treatmentsⁱ
 - › Acupuncture
 - › Exercise/physical activity ([See SPA-1](#))
 - › Lifestyle modifications^k ([See HL-1](#))
 - › Weight loss if overweight or obese ([See SNWM-1](#))
 - › Integrative therapies including cognitive behavioral therapy (CBT), yoga, and hypnosis

Vaginal dryness



- Non-hormonal treatments
 - › Vaginal moisturizers, vaginal gels, oils, topical vitamin D or E (category 2B)
 - › Lubricants for sexual activity
- Local estrogen treatmentⁿ (rings, suppositories, creams) (category 2B)
 - › Limited data in breast cancer survivors suggest minimal systemic absorption with rings and suppositories. Therefore, if estrogen based treatment is warranted, rings and suppositories are preferred over creams for survivors of hormonally sensitive tumors.
- Other topical prescriptions (ie, testosterone)
- Consider referral to appropriate specialist for management



Sexual Function

- Screening

BRIEF SEXUAL SYMPTOM CHECKLIST FOR WOMEN¹

Please answer the following questions about your overall sexual function:

1. Are you satisfied with your sexual function?

☐ Yes ☐ No

If no, please continue.

2. How long have you been dissatisfied with your sexual function?

3a. The problem(s) with your sexual function is:
(mark one or more)

☐ 1 Problem with little or no interest in sex

☐ 2 Problem with decreased genital sensation (feeling)

☐ 3 Problem with decreased vaginal lubrication (dryness)

☐ 4 Problem reaching orgasm

☐ 5 Problem with pain during sex

☐ 6 Other:

3b. Which problem is most bothersome? (circle)

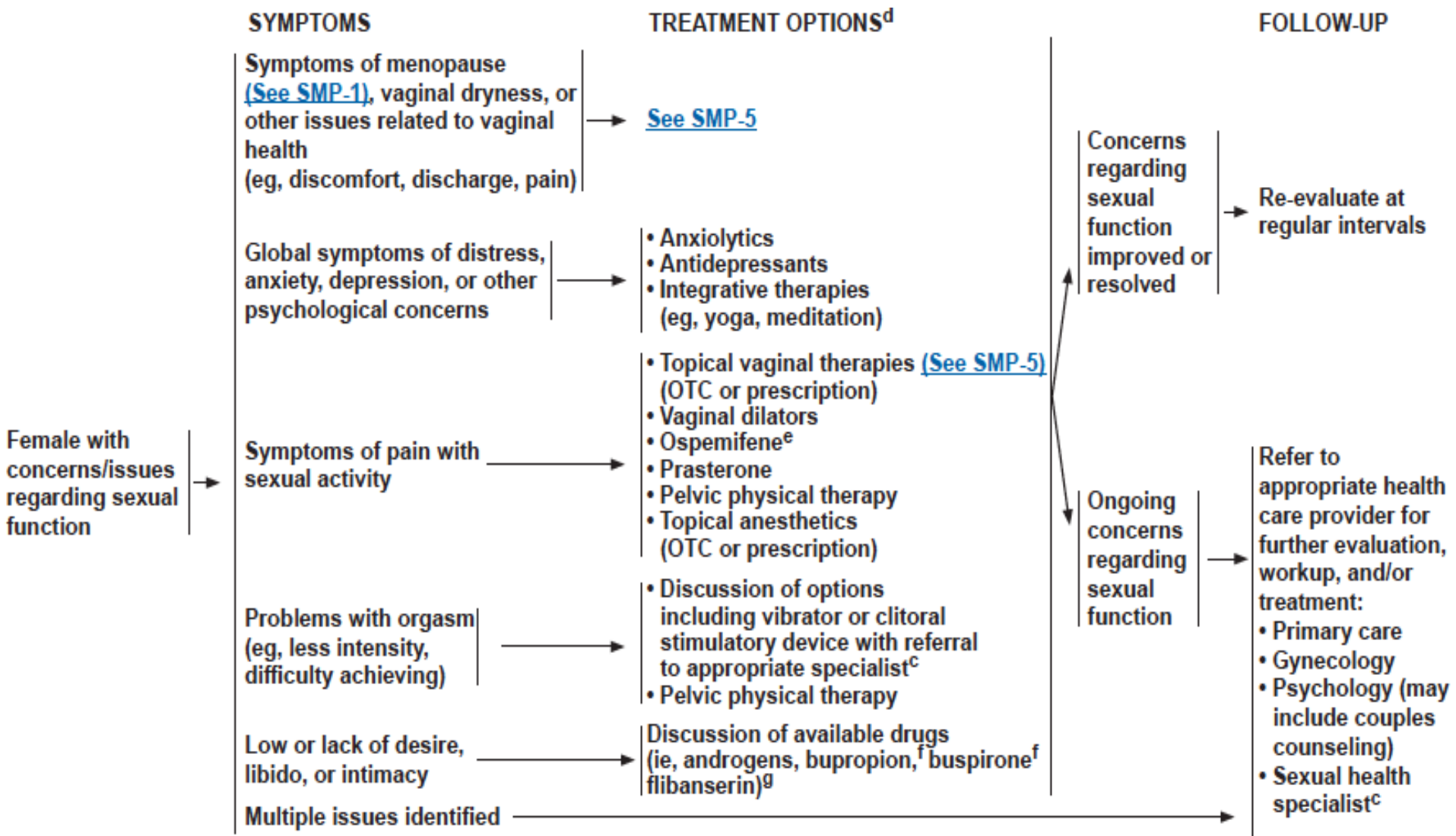
1 2 3 4 5 6

4. Would you like to talk about it with your doctor?

☐ Yes ☐ No



Treatment of Sexual Problems





PREVENTIVE HEALTH

General principles:

- Achieve and maintain a healthy lifestyle: Physical activity, diet, weight
- Health Lifestyles
 - Increase health & QOL
 - May reduce the risk of recurrence and death



Counseling and Support for Health Promotion

- Attain normal BMI
- Develop regular physical activity
- Maintain a healthy diet
- Minimize Alcohol
- Avoid Tobacco
- Sun Safety
- Regular visits to PCP for preventive screenings and immunization
 - Annual flu shot
 - Pneumococcal vaccin
 - Tetanus (TD/TDAP)
 - HPV for those $< \text{ or } = 26$ y.o.
 - Shingles (zoster) for survivors >60 who are not immunocompromised



LOOKING FORWARD



Overarching Needs Going Forward

- Disparities
- Education to all
- Symptom care plans as a tool; not an end in itself
- Coordinate care
- Risk stratified approach



European perspective: CanCon's 2017 Guide Survivorship & Rehabilitation (Ch. 7)

Main messages/challenges going forward:

1. Survivorship needs must be **anticipated**, **personalized** and **implemented** into care pathways, with **active participation** of survivors and relatives.
2. Requires improvement of:
 1. **early detection** of patients' needs
 2. survivor **access to rehabilitation, psychosocial and palliative care services** is required
 3. integrated and **multiprofessional** care approach with a **coordination of community care providers** and services to implement a **survivorship care plan** that enhances patient's **self-management** and quality of life.



CanCon Survivorship & Rehabilitation (cont'd)

4. For children, adolescents and young adults survivors, **late health and psychosocial effects** of cancer and its treatments need to be anticipated and addressed.
5. **More research** in the area of survivorship is needed to provide data on late effects, as well as the **impact and cost-effectiveness** of supportive care, rehabilitation, palliative and psychosocial care intervention



US Perspective on Future challenges (NCI)

- Aging populations
- Ethnic diversity
- Better tailored & coordinated care to decrease preventable morbidity and mortality
- Personalized risk analysis (e.g. omics) to ID host factors that put some individuals at greater risk and r/t specific treatments
- Implementation of best practices into a wide range of real-world settings (under-served, low resource)



- Evaluate effects of various state/country control plans; share progress among state/countries
 - Need for increased focus on financial toxicity & impact of cancer on employment – especially among young survivors
 - Ensure a focus on equitable access to affordable survivorship care
 - Work to preserve funding stream for survivorship research
-
- Rowland et al; Beyond Lost in Transition, JCO 2017



NCCN Resources for Providers



National
Comprehensive
Cancer
Network®

NCCN Guidelines Version 2.2017 Survivorship

[NCCN Guidelines Index](#)
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[Discussion](#)

SURVIVORSHIP RESOURCES FOR HEALTH CARE PROFESSIONALS AND PATIENTS*

| General Online Information | |
|--|---|
| National Coalition for Cancer Survivorship (NCCS) | http://www.canceradvocacy.org/ |
| American Association for Cancer Research (AACR) • A six-part podcast series about survivorship in partnership with CR Magazine and The Wellness Community: | http://www.aacr.org/ http://www.crmagazine.org/archive/CRpodcasts/Pages/SurvivingThriving.aspx |
| American Cancer Society (ACS) • Survivorship information • Cancer Survivors Network • National Cancer Survivorship Resource Center • Physical Side Effects information, including sexual function | http://www.cancer.org/index http://www.cancer.org/treatment/survivorshipduringandaftertreatment/index http://csn.cancer.org/ http://www.cancer.org/SurvivorshipCenter http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/index |
| American Institute for Cancer Research (AICR): Survivorship information • Survivorship information • Nutrition, physical activity, weight management | http://www.aicr.org/patients-survivors/after-cancer-treatment.html |
| American Society of Clinical Oncology (ASCO) • Survivorship information for patients • Tools and resources for oncology providers | http://www.cancer.net/survivorship https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-compendium |
| Cancer Care: Free, professional support services for anyone affected by cancer | www.cancercare.org |
| Centers for Disease Control and Prevention: Survivorship information | http://www.cdc.gov/cancer/survivorship/index.htm |
| Leukemia & Lymphoma Society: Survivorship information | http://www.lls.org/diseaseinformation/managingyourcancer/survivorship/ |
| LIVESTRONG | http://www.livestrong.org/ |
| National Cancer Institute: Cancer Survivorship Research • Facing Forward series, designed to educate cancer survivors, family members, and health care providers about the challenges associated with life after cancer treatment | http://survivorship.cancer.gov http://cancercontrol.cancer.gov/ocs/resources/ffseries.html |
| National Comprehensive Cancer Network (NCCN) • Life After Cancer: Patient and Caregiver Resources and Information | http://www.nccn.org/index.asp http://www.nccn.org/patients/resources/life_after_cancer/ |
| MedlinePlus: Current accurate information by cancer site | http://www.nlm.nih.gov/medlineplus/cancers.html |
| Oncology Nursing Society: Putting Evidence Into Practice | https://www.ons.org/practice-resources/pep |
| Help Lines | |
| American Cancer Society | 1.800.227.2345 http://www.cancer.org |
| American Psychosocial Oncology Society | 1.866.276.7443 http://apos-society.org/ |
| Cancer Support Community | 1.888.793.9355 http://www.cancersupportcommunity.org/ |
| LIVESTRONG SurvivorCare | 1.855.220.7777 |
| National Cancer Institute's Cancer Information Service | 1.800.4.CANCER |
| National Suicide Prevention Lifeline | 1-800-273-TALK http://suicidepreventionlifeline.org |



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