

# National Cancer Survivorship Resource Center Toolkit

## Provider Tools

Implementing Clinical Practice Guidelines for Cancer Survivorship Care



## INTRODUCTION AND OVERVIEW

More Americans are surviving cancer than ever. As the number of cancer survivors living years beyond their cancer diagnosis has grown, so has the emphasis on enhancing health and quality of life before, during and after cancer treatment. Cancer survivors are at risk for physical, psychosocial and practical impacts from cancer and its treatment, and it is essential that they have comprehensive follow-up care after treatment ends.

This toolkit provides resources to help with implementing the American Cancer Society cancer survivorship care guidelines for colorectal, head and neck and prostate cancers and the American Cancer Society/American Society of Clinical Oncology cancer survivorship care guideline for breast cancer. In addition to the guidelines, information is included on training opportunities for primary care providers and patient materials to help activate cancer survivors to be full participants in their survivorship care.

This toolkit was created to be used by:

- Primary care providers
- Oncology providers
- Comprehensive Cancer Control professionals
- Patient navigators

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pages in a new tab

The goals of this toolkit are to:

- Educate primary and oncology care providers about clinical follow-up care needs of cancer survivors
- Provide tools primary and oncology care providers can implement to help improve care for cancer survivors
- Equip patients with tools to help them discuss their long-term health with providers
- Highlight free continuing education resources for improving survivorship care

The information and free resources provided in this toolkit can be used to enhance practice and help to ensure cancer survivors receive evidence-based follow-up care.

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[bit.ly/NCSRCToolkit](https://bit.ly/NCSRCToolkit)

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## PROJECT STAFF: NATIONAL CANCER SURVIVORSHIP RESOURCE CENTER

- Catherine Alfano, PhD  
*Vice President, Survivorship, American Cancer Society*  
*Co-Principal Investigator/Project Director*
- Nicole Erb, BA  
*Program Manager, American Cancer Society*
- Rachel Spillers Cannady, BS  
*American Cancer Society*
- Patrice Bowles, BBA  
*Program Coordinator, American Cancer Society*
- Kerry Beckman, MPH, CHES  
*Research Analyst, American Cancer Society*
- Mandi Pratt-Chapman, MA  
*Associate Center Director for Patient-Centered Initiatives and Health Equity, GW Cancer Center*  
*Director, GW Cancer Institute*  
*Co-Principal Investigator/Project Director*
- Anne Willis, MA  
*Former Director of Patient-Centered Programs, GW Cancer Institute*
- Shaira Morales  
*Project Manager, GW Cancer Institute*
- Monique Dyson, MS, CHES  
*Project Coordinator, GW Cancer Institute*
- Aubrey Van Kirk Villalobos, MPH, MEd  
*Director, Comprehensive Cancer Control, GW Cancer Institute*
- Allison Harvey, MPH, CHES  
*Senior Manager, Health Care Professional Education, GW Cancer Institute*
- Kelli Vos, MSPH  
*Communications Coordinator, GW Cancer Institute*

## ABOUT THE NATIONAL CANCER SURVIVORSHIP RESOURCE CENTER

The [National Cancer Survivorship Resource Center](#) (The Survivorship Center) is a collaboration between the [American Cancer Society](#), the [George Washington University Cancer Institute](#) and the [Centers for Disease Control and Prevention](#) (CDC), funded through a 5-year cooperative agreement from the CDC. The Survivorship Center's mission is to improve the quality of life of cancer survivors and caregivers and reduce death and disability due to cancer by focusing on the importance of improving functioning and helping survivors achieve optimal health and well-being. The Survivorship Center achieves its mission by:

- Providing evidence-based information, resources, and support to cancer survivors, caregivers, friends, and family;
- Improving the survivorship knowledge and skills of health care professionals, community-based organizations and government organizations; and
- Recommending action to policy- and decision-makers.

The Survivorship Center is focused on:

- Creating [breast](#), [colorectal](#), [head and neck](#) and [prostate](#) cancer survivorship clinical care guidelines for primary care providers.
- Implementing health care provider education and training, such as the [Cancer Survivorship E-Learning Series for Primary Care Providers](#); and a smartphone application for primary care providers to make the cancer survivorship care guidelines available at their fingertips.
- Developing resources, including the [Prescription for Cancer Information](#) for health care providers and [Life After Treatment Guide](#) for cancer survivors.

Learn more about [the Survivorship Center](#) at [cancer.org/survivorshipcenter](http://cancer.org/survivorshipcenter).

## ABOUT THE AMERICAN CANCER SOCIETY

For 100 years, the [American Cancer Society](#) has worked relentlessly to save lives and create a world with less cancer. Together with millions of our supporters worldwide, we help people stay well and get well, find cures and fight back against cancer.

## ABOUT THE GW CANCER INSTITUTE

Created in 2003, the vision of the [GW Cancer Institute](#) is a cancer-free world and health care that is patient-centered, accessible and equitable. The institute's mission is to foster healthy communities, prepared patients, responsive health care professionals and supportive health care systems through applied cancer research, education, advocacy and translation of evidence to practice. In 2015 it became part of the newly established GW Cancer Center.

## ABOUT THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The [CDC](#) works 24/7 saving lives and protecting people from health threats to have a more secure nation. Whether threats are chronic or acute, man-made or natural, human error or deliberate attack, global or domestic, CDC is the U.S. health protection agency. Through the Division of Cancer Prevention and Control, CDC is a national leader in developing, implementing, and promoting public health strategies that ease the cancer burden through primary prevention, early detection, survivor support and end-of-life care.

## ACKNOWLEDGEMENTS AND DISCLAIMERS

Development of this toolkit was made possible by cooperative agreement #5U55DP003054 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not represent the official views of the Centers for Disease Control and Prevention. The views expressed here do not necessarily reflect the official policies of the U.S. Department of Health and Human Services; nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. government.

If you have questions about the National Cancer Survivorship Resource Center, contact [survivorship@cancer.org](mailto:survivorship@cancer.org). For questions about this toolkit or the GW Cancer Institute, contact [gwci@gwu.edu](mailto:gwci@gwu.edu).

# National Cancer Survivorship Resource Center Toolkit

## Provider Tools

### Implementing Clinical Practice Guidelines for Cancer Survivorship Care

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## WHAT PRIMARY CARE PROVIDERS SHOULD KNOW ABOUT CANCER SURVIVORSHIP CARE

- The number of cancer survivors is growing dramatically with the aging of the U.S. baby boomer population.
- Cancer survivors face physical, psychosocial and practical impacts from cancer and its treatment.
- More emphasis is being placed on long-term follow-up care for cancer survivors to improve quality of life and health outcomes.
- Primary care providers play a critical role in clinical follow-up care and should ask for a Survivorship Care Plan from the treating clinician to guide care.
- New Commission on Cancer Accreditation Standards require (1) Survivorship Care Plans (treatment summary + follow-up care plan) be given to and discussed with patients treated with curative intent who are finishing active treatment, and (2) patients to be screened for distress and psychosocial health needs. As a result, these practices are becoming part of the standard of care.
- American Cancer Society Cancer Survivorship Care Guidelines are available to guide the content of Survivorship Care Plans for colorectal, head and neck and prostate cancer survivors. A joint American Cancer Society/American Society of Clinical Oncology Cancer Survivorship Care Guideline is available to guide the content of Survivorship Care Plans for breast cancer survivors. View them at: [www.cancer.org/professionals](http://www.cancer.org/professionals).
- Patients need to be educated about the long-term and late effects of cancer, interventions available to them to prevent or treat these problems, as well as ways to stay as healthy as possible after treatment.
- Training opportunities are available at <http://bit.ly/PCPE-Learning> and <http://tinyurl.com/GWOnlineAcademy>.

## WHAT ONCOLOGISTS SHOULD KNOW ABOUT CANCER SURVIVORSHIP CARE

- New Commission on Cancer Accreditation Standards require (1) Survivorship Care Plans (treatment summary + follow-up care plan) be given to and discussed with patients treated with curative intent who are finishing active treatment, and (2) patients to be screened for distress and psychosocial health needs. As a result, these practices are becoming part of the standard of care.
- American Cancer Society Cancer Survivorship Care Guidelines are available to guide the content of Survivorship Care Plans for colorectal, head and neck and prostate cancer survivors. A joint American Cancer Society/American Society of Clinical Oncology Cancer Survivorship Care Guideline is available to guide the content of Survivorship Care Plans for breast cancer survivors. View them at: [www.cancer.org/professionals](http://www.cancer.org/professionals).
- Primary care providers play a critical role in clinical follow-up care and should be given a Survivorship Care Plan by the treating clinician to guide post-treatment care.
- Patients need to be educated about the long-term and late effects of cancer, interventions available to them to prevent or treat these problems as well as ways to stay as healthy as possible after treatment.
- Training opportunities are available at <http://bit.ly/PCPE-Learning> and <http://tinyurl.com/GWOnlineAcademy>.

## WHAT COMPREHENSIVE CANCER CONTROL PROFESSIONALS SHOULD KNOW ABOUT CANCER SURVIVORSHIP CARE

- Both primary care providers and oncologists need to be educated about the needs of cancer survivors, so they can help make sure post-treatment care is provided and coordinated.
- New Commission on Cancer Accreditation Standards require (1) Survivorship Care Plans (treatment summary + follow-up care plan) be given to and discussed with patients treated with curative intent who are finishing active treatment, and (2) patients to be screened for distress and psychosocial health needs. As a result, these practices are becoming part of the standard of care.
- American Cancer Society Cancer Survivorship Care Guidelines are available to guide the content of Survivorship Care Plans for prostate, colorectal and head and neck cancer survivors. A joint American Cancer Society/American Society of Clinical Oncology Guideline is available to guide the content of Survivorship Care Plans for breast cancer survivors. View them at: [www.cancer.org/professionals](http://www.cancer.org/professionals).
- Patients need to be educated about the long-term and late effects of cancer, interventions available to them to prevent or treat these problems as well as ways to stay as healthy as possible after treatment.
- Comprehensive Cancer Control programs play a critical role in providing information to key stakeholders, including clinicians and patients.
- Training opportunities are available at <http://bit.ly/PCPE-Learning> and <http://tinyurl.com/GWOnlineAcademy>.



# GENERAL CANCER SURVIVORSHIP CARE COMPONENTS

## SURVEILLANCE AND SCREENING

- Check for early local or regional cancer recurrence.
- Detect recurrence or second primary cancers early.
- For average-risk, asymptomatic individuals, follow American Cancer Society guidelines for breast, cervical, colorectal, endometrial, lung and prostate cancer screening.

## ASSESSMENT AND MANAGEMENT OF PHYSICAL AND PSYCHOSOCIAL IMPACTS

- Follow tumor-specific guidelines whenever possible, including breast-, colorectal-, head and neck- and prostate-specific American Cancer Society Survivorship Care Guidelines.
- Assessment and management of physical and psychosocial impacts is a critical function of follow-up care.
- For most cancers, limited evidence is available on the impacts and their management.
- Use American Society of Clinical Oncology and National Comprehensive Cancer Network symptom-based guidelines.

## CARE COORDINATION

- Primary care providers and the oncology team should maintain communication throughout diagnosis, treatment and post-treatment care to help ensure care is evidence-based and well-coordinated.
- Primary care providers should consult with the cancer treatment team and request a treatment summary and survivorship care plan.
- Coordinate care with other medical specialists to address physical effects. Refer survivors to behavioral specialists to address psychosocial issues (e.g., cognitive dysfunction, depression, fear of recurrence, body image and sexual dysfunction).
- Refer survivors to prehabilitation and rehabilitation specialists as needed to address issues (e.g., lingering fatigue).
- Periodically update the survivor's family history; new breast or colorectal cancers in the family might make the survivor a candidate for cancer genetic testing.
- Encourage the inclusion of caregivers, spouses or partners in usual cancer survivorship care and support.
- Refer survivors to appropriate community-based and peer support resources.

## HEALTH PROMOTION

- Follow the American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Survivors, including:
  - Counsel survivors to achieve and maintain a healthy weight. Weight management is considered a priority standard of care.
  - Counsel survivors to avoid inactivity and engage in regular physical activity (minimum 150 minutes/week + strength training minimum 2 days/week). Physical activity significantly improves quality of life, physical functioning, peak oxygen consumption and reduces symptoms of fatigue.
  - Counsel survivors to achieve a diet that is high in vegetables, fruits and whole grains.
- Counsel survivors to avoid tobacco products or offer cessation counseling and/or refer survivors to cessation counseling and resources.
- Counsel survivors to avoid or limit alcohol consumption. Limit to no more than 1 drink per day for women and no more than 2 drinks per day for men.

These are the basic components of survivorship care. Care should be customized based on the individual's age, specific diagnosis and treatment protocol.

## BREAST CANCER SURVIVORSHIP CARE: LONG-TERM AND LATE EFFECTS SUMMARY

<b>Long-term Effects</b> Start during treatment and persist	<b>Late Effects</b> Start after treatment ends
<b>Surgery Effects</b>	
<ul style="list-style-type: none"> <li>• Lack of skin sensitivity</li> <li>• Body image issues</li> <li>• Sexual dysfunction</li> <li>• Numbness</li> <li>• Pain</li> <li>• Limited range of motion</li> <li>• Weakness</li> <li>• Poor cosmetic outcome</li> </ul>	<ul style="list-style-type: none"> <li>• Lymphedema</li> <li>• Neuropathy</li> </ul>
<b>Radiation Therapy to the Breast/Chest Wall/Regional Lymph Nodes Effects</b>	
<ul style="list-style-type: none"> <li>• Fatigue<sup>a,b</sup></li> <li>• Skin sensitivity/pain</li> <li>• Sexual dysfunction</li> <li>• Pain</li> <li>• Pneumonitis<sup>a,b</sup></li> <li>• Poor cosmetic outcome</li> <li>• Breast atrophy/asymmetrical breast volume</li> <li>• Lymphedema<sup>a</sup></li> <li>• Numbness or weakness of the upper extremity<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Skin discoloration</li> <li>• Breast may be slightly smaller and firmer than the nonirradiated side (breast asymmetry)</li> <li>• Skin sensitivity/pain</li> <li>• Telangiectasia</li> <li>• Sexual dysfunction</li> <li>• Lymphedema<sup>a</sup></li> <li>• Shortness of breath (lung pneumonitis or fibrosis)<sup>a,b</sup></li> <li>• Cardiovascular disease (e.g., pericardial effusion, pericarditis)<sup>b</sup></li> <li>• Numbness or weakness of the upper extremity<sup>b,c</sup></li> <li>• Second primary cancers (e.g., soft-tissue sarcomas of thorax, shoulder, and pelvis; lung cancer)<sup>a,b</sup></li> </ul>
<b>Chemotherapy Effects</b>	
<ul style="list-style-type: none"> <li>• Cognitive impairment</li> <li>• Fatigue</li> <li>• Ovarian failure with or without menopausal symptoms</li> <li>• Sexual dysfunction</li> <li>• Change in libido</li> <li>• Infertility</li> <li>• Weight gain</li> <li>• Obesity</li> <li>• Neuropathy, especially after taxanes</li> <li>• Oral health issues</li> <li>• Hair loss</li> </ul>	<ul style="list-style-type: none"> <li>• Osteoporosis/osteopenia</li> <li>• Increased risk of cardiovascular disease (cardiomyopathy, congestive heart failure) with anthracycline-based chemotherapy</li> <li>• Increased risk of leukemia and myelodysplastic syndrome with alkylating agents, anthracyclines, other topoisomerase II inhibitors, and other agents with immunosuppressive potential</li> </ul>

<sup>a</sup> Risks are increased in patients who also received radiotherapy to the supraclavicular lymph nodes.

<sup>b</sup> Risks are increased in patients who also received radiotherapy to the internal mammary lymph nodes.

<sup>c</sup> There is a need to be careful, because these can also be signs of recurrent cancer, typically with pain; an appropriate consultation with the radiation oncologist may be warranted.

**Note: This guideline is intended for female breast cancer survivors.**

<b>Long-term Effects</b> Start during treatment and persist	<b>Late Effects</b> Start after treatment ends
<b>Hormonal Therapy Effects</b>	
<b>Tamoxifen</b> <ul style="list-style-type: none"> <li>• Hot flashes</li> <li>• Changes in menstruation</li> <li>• Mood changes</li> <li>• Increased triglycerides</li> </ul>	<ul style="list-style-type: none"> <li>• Increased risk of stroke</li> <li>• Increased risk of endometrial cancer</li> <li>• Increased risk of blood clots</li> <li>• Osteopenia in premenopausal women</li> </ul>
<b>Aromatase Inhibitors</b> <ul style="list-style-type: none"> <li>• Vaginal dryness</li> <li>• Decreased libido</li> <li>• Musculoskeletal symptoms/pain</li> <li>• Cholesterol elevation</li> </ul>	<ul style="list-style-type: none"> <li>• Increased risk of osteoporosis</li> <li>• Increased risk of fractures</li> </ul>
<b>Targeted Therapy Effects</b>	
<b>Trastuzumab</b> <ul style="list-style-type: none"> <li>• Increased risk of cardiac dysfunction</li> </ul>	
<b>General Psychological Long-term and Late Effects</b>	
<ul style="list-style-type: none"> <li>• Depression</li> <li>• Distress—multifactorial unpleasant experience of psychological, social, and/or spiritual nature</li> <li>• Worry, anxiety</li> <li>• Fear of recurrence</li> <li>• Fear of pain</li> <li>• End-of-life concerns: death and dying</li> <li>• Changes in sexual function and/or desire</li> <li>• Challenges with body image</li> <li>• Challenges with self-image</li> <li>• Relationship and other social role difficulties</li> <li>• Return-to-work concerns and financial challenges</li> </ul>	
<b>More Information</b>	
View the American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline at: <a href="http://bit.ly/BrCaCare">http://bit.ly/BrCaCare</a>	

**Note: This guideline is intended for female breast cancer survivors.**



# AMERICAN CANCER SOCIETY/AMERICAN SOCIETY OF CLINICAL ONCOLOGY BREAST CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY

Assessment and Management of Long-term and Late Effects



## SEXUAL FUNCTION AND FERTILITY

- Assess for sexual dysfunction or problems with sexual intimacy including sexual desire disorder (M-H), arousal or lubrication concerns (L-M), dyspareunia (M), orgasm concerns (M), loss of sexual function (U), loss of sexual sensitivity of the skin (U), vaginal dryness (U)
- Assess for reversible contributing factors and treat when appropriate
- Offer nonhormonal, water-based lubricants and moisturizers for vaginal dryness
- Refer for psychoeducational support, group therapy, sexual counseling, marital counseling or intensive psychotherapy when appropriate
- Refer survivors of childbearing age who experience infertility to a specialist in reproductive endocrinology and infertility



## MUSCULOSKELETAL HEALTH

- Assess for musculoskeletal symptoms by asking about symptoms at each encounter
- Ask about:
  - Numbness of upper extremity/limb (M-H)
  - Musculoskeletal pain (L-H)
  - Difficulties with ipsilateral upper extremity: decreased/limited range of motion (L-H)
  - Myalgias (M)
  - Arthralgias (M)
  - Weakness of upper extremity/limb (L-M)
  - Axillary web syndrome (U)
  - Difficulties with ipsilateral upper extremity: adhesive capsulitis (U)
  - Difficulties with ipsilateral upper extremity: rotator cuff injury (U)
- Offer one or more of the following interventions based on clinical indication: acupuncture, physical activity, referral for physical therapy or rehabilitation



## BONE HEALTH

- Assess for bone loss, osteoporosis, osteopenia (H)
- Refer postmenopausal survivors for baseline dual-energy x-ray absorptiometry (DEXA) scan
- Refer for repeat DEXA scans every 2 years for women taking an aromatase inhibitor, premenopausal women taking tamoxifen and/or a gonadotropin-releasing hormone (GnRH) agonist and women who have chemotherapy-induced premature menopause



## COGNITIVE FUNCTION

- Ask patients if they are experiencing cognitive difficulties (problems with concentration, executive function and memory; in treatment (H), after treatment (M))
- Assess for reversible contributing factors of cognitive impairment and treat when possible
- Refer patients with signs of cognitive impairment for neurocognitive assessment and rehabilitation, including group cognitive training if available



## PREMATURE MENOPAUSE/HOT FLASHES

- Assess for premature menopause including hot flashes (H), changes in menstruation (U), chemotherapy-related early menopause (U)
- Offer SNRIs, selective serotonin reuptake inhibitors (SSRIs), gabapentin, lifestyle modifications and/or environmental modifications to help mitigate vasomotor symptoms of premature menopause



## BODY IMAGE

- Assess for body image/appearance concerns (M-H) including breast asymmetry and atrophy, hair loss, sexual dysfunction/chemotherapy-related early menopause, loss of breast, obesity, poor cosmetic outcome, scarring and/or lymphedema after surgery, skin changes from radiation, skin discoloration, telangiectasia, weight gain
- Offer adaptive devices and/or surgery when appropriate

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

**Note: This guideline is intended for female breast cancer survivors.**

# AMERICAN CANCER SOCIETY/AMERICAN SOCIETY OF CLINICAL ONCOLOGY BREAST CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)

## Assessment and Management of Long-term and Late Effects



### PAIN AND NEUROPATHY

- Assess for pain and contributing factors (chronic pain (M-H), lack of skin sensitivity (U), skin sensitivity/pain (U)) with a simple pain scale and history of patient's complaint
- Assess for peripheral neuropathy (M) and contributing factors by asking about symptoms
- Offer interventions for pain
- Refer to appropriate specialist depending on etiology of pain once underlying etiology has been determined
- Offer physical activity for neuropathy
- Offer duloxetine for patients with neuropathic pain, numbness and tingling (M)



### LYPHHEDEMA

- Counsel on how to prevent/reduce risk of lymphedema (M), including weight loss for those who are overweight or obese
- Refer patients with clinical symptoms or swelling suggestive of lymphedema to therapist knowledgeable about diagnosis and treatment



### FATIGUE

- Assess for fatigue (M-H)
- Treat any causative factors, including anemia, thyroid dysfunction and cardiac dysfunction
- Offer treatment or referral for factors that may impact fatigue for those who do not have an identifiable cause of fatigue
- Counsel patients to engage in regular physical activity and refer for cognitive behavioral therapy as appropriate



### DISTRESS, DEPRESSION AND ANXIETY

- Assess for distress (U), depression (L-M) and/or anxiety (L-M)
- Conduct probing assessment for patients at higher risk of depression
- Offer in-office counseling, pharmacotherapy and/or refer to appropriate psycho-oncology and mental health resources as clinically indicated if needed



### CARDIOTOXICITY

- Monitor lipid levels and provide cardiovascular monitoring as indicated
- Educate on healthy lifestyle modifications, potential cardiac risk factors and when to report relevant symptoms



### OTHER CONSIDERATIONS

#### More psychosocial effects (U):

- Fear of recurrence
- Fear of pain
- End-of-life concerns: Death and dying
- Changes in sexual function and/or desire
- Challenges with body image
- Challenges with self-image
- Relationship and other social role difficulties
- Return-to-work concerns and financial challenges

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

**Note: This guideline is intended for female breast cancer survivors.**

# AMERICAN CANCER SOCIETY/AMERICAN SOCIETY OF CLINICAL ONCOLOGY BREAST CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)



## SURVEILLANCE AND SCREENING

- H&P every 3-6 months for first 3 years after primary therapy, every 6-12 months for next 2 years and annually thereafter by the treating oncology team
- Refer women who received a unilateral mastectomy for annual mammography on the intact breast and those with lumpectomies for annual mammography of both breasts
- Educate and counsel women about signs and symptoms of local or regional recurrence
- Assess cancer family history and offer genetic counseling if hereditary risk factors are suspected
- Counsel adherence to adjuvant endocrine (antiestrogen) therapy
- Screen for other cancers, as you would the general population
- Provide annual gynecologic assessment for postmenopausal women on selective estrogen receptor modulator therapies



## NOT RECOMMENDED

- Routine screening with MRI of the breast, unless patient meets high risk criteria for increased breast cancer surveillance per ACS guidelines
- Routine laboratory tests or imaging, except mammography if indicated for detection of disease recurrence in absence of symptoms



## HEALTH PROMOTION

- Assess information needs related to breast cancer and its treatment, side effects, other health concerns and available support services and provide or refer to appropriate resources to meet these needs
- Counsel survivors to achieve and maintain a healthy weight; weight management is considered a priority standard of care
- Counsel survivors to engage in regular physical activity including:
  - Aerobic exercise at least 150 minutes per week
  - Strength training exercise at least 2 days per week
- Counsel survivors to achieve a dietary pattern that is high in vegetables, fruits, whole grains, legumes and low in saturated fats
- Assess for tobacco use and offer and/or refer survivors to cessation counseling and resources and counsel survivors to avoid tobacco products
- Counsel survivors to limit alcohol consumption to no more than 1 drink per day for women



## CARE COORDINATION

- Consult with cancer treatment team and request a treatment summary and survivorship care plan
- Maintain communication with the oncology team throughout the patient's diagnosis, treatment and post-treatment care to ensure care is evidence-based and well-coordinated
- Encourage the inclusion of caregivers, spouses or partners in usual breast cancer survivorship care and support

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

**Note: This guideline is intended for female breast cancer survivors.**

View full-text guideline at <http://bit.ly/BrCaCare>

# BREAST CANCER SURVIVORSHIP CARE GUIDELINE CHECKLIST FOR PROVIDERS

Clinical follow-up care provided to breast cancer survivors should be individualized based on age, specific diagnosis and treatment protocol.

## Surveillance

- Individualize clinical follow-up care provided to breast cancer survivors based on age, specific diagnosis and treatment protocol as recommended by oncology team. Make sure patient receives detailed cancer-related history and physical exam every 3-6 months for first 3 years after primary therapy, every 6-12 months for the next 2 years, and annually thereafter by the treating oncology team.
- Refer women who received a unilateral mastectomy for annual mammography on the intact breast and those with lumpectomies for annual mammography of both breasts. Routine screening with MRI of the breast is not recommended unless patient meets high risk criteria for increased breast cancer surveillance as per ACS guidelines.
- Routine laboratory tests or imaging is not recommended, except mammography if indicated, for detection of disease recurrence in absence of symptoms.
- Educate and counsel women about signs and symptoms of local or regional recurrence.
- Assess cancer family history. Offer genetic counseling if hereditary risk factors suspected.
- Counsel patients to adhere to adjuvant endocrine (antiestrogen) therapy.

## Screening for Second Primary Cancers

- [Screen for other cancers](#), as you would the general population. Provide annual gynecologic assessment for postmenopausal women on selective estrogen receptor modulator therapies.

## Assessment and Management of Physical and Psychosocial Long-Term and Late Effects

- Assess for **body image/appearance concerns**. Offer adaptive devices and/or surgery when appropriate. Refer for psychosocial care as indicated.
- Counsel on how to prevent/reduce risk of **lymphedema**, including weight loss for those who are overweight or obese. Refer patients with clinical symptoms or swelling suggestive of lymphedema to therapist knowledgeable about diagnosis and treatment.
- Monitor **lipid levels** and provide cardiovascular monitoring, as indicated. Educate on healthy lifestyle modifications, potential cardiac risk factors, and when to report relevant symptoms.
- Ask patients if they are experiencing **cognitive difficulties**. Assess for reversible contributing factors of cognitive impairment and treat when possible. Refer patients with signs of cognitive impairment for neurocognitive assessment and rehabilitation, including group cognitive training if available.
- Assess for **distress, depression** and/or **anxiety**. Conduct probing assessment for patients at higher risk of depression. Offer in-office counseling, pharmacotherapy and/or refer to appropriate psycho-oncology and mental health resources as clinically indicated.

**Note: This guideline is intended for female breast cancer survivors.**

- Assess for **fatigue** and treat any causative factors, including **anemia**, **thyroid dysfunction** and **cardiac dysfunction**. Offer treatment or referral for factors that may impact fatigue (e.g., mood disorder, sleep disturbance, pain) for those who do not have an identifiable cause of fatigue. Counsel patients to engage in regular physical activity and refer for cognitive behavioral therapy as appropriate.
- Assess for **musculoskeletal symptoms** by asking about symptoms at each encounter. Offer one or more of the following interventions based on clinical indication: acupuncture, physical activity, referral for physical therapy or rehabilitation.
- Assess for **pain** and contributing factors with simple pain scale and comprehensive history of complaint. Offer interventions for pain such as acetaminophen, non-steroidal anti-inflammatory drugs, physical activity, and/or acupuncture. Refer to appropriate specialist, depending on etiology of pain once underlying etiology has been determined. Assess for **peripheral neuropathy** and contributing factors by asking about symptoms. Offer physical activity for neuropathy. Offer duloxetine for patients with neuropathic pain, numbness and tingling.
- Assess for **sexual dysfunction** or problems with sexual intimacy. Assess for reversible contributing factors and treat when appropriate. Offer nonhormonal, water-based lubricants and moisturizers for vaginal dryness. Refer for psychoeducational support, group therapy, sexual counseling, marital counseling or intensive psychotherapy when appropriate.
- Offer serotonin-norepinephrine reuptake inhibitors (SNRIs), selective serotonin reuptake inhibitors (SSRIs), gabapentin, lifestyle modifications and/or environmental modifications to help mitigate **vasomotor symptoms** or **premature menopausal symptoms**.
- Refer postmenopausal survivors for a baseline dual-energy x-ray absorptiometry (DEXA) scan. Refer for repeat DEXA scans every 2 years for women taking an aromatase inhibitor, premenopausal women taking tamoxifen and/or a gonadotropin-releasing hormone (GnRH) agonist and women who have chemotherapy-induced premature menopause.
- Refer survivors of childbearing age who experience **infertility** to a specialist in reproductive endocrinology and infertility as soon as possible.

### Health Promotion

- Assess information needs related to breast cancer and treatment, side effects, other health concerns and available support services. Provide or refer to appropriate resources.
- Counsel to achieve and maintain a healthy weight. Counsel overweight or obese survivors to limit consumption of high-calorie foods and beverages and increase physical activity to promote and maintain weight loss.
- Counsel to engage in regular physical activity consistent with the ACS guideline and specifically: avoid inactivity and return to normal daily activities as soon as possible after diagnosis, aim for at least 150 minutes of moderate or 75 minutes of vigorous aerobic exercise per week and include strength training exercises at least 2 days per week. Strength training should be emphasized for women who are treated with adjuvant chemotherapy or hormone therapy.
- Counsel to achieve a dietary pattern that is high in vegetables, fruits, whole grains and legumes; low in saturated fats; and limited in alcohol consumption.

**Note: This guideline is intended for female breast cancer survivors.**



- Counsel to avoid smoking. Refer survivors who smoke to cessation counseling and resources.

### **Care Coordination/Practice Implications**

- Consult with cancer treatment team and obtain a treatment summary and survivorship care plan.
- Maintain communication with oncology team throughout diagnosis, treatment and post-treatment to ensure care is evidence-based and well-coordinated.
- Encourage the inclusion of caregivers, spouses or partners in usual breast cancer survivorship care and support.

View the American Cancer Society/American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline at: <http://bit.ly/BrCaCare>

**Note: This guideline is intended for female breast cancer survivors.**

## COLORECTAL CANCER SURVIVORSHIP CARE: LONG-TERM AND LATE EFFECTS SUMMARY

<b>Long-term Effects</b> Start during treatment and persist	<b>Late Effects</b> Start after treatment ends
<b>Surgery Effects</b>	
<ul style="list-style-type: none"> <li>• Ostomy care and complications</li> <li>• Urogenital/sexual dysfunction - e.g., erectile dysfunction, dyspareunia, vaginal dryness, incontinence</li> <li>• Frequent and/or urgent bowel movements or loose bowels</li> <li>• Gas and/or bloating</li> <li>• Incisional hernia</li> </ul>	<ul style="list-style-type: none"> <li>• Increased risk of bowel obstruction</li> </ul>
<b>Pelvic Radiation Therapy Effects</b>	
<ul style="list-style-type: none"> <li>• Urogenital dysfunction/sexual dysfunction - e.g., erectile dysfunction, dyspareunia, vaginal dryness, incontinence</li> <li>• Gas</li> <li>• Chronic diarrhea</li> <li>• Rectal ulceration and/or bleeding</li> <li>• Rectal emptying problems/incontinence</li> <li>• Frequent bowel movements</li> <li>• Abdominal pain</li> <li>• Localized skin changes</li> </ul>	<ul style="list-style-type: none"> <li>• Infertility</li> <li>• Bowel obstruction</li> <li>• Bone fracture in sacral region</li> <li>• Second primary cancers in the radiation field</li> </ul>
<b>Chemotherapy Effects</b>	
<ul style="list-style-type: none"> <li>• Peripheral chronic neuropathy</li> <li>• Cognitive function deficits - e.g., confusion, lethargy</li> <li>• Chronic fatigue</li> </ul>	<ul style="list-style-type: none"> <li>• Dental/oral complications</li> </ul>
<b>General Psychological Long-term and Late Effects</b>	
<ul style="list-style-type: none"> <li>• Depression</li> <li>• Distress—multifactorial unpleasant experience of psychological, social and/or spiritual nature</li> <li>• Worry, anxiety</li> <li>• Fear of recurrence</li> <li>• Fear of pain</li> <li>• End-of-life concerns: Death and dying</li> <li>• Changes in sexual function and/or desire</li> <li>• Challenges with body image (secondary to surgery, hormonal therapy)</li> <li>• Challenges with self-image</li> <li>• Relationship and other social role difficulties</li> <li>• Return-to-work concerns and financial challenges</li> </ul>	
<b>More Information</b>	
View the American Cancer Society Colorectal Cancer Survivorship Care Guideline at: <a href="http://bit.ly/acscolorc">http://bit.ly/acscolorc</a>	



# AMERICAN CANCER SOCIETY COLORECTAL CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY

Assessment and Management of Long-term and Late Effects



## SEXUAL FUNCTION AND FERTILITY

- Discuss urogenital dysfunction/sexual dysfunction, dyspareunia (H), vaginal dryness (H), ovarian failure (U), premature menopause (U), gonadotoxicity (U)
- Discuss ejaculatory problems (H), erectile dysfunction (H) and sexual dysfunction (M) with survivors of rectal cancer
- For women with vaginal dryness or dyspareunia recommend vaginal moisturizers and water or silicone-based lubricants during intercourse
- For men with erectile dysfunction, treat with oral phosphodiesterase-5 inhibitors
- Men who receive pelvic radiotherapy or oxaliplatin may be at higher risk for gonadotoxicity (limited evidence)
  - Evaluate for Leydig cell dysfunction
  - Initiate testosterone replacement as indicated
- Monitor and manage sexual dysfunction as needed
- Monitor and refer for psychosocial support for increased distress, depression and anxiety and poorer quality of life
- Higher risk criteria:
  - Women who received pelvic radiotherapy
  - Men who received pelvic radiotherapy or oxaliplatin
  - Female rectal survivors with stoma



## URINARY FUNCTION

- Assess for stress and urge urinary incontinence (H), hematuria (U), dysuria (U), frequency (U) and overflow urinary incontinence (U)
- Recommend Kegel exercises for stress incontinence unless denervation occurred during surgery
- Recommend anticholinergic drugs for stress incontinence
- Recommend antimuscarinic drugs for urge or mixed incontinence
- Patients with hypocontractile bladders may require catheterization
- Refer patients with prolonged urinary retention postoperatively to urologist
- Recommend limiting caffeine and fluid intake and avoiding foods that irritate the bladder such as citrus and tomatoes for irritative symptoms
- Refer patients who received radiation with persistent hematuria to a urologist for cystoscopy to investigate secondary causes

## BOWEL/GI FUNCTION



- Discuss chronic diarrhea (M), frequency and/or urgency of bowel movements (U), loose bowels (U), bowel function and symptoms
- Assess for rectal ulceration (U) and/or bleeding (U), rectal emptying problems/incontinence (U), incisional hernia with complications (U), sphincter dysfunction (U), rectal urgency and frequency (U)
- Refer survivors with persistent rectal symptoms (e.g. bleeding, sphincter dysfunction, rectal urgency and frequency) to the appropriate specialist

## FATIGUE



- Assess for long-term (after 5 years) and short-term (within 5 years) fatigue (M) with validated instrument
- Recommend psychosocial support interventions and/or mind-body interventions
- Recommend 150 minutes of physical activity per week plus strength training per American Cancer Society Nutrition and Physical Activity Guidelines for Cancer Survivors
- Recommend optimizing nutrition per American Cancer Society Nutrition and Physical Activity Guidelines for Cancer Survivors
- For chronic fatigue, refer to rehabilitation

## NEUROPATHY



- Assess for neuropathy (M)
- Focus on prevention: strong evidence for therapy is lacking
- Treat with duloxetine (moderate recommendation)
- No evidence to support tricyclic antidepressants, gabapentin or topical gel containing baclofen, amitriptyline HCL and ketamine, but these therapies have been used for other neuropathic pain conditions
- Refer to rehabilitation and pain management as needed
- Higher risk criteria:
  - Patients who receive a cumulative dose of oxaliplatin > 900mg/m<sup>2</sup>
  - Patients with pre-existing neuropathy, alcoholism and diabetes mellitus

High prevalence ≥50% (H), Mid Prevalence 21-49% (M), Low-Prevalence ≤20% (L), Unknown Prevalence (U)

# AMERICAN CANCER SOCIETY COLORECTAL CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)

## Assessment and Management of Long-term and Late Effects



### COGNITIVE FUNCTION

- Assess for problems with cognitive impairment
- Assess for memory problems (M), decreased executive functioning skills (U), slower processing time or reaction response (U), diminished organizational skills (U), loss of language or math skills (U) and/or difficulty with concentration or attention (U)
- Screen for problems such as depression and anxiety that might worsen cognition and refer for treatment
- Refer patients with a positive screen for formal neurocognitive training



### PAIN

- Assess for chronic proctitis (L) and incisional hernia with complications
- Consider opioid analgesics, utilization of pain management services, if available and incorporation of behavioral interventions/physical activity and/or rehabilitation/physical therapy



### DISTRESS, DEPRESSION AND ANXIETY

- Screen for anxiety (L), depression (M) and distress (U) periodically (at least annually)
- Manage distress/depression using in-office counseling resources, pharmacotherapy or prescribe exercise as appropriate
- If office-based counseling and treatment are insufficient, refer survivors experiencing distress/depression for further evaluation and/or treatment by appropriate specialist
- Higher risk criteria:
  - Those with stoma and those with sexual dysfunction



### DENTAL/ORAL

- Monitor for mucositis (U), loss of taste (U) and dry mouth (U)
- Recommend saliva substitutes or medications to provide symptom relief
- Recommend attention to good oral hygiene (i.e. flossing, brushing with fluoride toothpaste, regular dental care)



### OSTOMY/STOMA

- Assess for urinary retention (L) and urinary incontinence (L)
- Monitor and manage sexual dysfunction as needed
- Monitor and refer for psychosocial support for increased distress, depression and anxiety and poorer quality of life



### OTHER CONSIDERATIONS

- More psychosocial effects (U):
- Fear of recurrence
  - Fear of pain
  - End-of-life concerns: Death and dying
  - Changes in sexual function and/or desire
  - Challenges with body image (secondary to surgery, hormonal therapy)
  - Challenges with self-image
  - Relationship and other social role difficulties
  - Return-to-work concerns and financial challenges

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

# AMERICAN CANCER SOCIETY COLORECTAL CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)



## SURVEILLANCE AND SCREENING

### 1-2 Years Post-Treatment

- H&P every 3-6 months
- CEA every 3-6 months if patient is a potential candidate for further intervention
- Chest/abdominal/pelvic CT every 12 months (stages I-II if at high risk for recurrence and stage III)
- Colonoscopy in year 1; if advanced adenoma, repeat in 1 year, if not, repeat in 3 years

### 3-5 Years Post-Treatment

- H&P every 6 months
- CEA every 6 months if patient is a candidate for further intervention
- Chest/abdominal/pelvic CT every 12 months (stages I-II if at high risk for recurrence and stage III)
- Colonoscopy in year 4; if no advanced adenoma, repeat every 5 years

### 5+ Years Post-Treatment

- Colonoscopy every 5 years starting 9 years after resection if no advanced adenoma



### NOT RECOMMENDED

- PET/CT Scan
- Routine blood tests (e.g. CBC, liver function test)
- After 5 years, routine CEA monitoring
- After 5 years, routine CT scans
- After 5 years, proctoscopy (rectal cancer only)
- Routine use of PET/CT at any stage

### OPTIMAL TIMING UNKNOWN



- Women with known or suspected HNPCC genetic mutation, strong family history of HNPCC or FAP may be at increased risk for endometrial cancer
- Screen survivors for breast, cervical and prostate cancers as average risk according to [ACS screening and early detection guidelines](#)
- Higher risk criteria:
  - Women with known or suspected HNPCC genetic mutation, strong family history of HNPCC or FAP



## HEALTH PROMOTION

- Assess information needs related to colorectal cancer and its treatment, side effects, other health concerns and available support services and provide or refer to appropriate resources to meet these needs
- Counsel survivors to achieve and maintain a healthy weight; weight management is considered a priority standard of care
- Counsel survivors to engage in regular physical activity including:
  - Aerobic exercise at least 150 minutes per week
  - Strength training exercise at least 2 days per week
- Counsel survivors to achieve a dietary pattern that is high in vegetables, fruits and whole grains, low in saturated fats and includes sufficient dietary fiber
- Assess for tobacco use and offer and/or refer survivors to cessation counseling and resources and counsel survivors to avoid tobacco products
- Counsel survivors to limit alcohol consumption to no more than 2 drinks per day for men and 1 drink per day for women
- Refer survivors with chronic bowel problems (U) or surgery that affects normal nutrient absorption to a registered dietitian



## CARE COORDINATION

- Consult with cancer treatment team and request a treatment summary and survivorship care plan
- Coordinate care with other medical specialists to address effects

High prevalence ≥50% (H), Mid Prevalence 21-49% (M), Low-Prevalence ≤20% (L), Unknown Prevalence (U)







View full-text guideline at <http://bit.ly/acscolorc>

## COLORECTAL CANCER (CRC) SURVIVORSHIP CARE GUIDELINE CHECKLIST FOR PROVIDERS

Clinical follow-up care provided to CRC survivors should be individualized based on age, specific diagnosis and treatment protocol.

### Surveillance

- Surveillance colonoscopy according to a risk-based schedule.

	Year 1 & 2	Years 3 to 5	5+ Years
History and Physical	Every 3 to 6 months	Every 6 months	Not Recommended 
Carcinoembryonic Antigen (CEA) Testing	Every 3 to 6 months if patient is a potential candidate for further intervention	Every 6 months if patient is a potential candidate for further intervention	Not Recommended 
Chest/Abdominal/Pelvic CT	Every 12 months in Stages I-II if patient is at high risk of recurrence, and Stage III	Every 12 months in Stages I-II if patient is at high risk for recurrence and Stage III	Not Recommended 
Colonoscopy	<b>In year 1:</b> If advanced adenoma, repeat in 1 year, if not repeat in 3 years	<b>In year 4:</b> If no advanced adenoma, repeat every 5 years	Every 5 years starting 9 years after resection if no advanced adenoma
Proctoscopy (rectal cancer survivors who undergo low anterior resection)	Not Recommended 	Not Recommended 	Not Recommended 

### Screening for Second Primary Cancers

- [Age- and gender-appropriate screening for patients with an average risk](#), except for female CRC survivors with Lynch Syndrome.
- Female CRC survivors with Lynch Syndrome: annual endometrial sampling and transvaginal ultrasound.

### Assessment and Management of Physical and Psychological Effects

- Ask if experiencing **diarrhea, rectal bleeding, rectal incontinence** or other **bowel dysfunction** and treat symptoms similar to the general population.
- Screen for **urinary incontinence** and **retention** and manage as you would a patient of average risk of urinary dysfunction.
- Ask if experiencing symptoms of **mucositis, loss of taste** or **dry mouth** and treat similar to population with average risk.
- Assess **fatigue** with a validated instrument, recommend physical activity similar to recommendations for general population, and refer to specialists for psychosocial support or rehabilitation as indicated.

- Screen for **cognitive problems**, and assess for **depression** and **anxiety** that may worsen cognition and refer for treatment.
- Screen for **psychosocial distress, depression** and **anxiety** using a validated screening tool; special attention should be paid to survivors with a stoma, and those who report **sexual dysfunction**. Monitor survivors with a stoma for **sexual dysfunction, distress, depression, anxiety** and QoL. Refer to specialists for support as indicated.
- Refer patients to appropriate mental health professionals or resources in the community as indicated. Follow-up to assess adherence and ensure need was met, identify potential barriers and seek alternative approaches as needed.
- Address **sexual function**. Refer survivors of childbearing age who experience **infertility** due to treatment for psychosocial support.
- Assess for **neuropathy** survivors who received oxaliplatin with Total Neuropathy Score or other validated tool and refer to rehabilitation and pain management specialists as indicated.
- Monitor patients who received pelvic irradiation for **chronic proctitis** and manage symptoms as indicated.
- Monitor survivors who are obese or who have had prior coronary artery disease and received 5-fluorouracil or capecitabine for **cardiovascular disease**.

Assessment Tools			
Fatigue	Cognitive Problems	Mental Health	Neuropathy
1. <a href="#">M.D. Anderson Symptom Inventory (MDASI)</a>	1. <a href="#">Mini Mental State Exam (MMSE)</a>	1. <a href="#">Distress Thermometer</a>	1. <a href="#">National Cancer Institute-Common Terminology Criteria for Adverse Events (NCI-CTCAE)</a>
2. <a href="#">Brief Fatigue Inventory</a>	2. <a href="#">Functional Assessment of Cancer Therapy-Cognitive (FACT-Cog)</a>	2. <a href="#">Survivor Unmet Needs Survey (SUNS)</a>	2. <a href="#">Functional Assessment of Cancer Therapy/Gynecologic Oncology Group Oxaliplatin-Specific Neurotoxicity questionnaire (FACT/GOG-Ntx)</a>
3. <a href="#">Functional Assessment of Cancer Therapy-General (FACT-G-7)</a>		3. <a href="#">Hospital Anxiety and Depression Scale (HADS)</a>	3. <a href="#">Total Neuropathy Score (TNSc)</a>
4. <a href="#">Fatigue Symptom Inventory (FSI)</a>		4. <a href="#">Center for Epidemiologic Studies Depression Scale (CES-D)</a>	
5. <a href="#">Multidimensional Fatigue Symptom Inventory-Short Form (MFSI-SF)</a>			
6. <a href="#">FACT-C</a>			

### Health Promotion

- Provide routine general medical care and health promotion recommendations, and continue to treat patients' chronic conditions, recognizing cancer treatments worsen severity of many underlying chronic conditions.

### Care Coordination and Practice Implications

- Initiate and maintain direct communication with all specialists involved in patient's oncology care and symptom management.
- Request treatment summary and follow-up care plan to guide coordination of follow-up care post-treatment.

View the American Cancer Society Colorectal Cancer Survivorship Care Guideline at:  
<http://bit.ly/acscolorc>



# HEAD AND NECK CANCER SURVIVORSHIP CARE: LONG-TERM AND LATE EFFECTS SUMMARY

<b>Long-term Effects</b> Start during treatment and persist	<b>Late Effects</b> Start after treatment ends	
<b>Surgery Effects (Neck Dissection, Laryngectomy)</b>		
<b>Shoulder function</b> <ul style="list-style-type: none"> <li>Shoulder mobility, pain</li> </ul> <b>Oral health complications</b> <ul style="list-style-type: none"> <li>Xerostomia</li> <li>Dysphagia</li> <li>Oral infections</li> </ul> <b>Musculoskeletal effects</b> <ul style="list-style-type: none"> <li>Trismus</li> <li>Impaired neck motion, pain</li> <li>Stricture</li> </ul>	<ul style="list-style-type: none"> <li>Spinal nerve abnormalities</li> <li>Lymphedema</li> <li>Neuropathy</li> <li>Cervical radiculopathy</li> </ul>	
<b>Radiation Therapy Effects (IMRT, Mediastinal RT)</b>		
<b>Oropharyngeal</b> <ul style="list-style-type: none"> <li>Xerostomia</li> <li>Dysphagia</li> </ul> <b>Neuromuscular</b> <ul style="list-style-type: none"> <li>Cervical dystonia</li> <li>Trismus</li> </ul> <b>Musculoskeletal</b> <ul style="list-style-type: none"> <li>Shoulder dysfunction</li> </ul> <b>Integumentary</b> <ul style="list-style-type: none"> <li>Radiation dermatitis</li> </ul> <b>Lymphovascular</b> <ul style="list-style-type: none"> <li>Lymphedema</li> </ul> <b>Oral health complications</b> <ul style="list-style-type: none"> <li>Xerostomia</li> <li>Oral infections</li> </ul>	<b>Vision</b> <ul style="list-style-type: none"> <li>Premature cataracts</li> </ul> <b>Cardiovascular</b> <ul style="list-style-type: none"> <li>Carotid obstruction</li> <li>Baroreceptor failure</li> </ul> <b>Oropharyngeal</b> <ul style="list-style-type: none"> <li>Xerostomia</li> <li>Dysphagia</li> <li>Dysarthria</li> </ul> <b>Pulmonary</b> <ul style="list-style-type: none"> <li>Pulmonary fibrosis</li> </ul> <b>Neuromuscular</b> <ul style="list-style-type: none"> <li>Cervical dystonia</li> <li>Trismus</li> <li>Brachial plexopathy</li> <li>Cervical radiculopathy</li> </ul>	<b>Musculoskeletal</b> <ul style="list-style-type: none"> <li>Osteonecrosis</li> </ul> <b>Lymphovascular</b> <ul style="list-style-type: none"> <li>Lymphedema</li> </ul> <b>Sensory complications</b> <ul style="list-style-type: none"> <li>Carotid stenosis</li> <li>Hearing loss</li> <li>Ocular issues</li> <li>Altered or loss of taste</li> </ul>
<b>Chemotherapy Effects</b>		
<b>Neuromuscular</b> <ul style="list-style-type: none"> <li>Sensor/motor neuropathy</li> <li>Sensory ataxia</li> <li>Gait dysfunction</li> <li>Vertigo</li> </ul> <b>Other effects</b> <ul style="list-style-type: none"> <li>Hot flashes/sweats</li> <li>Weight gain, abdominal obesity</li> <li>Fatigue/decreased activity</li> <li>Anemia</li> <li>Body hair loss</li> <li>Dry eyes</li> </ul>	<b>Neuromuscular</b> <ul style="list-style-type: none"> <li>Cardiac abnormality, cardiomyopathy</li> </ul> <b>Other effects</b> <ul style="list-style-type: none"> <li>Osteoporosis, fractures</li> <li>Metabolic syndrome</li> <li>Cardiovascular disease—possible increased risk of myocardial infarction</li> <li>Diabetes; decreased sensitivity to insulin and oral glycemic agents</li> <li>Increased cholesterol</li> <li>Increased fat mass and decreased lean muscle mass/muscle wasting</li> <li>Venous thromboembolism</li> <li>Vertigo</li> <li>Cognitive dysfunction</li> </ul>	

### General Psychological Long-term and Late Effects

- Depression
- Distress—multifactorial unpleasant experience of psychological, social, and/or spiritual nature
- Worry, anxiety
- Fear of recurrence
- Pain-related concerns
- End-of-life concerns: Death and dying
- Changes in sexual function and/or desire
- Challenges with body image (secondary to surgery, laryngectomy, radiation)
- Challenges with self-image
- Relationship and other social role difficulties
- Return-to-work concerns and financial challenges

### More Information

View the American Cancer Society Head and Neck Cancer Survivorship Care Guideline at: [bit.ly/acsheadneck](https://bit.ly/acsheadneck)



# AMERICAN CANCER SOCIETY HEAD AND NECK CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY

Assessment and Management of Long-term and Late Effects



## MUSCULOSKELETAL AND NEUROMUSCULAR

- Assess for spinal accessory nerve palsy (U) and refer to rehabilitation specialist to improve range of motion and ability to perform daily tasks, with more complex clinical situations referred to a Physical Medicine and Rehabilitation physician for expert assessment
- Assess for cervical dystonia (U) and refer for comprehensive neuromusculoskeletal management if cervical dystonia or neuropathy (U) found
- Prescribe nerve stabilizing agents such as pregabalin, gabapentin and duloxetine or refer to a specialist for botulinum toxin type A injections into the affected muscles for pain management and spasm control as indicated
- Assess for shoulder pain and dysfunction (H) after neck dissection
- Conduct baseline assessment of shoulder function post-treatment and continue to assess for emerging pain or functional impairment, referring to rehabilitation specialist for improvement to pain, disability and range of motion
- Refer to rehabilitation specialists and dental professionals to prevent and treat trismus (M) and prescribe nerve-stabilizing agents to combat pain and spasms as indicated



## SWALLOWING

- Assess for complaints of dysphagia (U), postprandial cough, unexplained weight loss and/or pneumonia and refer to an experienced rehabilitation specialist for instrumental evaluation of swallowing function to assess and manage dysphagia and possible aspiration (U)
- Refer to appropriate clinician as needed to address psychosocial barriers to swallowing recovery
- Refer to speech-language pathologist for videofluoroscopy as the first-line test for suspected stricture (L-M) due to high degree of coexisting physiologic dysphagia
- Refer to gastroenterologist or head and neck surgeon for esophageal dilation in cases of stricture



## HEARING LOSS, VERTIGO VESTIBULAR NEUROPATHY

- Assess for loss of hearing (U), vertigo (U) or vestibular neuropathy (U) and refer to appropriate specialists
- Evaluate survivors with history of ototoxic drug exposure for chronic, potentially progressive sensorineural hearing loss



## REFLUX

- Monitor for developing or worsening gastroesophageal reflux disease
- Counsel on increased risk of esophageal cancer and associated symptoms
- Recommend proton pump inhibitors or antacids, sleeping with a wedge pillow or 3-inch blocks under head of bed, not eating or drinking three hours before bed, tobacco cessation and alcohol avoidance
- Refer to gastroenterologist if symptoms are not relieved by these treatments



## LYMPHEDEMA

- Assess for lymphedema (H) using NCI's Common Terminology Criteria for Adverse Events v. 4.03 or refer for endoscopic evaluation of mucosal edema of the oropharynx and larynx, tape measurements, sonography or external photographs
- Refer to a rehabilitation specialist for treatment consisting of manual lymphatic drainage and, if tolerated, compressive bandaging



## FATIGUE

- Assess for fatigue (U) and treat any causative factors (e.g., anemia, thyroid or cardiac dysfunction)
- Offer treatment or referral for factors that may impact fatigue (e.g., mood disorders, sleep disturbance, pain)
- Counsel survivors to engage in regular physical activity and refer for cognitive behavioral therapy as appropriate



## TASTE

- Assess for altered or loss of taste (U)
- Refer to a registered dietitian for dietary counseling and assistance in additional seasoning of food, avoiding unpleasant food and expanding dietary options



## THYROID

- Assess for hypothyroidism (L-H)
- Evaluate thyroid function by measuring thyroid stimulating hormone levels every 6-12 months

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

# AMERICAN CANCER SOCIETY HEAD AND NECK CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)

## Assessment and Management of Long-term and Late Effects



### SLEEP DISTURBANCE/APNEA

- Screen for sleep disturbance (U) by asking survivors and partners about snoring and symptoms of sleep apnea (U)
- Refer to sleep specialist for a sleep study if sleep apnea is suspected
- Manage sleep disturbance similar to patients in the general population
- Recommend nasal decongestants, nasal strips, cool mist humidifiers and sleeping in a propped-up position to reduce snoring and mouth-breathing
- Refer to dental professional to test fit of dentures, counsel to remove dentures at night to avoid irritation



### SPEECH/VOICE

- Assess for speech disturbance (U)
- Refer to experienced speech-language pathologist specialist if communication disorder exists
- Radiation-associated lower cranial neuropathies (L) may cause delayed speech or voice deterioration in long-term survivors



### BODY AND SELF-IMAGE

- Assess for body (H) and self-image concerns
- Refer for psychosocial care as indicated



### DISTRESS, DEPRESSION AND ANXIETY

- Assess for distress (H), depression (L-H) and/or anxiety (L) periodically (3 months post treatment and at least annually) using a validated screening tool
- Offer in-office counseling and/or pharmacotherapy and/or refer to appropriate psycho-oncology and mental health resources as clinically indicated if signs of distress, depression or anxiety are present
- Refer to mental health specialists for specific quality of life concerns, such as social workers for issues like financial and employment challenges or addiction specialists for substance abuse



### DENTAL/ORAL

- Counsel close follow-up with dental professional and reiterate that proper preventive care can help reduce caries (U) and gingival disease
- Counsel to avoid tobacco, alcohol (including mouthwash containing alcohol), spicy or abrasive foods, extreme temperature liquids, sugar-containing chewing gum or sugary soft drinks and acidic or citric liquids
- Refer to dental professional specializing in the care of oncology patients
- Assess for periodontitis (U) and refer to a dentist or periodontist for thorough evaluation
- Counsel regular examination of the gingival attachment as normal part of ongoing dental care
- Assess for xerostomia (U) and counsel use of alcohol-free mouth rinses, consuming a low-sucrose diet and avoiding caffeine, spicy and highly acidic foods and tobacco
- Avoid dehydration by drinking fluoridated tap water but explain that consumption of water will not eliminate xerostomia
- Monitor for swelling of jaw and/or jaw pain indicating possible osteonecrosis (U)
- Administer conservative treatment protocols such as broad-spectrum antibiotics and daily saline or aqueous chlorhexidine gluconate irrigations for early stage lesions
- Refer to head and neck surgeon for consideration of hyperbaric oxygen therapy for early and intermediate lesions, for debridement of necrotic bone while undergoing conservative management or for external mandible bony exposure through the skin
- Assess for oral infections/candidiasis (L) and refer to qualified dental professional for treatment and management of complex oral conditions and infections
- Consider systemic fluconazole and/or localized therapy of clotrimazole troches to treat oral fungal infections
- Higher risk criteria:
  - Poor dental care
  - Comorbid states (e.g., autoimmune diseases, poor nutritional status, diabetes, alcohol abuse, tobacco use and poor general health status)
  - Those treated with radiation or chemotherapy and experiencing long-term xerostomia as a result, or loss of gingival attachment
  - Xerostomia-inducing medications (e.g., anticholinergics, antihypertensives, antihistamines, neurology and nervous system drugs and decongestants)
  - Those who experience surgical ablation of the salivary glands or associated ducts
  - Radiation therapy to oral cavity and salivary glands increases risk of osteonecrosis

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

# AMERICAN CANCER SOCIETY HEAD AND NECK CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)



## SURVEILLANCE AND SCREENING

- Individualize clinical follow-up care based on age, specific diagnosis and treatment
- Conduct detailed cancer-related history and physical exam according to schedule based on risk:
  - Every 1-3 months for the first year after primary treatment
  - Every 2-6 months for the second year
  - Every 4-8 months for years 3-5
  - Annually after 5 years
- Confirm continued follow-up with otolaryngologist or HNC specialist for HN-focused exam
- Educate about signs and symptoms of local recurrence and refer to HNC specialist if signs and symptoms of local recurrence present
- Screen for lung cancer according to ASCO or NCCN recommendations for annual lung cancer screening with LDCT for high-risk patients based on smoking history
- Screen for other head and neck and esophageal cancer as would for patients of increased risk
- Screen for other cancers as in general population according to [American Cancer Society screening and early detection guidelines](#)



## HEALTH PROMOTION

- Assess information needs related to HNC and its treatment, side effects, other health concerns and available support services and provide or refer to appropriate resources
- Counsel survivors to achieve and maintain a healthy weight; weight management is considered a priority standard of care
- Counsel survivors on nutrition strategies to maintain a healthy weight for those at risk of cachexia
- If overweight or obese, counsel to limit consumption of high-calorie foods and beverages
- Counsel survivors to engage in regular physical activity including:
  - Aerobic exercise at least 150 minutes per week
  - Strength training exercise at least 2 days per week
- Counsel survivors to achieve a dietary pattern that is high in vegetables, fruits and whole grains, low in saturated fats and sufficient in dietary fiber
- Assess for nutrition-related challenges and refer to a registered dietitian or specialist
- Assess for tobacco use and offer and/or refer survivors to cessation counseling and resources and counsel survivors to avoid tobacco products
- Counsel survivors to avoid alcohol consumption
- Counsel survivors to maintain regular dental care including frequent visits to dental professionals, early interventions for dental complications and meticulous oral hygiene



## CARE COORDINATION

- Consult with cancer treatment team and request a treatment summary and survivorship care plan
- Maintain communication with cancer treatment team throughout diagnosis, treatment and post-treatment care to ensure care is evidence-based and well-coordinated
- Refer to dentist to provide diagnosis and treatment of dental caries, periodontal disease and other intraoral conditions including mucositis and oral infections, and communicate with dentist on follow-up recommendations and patient education
- Coordinate care with other medical specialists to address comorbidities, symptoms and effects
- Encourage inclusion of caregivers, spouses or partners in usual HNC survivorship care and support

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

View full-text guideline at [bit.ly/acshheadneck](https://bit.ly/acshheadneck)

# HEAD AND NECK CANCER SURVIVORSHIP CARE GUIDELINE CHECKLIST FOR PROVIDERS

Clinical follow-up care provided to head and neck cancer survivors should be individualized based on age, specific diagnosis and treatment protocol.

## Surveillance

- Conduct detailed cancer-related history and physical exam according to schedule based on risk:
  - Every 1-3 months for the first year after primary treatment
  - Every 2-6 months for the second year
  - Every 4-8 months for years 3-5
  - Annually after 5 years
- Confirm continued follow-up with otolaryngologist or HNC specialist for HN-focused exam.
- Educate about signs and symptoms of local recurrence and refer to HNC specialist if signs and symptoms of local recurrence present.

## Screening for Second Primary Cancers

- Screen head and neck cancer survivors for other cancers as for patients in the general population according to [ACS Early Detection Recommendations](#).
- Screen head and neck cancer survivors for lung cancer according to ASCO or NCCN recommendations for annual lung cancer screening with low-dose CT for high-risk patients based on smoking history.
- Screen for other head and neck and esophageal cancer as for patients with increased risk.

## Assessment and Management of Physical and Psychological Effects

- Discuss musculoskeletal and neuromuscular effects, including **spinal accessory nerve palsy, cervical dystonia, muscle spasms, neuropathies, shoulder dysfunction and trismus**. Refer to rehabilitation specialists, dental professionals or more complex clinical situations to a physical medicine and rehabilitation physician for expert assessment.
- Assess for **dysphagia, postrandial cough, unexplained weight loss** and/or **pneumonia** and refer to an experienced speech-language pathologist for instrumental evaluation of swallowing function to assess and manage **dysphagia** and possible **aspiration**. Refer to appropriate clinician as needed to address psychosocial barriers to swallowing recovery. Refer to speech-language pathologist for videofluoroscopy as the first-line test for suspected **stricture** due to high degree of coexisting physiologic dysphagia. Refer to gastroenterologist or head and neck surgeon for esophageal dilation in cases of stricture.
- Monitor for developing or worsening **gastroesophageal reflux disease**. Counsel on increased risk of **esophageal cancer** and associated symptoms. Recommend proton pump inhibitors or antacids, sleeping with wedge pillow or three-inch blocks under head of bed, not eating or drinking three hours before bedtime, tobacco cessation and alcohol avoidance. Refer to gastroenterologist if symptoms are not relieved by these treatments.

- Assess for **lymphedema** using NCI's Common Terminology Criteria for Adverse Events v. 4.03 or refer for endoscopic evaluation of **mucosal edema** of the oropharynx and larynx, tape measurements, sonography or external photograph. Refer to a rehabilitation specialist for treatment consisting of manual lymphatic drainage and, if tolerated, compressive bandaging.
- Assess for **fatigue** and treat any causative factors (e.g., anemia, thyroid or cardiac dysfunction). Offer treatment or referral for factors that may impact fatigue (e.g., mood disorders, sleep disturbance, pain). Counsel survivors to engage in regular physical activity and refer for cognitive behavioral therapy as appropriate.
- Discuss **altered or loss of taste**. Refer to a registered dietitian for dietary counseling and assistance in additional seasoning of food, avoiding unpleasant food and expanding dietary options.
- Assess for **hearing loss, vertigo** and **vestibular neuropathy**. Refer to appropriate specialists as needed.
- Screen for **sleep disturbance** by asking survivors and partners about **snoring** and symptoms of **sleep apnea**. Refer survivors to a sleep specialist for a sleep study if sleep apnea is suspected. Manage sleep disturbance similar to patients in the general population. Recommend nasal decongestants, nasal strips, cool mist humidifiers and sleeping in the propped-up position to reduce snoring and mouth-breathing. Refer to a dental professional to test the fit of dentures and counsel to remove dentures at night to avoid irritation.
- Assess for **speech disturbance** and refer to experienced speech-language pathologist specialist if communication disorder exists.
- Evaluate thyroid function and assess for **hypothyroidism** by measuring thyroid stimulating hormone levels every 6-12 months.
- Counsel close follow-up with dental professional and reiterate that proper preventive care can help reduce **caries** and **gingival disease**. Counsel to avoid tobacco, alcohol (including mouthwash containing alcohol), spicy or abrasive foods, extreme temperature liquids, sugar-containing chewing gum or sugary soft drinks and acidic or citric liquids. Refer to a dental professional specializing in the care of oncology patients.
- Assess for **periodontitis** and refer to a dentist or periodontist for thorough evaluation. Counsel to seek regular treatment from and follow recommendations of a qualified dental professional and reinforce proper examination of the gingival attachment is a normal part of ongoing dental care.
- Assess for **xerostomia** and counsel to use alcohol-free mouth rinses, consume a low-sucrose diet, avoid caffeine, spicy and highly acidic foods and tobacco. Counsel to avoid dehydration by drinking fluoridated tap water, but explain that consumption of water will not eliminate **xerostomia**.
- Monitor for swelling of the jaw and/or jaw pain indicating possible **osteonecrosis**. Administer conservative treatment protocols such as broad-spectrum antibiotics and daily saline or aqueous chlorhexidine gluconate irrigations for early-stage lesions. Refer to a head and neck surgeon for consideration of hyperbaric oxygen therapy for early and intermediate lesions, for debridement of necrotic bone while undergoing conservative management, or for external mandible bony exposure through the skin.
- Assess for **oral infections/candidiasis**. Refer to qualified dental professional for treatment and management of complicated oral conditions and infections. Consider

systemic fluconazole and/or localized therapy of clotrimazole troches to treat **oral fungal infections**.

- Assess for body and self-image concerns and refer for psychosocial care as indicated.
- Assess for **distress/depression** and/or **anxiety** three months post treatment and at least annually using a simple screening tool, such as the [Distress Thermometer](#). Manage **distress/depression/anxiety** using in-office counseling resources or pharmacotherapy as appropriate. Refer survivors experiencing **distress/depression/anxiety** for further evaluation and/or treatment by appropriate specialists if needed. Refer to mental health specialists for specific quality of life concerns, such as social workers for issues like financial and employment challenges or addiction specialists for substance abuse.

Assessment Tools			
<a href="#">Center for Epidemiological Studies Depression Scale (CES-D)</a>	<a href="#">Generalized Anxiety Disorder (GAD)-7</a>	<a href="#">Distress Thermometer</a>	<a href="#">Patient Health Questionnaire (PHQ)-9</a>

### Health Promotion

- Assess information needs related to head and neck cancer and its treatment, side effects, other health concerns and available support services. Provide or refer to appropriate resources to meet these needs.
- Counsel to achieve and maintain healthy weight by limiting consumption of high-calorie foods and beverages and promoting increased physical activity.
- Counsel survivors on nutrition strategies to maintain a healthy weight for those at risk for cachexia.
- Counsel to engage in at least 150 minutes per week of physical activity; this may include weight-bearing exercises.
- Counsel to achieve a dietary pattern high in vegetables, fruits and whole grains.
- Counsel survivors if overweight or obese to limit consumption of high-calorie foods and beverages and increase physical activity to promote and maintain weight loss. Head and neck cancer survivors often experience significant, highly visible facial disfigurement and notable treatment-induced problems with eating, swallowing and breathing. Survivors may also experience loss of taste and smell, excessive dry mouth and other deficits of functioning in the oral cavity including negatively impacting the ability to eat. As a result, survivors may have difficulty gaining and maintaining a healthy weight. Avoiding wasting should be a primary aim of health promotion with these patients. Refer to registered dietician to address nutrition-related challenges.
- Counsel to avoid alcohol consumption.
- Assess for tobacco use and offer and/or refer to cessation counseling and resources. Counsel to avoid tobacco products.
- Counsel to maintain regular dental care including frequent visits to dental professionals, early interventions for dental complications and meticulous oral hygiene. Test dentures to ensure proper fit, and counsel to remove them at night to avoid irritation. Counsel that nasal strips can reduce snoring and mouth-breathing and that room humidifiers and nasal saline sprays can aid sleep as well.



- Train survivors to do at-home head and neck self-evaluations and instruct survivors to report any suspicions or concerns immediately.

### Care Coordination

- Consult with cancer treatment team and obtain a treatment summary and survivorship care plan.
- Maintain communication with oncology team throughout diagnosis, treatment and post-treatment care to ensure care is evidence-based and well-coordinated.
- Refer to dentist to provide diagnosis and treatment of dental **caries**, **periodontal disease** and other intraoral conditions including **mucoisitis** and **oral infections** and communicate with dentist on follow-up recommendations and patient education.
- Encourage inclusion of caregivers, spouses, or partners in usual head and neck cancer survivorship care.

View the American Cancer Society Head and Neck Cancer Survivorship Care Guideline at: [bit.ly/acsheadneck](https://bit.ly/acsheadneck)

## PROSTATE CANCER SURVIVORSHIP CARE: LONG-TERM AND LATE EFFECTS SUMMARY

<b>Long-term Effects</b> Start during treatment and persist	<b>Late Effects</b> Start after treatment ends
<b>Surgery Effects</b> (radical prostatectomy: open, laparoscopic, robotic-assisted)	
<b>Urinary dysfunction</b> <ul style="list-style-type: none"> <li>• Urinary incontinence (stress)</li> <li>• Urinary symptoms (urgency, frequency, nocturia, dribbling)</li> <li>• Urethral stricture formation (scarring at the urethra)</li> </ul> <b>Sexual dysfunction</b> <ul style="list-style-type: none"> <li>• Erectile dysfunction (ED)</li> <li>• Lack of ejaculation</li> <li>• Orgasm changes (without erection, associated with incontinence)</li> <li>• Penile shortening</li> </ul>	<ul style="list-style-type: none"> <li>• Disease progression</li> </ul>
<b>Radiation Therapy Effects</b> (external beam or brachytherapy)	
<b>Urinary dysfunction</b> <ul style="list-style-type: none"> <li>• Urinary incontinence</li> <li>• Dysuria, urgency, frequency, nocturia, dribbling)</li> <li>• Hematuria</li> <li>• Urethral stricture</li> </ul> <b>Sexual dysfunction</b> <ul style="list-style-type: none"> <li>• Progressive ED</li> <li>• Decreased semen volume</li> </ul> <b>Bowel dysfunction</b> <ul style="list-style-type: none"> <li>• Fecal urgency, frequency, incontinence</li> <li>• Blood in stool</li> <li>• Rectal inflammation, pain</li> </ul>	<ul style="list-style-type: none"> <li>• Disease progression</li> </ul> <b>Urinary dysfunction</b> <ul style="list-style-type: none"> <li>• Urethral stricture</li> <li>• Hematuria due to small blood vessel changes</li> </ul> <b>Sexual dysfunction</b> <ul style="list-style-type: none"> <li>• ED can be delayed in onset 6 to 36 months after therapy</li> </ul> <b>Bowel dysfunction</b> <ul style="list-style-type: none"> <li>• Rectal bleeding secondary to thinning/small blood vessel changes of anterior rectal wall mucosa</li> </ul>
<b>Hormone Therapy Effects</b> (androgen deprivation therapy)	
<b>Sexual dysfunction</b> <ul style="list-style-type: none"> <li>• Loss of libido</li> <li>• ED</li> </ul> <b>Other</b> <ul style="list-style-type: none"> <li>• Hot flushes/sweats</li> <li>• Weight gain, abdominal obesity</li> <li>• Change in body image</li> <li>• Excessive emotional reactions and frequent mood changes</li> <li>• Depression</li> <li>• Fatigue/decreased activity</li> <li>• Gynecomastia</li> <li>• Anemia</li> <li>• Body hair loss</li> <li>• Dry eyes</li> </ul>	<ul style="list-style-type: none"> <li>• Osteoporosis, fractures</li> <li>• Metabolic syndrome</li> <li>• Cardiovascular disease (possible increased risk of myocardial infarction)</li> <li>• Diabetes; decreased sensitivity to insulin and oral glycemic agents</li> <li>• Increased cholesterol</li> <li>• Increased fat mass and decreased lean muscle mass/muscle wasting</li> <li>• Venous thromboembolism</li> <li>• Vertigo</li> <li>• Cognitive dysfunction</li> <li>• Disease progression</li> </ul>

<b>Long-term Effects</b> Start during treatment and persist	<b>Late Effects</b> Start after treatment ends
<b>Expectant Management Effects</b> (active surveillance or watchful waiting)	
<ul style="list-style-type: none"> <li>• Stress, anxiety, worry</li> <li>• Risks associated with repeat biopsy (active surveillance), PSAs (prostate -specific antigen) and DREs (digital rectal exam)</li> <li>• Symptoms associated with disease progression</li> </ul>	<ul style="list-style-type: none"> <li>• Disease progression</li> </ul>
<b>General Psychological Long-term and Late Effects</b>	
<ul style="list-style-type: none"> <li>• Depression, depressive symptoms</li> <li>• Distress—multifactorial unpleasant experience of psychological, social, and/or spiritual nature</li> <li>• Worry, anxiety</li> <li>• Fear of recurrence</li> <li>• Pain-related concerns</li> <li>• End-of-life concerns: death and dying</li> <li>• Changes in sexual function and/or desire</li> <li>• Challenges with body image (secondary to surgery and/or hormonal therapy)</li> <li>• Challenges with self-image</li> <li>• Relationship and other social role difficulties</li> <li>• Return-to-work concerns and financial challenges</li> </ul>	
<b>More Information</b>	
View the American Cancer Society Prostate Cancer Survivorship Care Guideline at: <a href="https://bit.ly/ACSPrCa">bit.ly/ACSPrCa</a>	



## AMERICAN CANCER SOCIETY PROSTATE CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY

Assessment and Management of Long-term and Late Effects



### SEXUAL FUNCTION AND INTIMACY

- Discuss sexual function
- Use validated tools to monitor erectile function over time
- Erectile dysfunction (U) may be addressed through a variety of options, including penile rehabilitation or prescription of phosphodiesterase type 5 inhibitors (e.g., sildenafil, vardenafil, tadalafil)
- Refer men with persistent sexual dysfunction (U) to a urologist, sexual health specialist, or psychotherapist to review treatment and counseling options
- Encourage couples to discuss sexual intimacy and refer to counseling or support services as appropriate
- Instruct couples on use of sexual aids to improve erectile dysfunction (U) for men/male partners and for postmenopausal symptoms in female partners
- Refer to mental health professional with expertise in sex therapy



### URINARY FUNCTION

- Discuss urinary function (e.g. decreased bladder capacity (U), dribbling (U), dysuria (U), fistula (U), frequency (U), hematuria (U), hesitancy (U), nocturia (U), overactive bladder (U), radiation induced cystitis (U), slowing of stream (U), urethral stricture (U), urgency (U), incontinence (U), retention (U))
- Consider timed voiding, prescribing anticholinergic medications (e.g. oxybutynin) to address issues such as nocturia (U), frequency (U) or urgency (U)
- Consider alpha-blockers (e.g. tamsulosin) for slow stream (U)
- Refer survivors with post-prostatectomy incontinence (U) to a physical therapist for pelvic floor rehabilitation; at a minimum, instruct survivors about Kegel exercises
- Refer men with persistent leakage (U) or other urinary symptoms to a urologist for further evaluation (e.g. urodynamic testing, cystoscopy) and discussion of treatment options including surgical placement of a male urethral sling or artificial urinary sphincter for incontinence



### ANEMIA AND VASOMOTOR FUNCTION (SPECIFIC RISK FOR MEN RECEIVING ADT)

- Discuss hot flushes/sweats (M)
- Although not approved by the FDA for this indication, prescription of selective serotonin or noradrenergic reuptake inhibitors or gabapentin may offer symptom relief
- Assess for anemia (U), perform annual CBC to monitor hemoglobin levels

### BOWEL FUNCTION



- Discuss bowel function and symptoms (e.g. rectal bleeding (U))
- For men with a negative colorectal cancer screening result experiencing rectal bleeding (U), prescribe stool softeners, topical steroids or anti-inflammatories
- Refer survivors with persistent rectal symptoms (e.g. bleeding (U), sphincter dysfunction (U), rectal urgency (U) and frequency (U)) to the appropriate specialist

### CARDIOVASCULAR AND METABOLIC FUNCTION (SPECIFIC RISK FOR MEN RECEIVING ADT)



- Follow U.S. Preventive Services Task Force guidelines for evaluation and screening for cardiovascular (U) risk factors, blood pressure monitoring, lipid profiles and serum glucose (possible increased risk of myocardial infarction)
- Assess for body hair loss (U), muscle wasting (U), diabetes (U), dry eyes (U), excessive emotional reactions/frequent mood changes (U), gynecomastia (U), high cholesterol (U), metabolic syndrome (U), subcutaneous fat accumulation (U), venous thromboembolism (U), vertigo (U), weight gain/abdominal obesity/increased fat mass (U)

### DISTRESS, DEPRESSION, PSA ANXIETY



- Assess for distress (M), depression (L) and PSA anxiety (U) at least annually using a simple screening tool, such as the Distress Thermometer
- Manage distress/depression using in-office counseling resources or pharmacotherapy as appropriate
- Refer survivors experiencing distress/depression for further evaluation

### FRACTURE RISK/OSTEOPOROSIS



- Assess risk of fracture for men treated with ADT (U) or older radiation techniques (H) through baseline DEXA scan and calculation of a FRAX score
- For men determined to be high risk (U), prescribe weekly bisphosphonate therapy (oral alendronate at a dose of 70 mg) or annual intravenous zoledronic acid at a dose of 5 mg to increase bone density
- Denosumab is also approved by the FDA to treat men at increased risk of osteoporosis

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

# AMERICAN CANCER SOCIETY PROSTATE CANCER SURVIVORSHIP CARE GUIDELINE SUMMARY (CONTINUED)

## OTHER CONSIDERATIONS

- Fear of recurrence
  - Pain-related concerns
  - End-of-life concerns: death and dying
  - Changes in sexual function and/or desire
- More psychosocial effects (U):
- Challenges with body image (secondary to surgery and/or hormonal therapy)
  - Challenges with self-image
  - Relationship and other social role difficulties
  - Return to work concerns and financial challenges

## HEALTH PROMOTION

- Assess information needs related to prostate cancer and its treatment, side effects, other health concerns and available support services and provide or refer to appropriate resources to meet these needs
- Counsel survivors to achieve and maintain a healthy weight; weight management is considered a priority standard of care
- Counsel survivors to engage in regular physical activity including:
  - Aerobic exercise at least 150 minutes per week
  - Strength training exercise at least 2 days per week
- Counsel survivors to achieve a dietary pattern that is high in vegetables, fruits and whole grains
- Consume a diet emphasizing micronutrient-rich and phytochemical-rich vegetables and fruits, low amounts of saturated fat, intake of at least 600 IU of vitamin D per day and consuming adequate, but not excessive, amounts of dietary sources of calcium (not to exceed 1200 mg/day)
- Refer survivors with nutrition-related challenges (e.g. bowel problems that impact nutrient absorption (U) to a registered dietician
- Assess for tobacco use and offer and/or refer survivors to cessation counseling and resources and counsel survivors to avoid tobacco products
- Counsel survivors to avoid or limit alcohol consumption to no more than 2 drinks per day

## SURVEILLANCE AND SCREENING

- Measure serum PSA level every 6-12 months for the first 5 years, then annually thereafter
- Refer survivors with elevated or rising PSA level back to primary treating specialist for further follow-up and treatment
- Perform annual DRE in coordination with cancer specialist to avoid duplication
- Adhere to [American Cancer Society screening and early detection guidelines](#)
- Prostate cancer survivors having undergone radiation therapy may have slightly higher risk of bladder and colorectal cancers and may need to follow screening guidelines for higher-risk individuals, if available
- Perform thorough evaluation to rule out bladder cancer, including urologist referral for cystoscopy for survivors with hematuria
- Refer survivors with persistent rectal bleeding, pain or other symptoms of unknown origin to appropriate specialist as well as treating radiation oncologist to conduct a thorough evaluation for rectal cancer

## CARE COORDINATION

- Consult with cancer treatment team and request a treatment summary and survivorship care plan
- Maintain role as general medical care coordinator throughout the spectrum of prostate cancer detection, treatment and aftercare, focusing on preventive care and the management of preexisting comorbid conditions, regularly addressing the patient's overall physical and psychosocial status and those components of survivorship care that are mutually agreed upon with the treating clinicians
- Annually assess for the presence of long-term or late effects of prostate cancer and its treatment using validated tool
- Encourage the inclusion of caregivers, spouses or partners in usual prostate cancer survivorship care
- Refer survivors to appropriate community-based and peer support resources

High prevalence  $\geq 50\%$  (H), Mid Prevalence 21-49% (M), Low-Prevalence  $\leq 20\%$  (L), Unknown Prevalence (U)

View full-text guideline at [bit.ly/ACSPrCa](https://bit.ly/ACSPrCa)

## PROSTATE CANCER SURVIVORSHIP CARE GUIDELINE CHECKLIST FOR PROVIDERS

Clinical follow-up care provided to prostate cancer survivors should be individualized based on age, specific diagnosis and treatment protocol.

### Surveillance

- Measure serum PSA level every 6 to 12 months for first 5 years, then annually thereafter. Refer survivors with elevated or rising PSA level back to primary treating specialist for further follow-up and treatment.
- Perform annual DRE in coordination with cancer specialist to avoid duplication.

### Screening for Second Primary Cancers

- Adhere to [ACS screening and early detection guidelines](#). Prostate cancer survivors having undergone radiation therapy may have slightly higher risk of bladder and colorectal cancers and may need to follow screening guidelines for higher-risk individuals, if available.
- Perform thorough evaluation to rule out bladder cancer, including urologist referral for cystoscopy, for survivors with hematuria.
- Refer survivors with persistent **rectal bleeding, pain or other symptoms of unknown origin** to appropriate specialist and radiation oncologist to conduct a thorough evaluation for rectal cancer.

### Assessment and Management of Physical and Psychological Effects

- Discuss bowel function and symptoms (e.g., **rectal bleeding, sphincter dysfunction, rectal urgency** and **frequency**). For men with negative colorectal cancer screening result experiencing **rectal bleeding**, prescribe stool softeners, topical steroids or anti-inflammatories. Refer survivors with persistent rectal symptoms to appropriate specialist.
- Assess for **distress/depression/PSA anxiety** at least annually using a simple screening tool, such as the [Distress Thermometer](#). Manage **distress/depression** using in-office counseling resources or pharmacotherapy as appropriate. Refer survivors experiencing **distress/depression** for further evaluation and/or treatment by appropriate specialists if needed.
- Discuss sexual function. Use validated tools, such as the [Sexual Health Inventory for Men \(SHIM\)](#), to monitor erectile function over time. **Erectile dysfunction** may be addressed through a variety of options, including penile rehabilitation or prescription of phosphodiesterase type 5 inhibitors. Refer men with **persistent sexual dysfunction** to a urologist, sexual health specialist or psychotherapist to review treatment and counseling options.
- Encourage couples to discuss sexual intimacy and refer to counseling or support services as appropriate. Prescribe medication to address **erectile dysfunction**. Instruct couples on use of sexual aids to improve **erectile dysfunction** (men) and **postmenopausal symptoms** (women). Refer to mental health professional with expertise in sex therapy.
- Discuss urinary function (e.g., **urinary stream, difficulty emptying the bladder**) and **incontinence**. Consider timed voiding, prescribing anticholinergic medications (e.g., oxybutynin) to address issues such as **nocturia, frequency** or **urgency**. Consider alpha-

blockers (e.g., tamsulosin) for **slow stream**. Refer survivors with **postprostatectomy incontinence** to a physical therapist for pelvic floor rehabilitation; at a minimum, instruct survivors about Kegel exercises. Refer men with **persistent leakage** or **other urinary symptoms** to a urologist for further evaluation (e.g., urodynamic testing, cystoscopy) and discussion of treatment options including surgical placement of a male urethral sling or artificial urinary sphincter for **incontinence**.

- ❑ Perform annual CBC to monitor hemoglobin levels for **anemia** in men receiving androgen deprivation therapy (ADT).
- ❑ Follow [U.S. Preventive Services Task Force guidelines](#) for evaluation and screening for cardiovascular risk factors, blood pressure monitoring, lipid profiles, and serum glucose in men receiving ADT.
- ❑ Assess risk of fracture for men treated with ADT or older radiation techniques through baseline DEXA scan and calculation of a FRAX score. For men determined to be high risk, prescribe weekly bisphosphonate therapy (oral alendronate at a dose of 70 mg) or annual intravenous zoledronic acid at a dose of 5 mg to increase bone density. Denosumab is also approved by the FDA to treat men at increased risk of osteoporosis.
- ❑ For men receiving ADT who have vasomotor symptoms (e.g., hot flashes), prescription of selective serotonin or noradrenergic reuptake inhibitors or gabapentin may offer symptom relief (note that it is not approved by the FDA for this indication).

Assessment Tools		
<a href="#">Distress Thermometer</a>	<a href="#">Sexual Health Inventory for Men (SHIM)</a>	<a href="#">Expanded Prostate Cancer Index Composite for Clinical Practice (EPIC-CP)</a>

### Health Promotion

- ❑ Assess information needs related to prostate cancer and its treatment, side effects, other health concerns, and available support services. Provide or refer to appropriate resources to meet these needs.
- ❑ Counsel to achieve and maintain healthy weight by limiting consumption of high-calorie foods and beverages and promoting increased physical activity.
- ❑ Counsel to engage in at least 150 minutes per week of physical activity; this may include weight-bearing exercises.
- ❑ Counsel to achieve a dietary pattern high in vegetables, fruits and whole grains. Emphasize consumption of micronutrient-rich and phytochemical-rich vegetables and fruits, low amounts of saturated fat, intake of at least 600 IU of vitamin D per day and adequate amounts of dietary sources of calcium (not to exceed 1200 mg/d). Refer survivors with nutrition-related challenges (e.g., bowel problems that impact nutrient absorption) to registered dietitian.
- ❑ Counsel to avoid or limit alcohol consumption to no more than 2 drinks per day.
- ❑ Assess for tobacco use and offer and/or refer to cessation counseling and resources. Counsel to avoid tobacco products.

## Care Coordination

- Primary treating specialist is encouraged to provide a treatment summary and survivorship care plan to primary care provider when survivorship care is transferred. Primary care providers and treating oncology specialists should confer regarding survivorship care plan components and determine roles and responsibilities appropriate for survivor's condition and resources available in the primary care setting.
- Primary care providers should maintain role as general medical care coordinator throughout spectrum of prostate cancer detection, treatment, and aftercare, focusing on preventive care and management of preexisting comorbid conditions, regularly addressing patient's overall physical and psychosocial status, and those components of survivorship care mutually agreed upon with treating clinicians.
- Annually assess for presence of long-term or late effects of prostate cancer and its treatment. Use of a validated tool such as [EPIC-CP](#) may be helpful in this assessment.
- Encourage inclusion of caregivers, spouses, or partners in usual prostate cancer survivorship care.
- Refer to appropriate community-based and peer support resources.

View the American Cancer Society Prostate Cancer Survivorship Care Guideline at: [bit.ly/ACSPrCa](https://bit.ly/ACSPrCa)



## MORE RESOURCES FOR HEALTH CARE PROFESSIONALS

- [Information for Health Care Professionals](#): Resources and information about prevention, early detection and survivorship guidelines along with other cancer-related information from the American Cancer Society.
- [Prescription for Cancer Information](#): A tool to help health care professionals talk to survivors about resources available in their office or clinic, in the community, online and over the telephone.
- [Cancer Survivorship E-Learning Series for Primary Care Providers](#): An e-learning series to help primary care providers understand the needs of cancer survivors and deliver better clinical follow-up care. Continuing education credits are available at no cost to physicians, nurse practitioners, physician assistants, nurses and Certified Health Education Specialists. [Download the informational flyer](#) for more information.
- [Coming Soon!] Smartphone App for Primary Care Providers: The American Cancer Society has cancer survivorship care guidelines to help primary care and other clinicians provide clinical follow-up care to adult posttreatment survivors of breast, colorectal, head and neck, and prostate cancer. Evidence-based recommendations address surveillance for recurrence, screening for new cancers, symptom management, healthy lifestyle strategies, and care coordination. Download the app for clinicians to access the guidelines from your Apple or Android smartphone. Share the app with your network of colleagues, especially those in primary care.
- [Advancing Survivorship Care through the National Cancer Survivorship Resource Center: Developing American Cancer Society Guidelines for Primary Care Providers](#): The Survivorship Center has coordinated the work of experts in oncology, primary care and other health care professions to develop follow-up care guidelines for 10 priority cancer sites.
- [National Cancer Survivorship Resource Center: Tools for Health Care Professionals](#): Includes [breast](#), [colorectal](#), [head and neck](#) and [prostate](#) cancer survivorship care guidelines designed to help shape adult post-treatment survivorship care and to improve the quality of life for cancer survivors. These clinical follow-up care guidelines were developed for primary care providers and other clinicians who care for cancer survivors.
- [Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide](#): A brief guide detailing indicators and outcome measures that can be used to monitor the success of survivorship programs.
- [Guide for Delivering Quality Survivorship Care](#): Provides health care professionals with the knowledge, tools and resources to deliver high-quality follow-up care to cancer survivors.

## DISSEMINATION STRATEGIES AND MESSAGES

Looking to spread the word about the latest clinical follow-up care guidelines for cancer survivors but don't know where to start? This section provides strategies, ideas and messages for sharing this toolkit with primary care providers, oncologists, public health professionals, patients and caregivers. Use this section and adapt its messaging for your unique audiences and areas of expertise.

This section was reproduced and adapted from the GW Cancer Institute's *National Cancer Survivors Day® Social Media Toolkit*

### Social Media 101

According to a 2014 Pew Research Center survey, "74% of online adults use social networking sites." (Pew Research Center, 2014). In addition, Hughes (2010) found that, "one-third of adults access social media related to health" (p. 3). Social media represents a unique opportunity to reach a large audience of both consumers and professionals. It is more important than ever that online medical and health information is "trustworthy, engaging, and accessible to digitally empowered consumers" (Hootsuite, n.d., p. 2).

When designing and thinking about your social media strategy, consider your audience, the channel(s) you want to use, your objective(s), or what you are trying to achieve, as well as how you will measure success. Your social media activities should ultimately support your organization's goals (Hootsuite, n.d.).

### Social Media Channels

Social media is growing every day, along with opportunities for outreach. Remember that social media includes more than just Twitter and Facebook—it can include LinkedIn, blogs, websites and e-newsletters. Consider reaching out via multiple channels to increase reach when spreading the word about cancer survivorship care.

### Twitter Best Practices

- Keep Tweets short, between 100-110 characters. This allows other users to Retweet while adding their own comments.
- Add photos or videos. Adding a photo boosts Retweets by 62% on average (Twitter Government and Elections Team, 2014).
- Tweet at author or organizational Twitter handles when possible. If you are mentioning a person/organization at the beginning of a Tweet, add a period (.) before the Tweet, unless you only want the Tweet to be seen by people who are following both of you.



- Twitter, Tweetdeck, Sprout Social and Hootsuite all have options to shorten links as you write Tweets.
- Promote engagement with other organizations by favoriting or Retweeting their content. You can even add your own comment before Retweeting.
- Be responsive and recognize Retweets, @ mentions and when others share your content. It doesn't take much, but a simple "thank you" goes a long way toward building engagement.
- Remember that Tweets cannot be edited once they are posted, so proofread before you post!

### Facebook Best Practices

- Shorter posts (around 250 characters) get up to 60% more distribution than longer posts (CDC, n.d.).
- Use photos or videos to make your posts stand out. Posts with photos receive up to 50% more likes than non-photo posts (Hershkowitz & Lavrusik, 2013). However, be aware of Facebook's policies about what can be posted and identifying people in photos without consent (CDC, n.d.).
- Use a conversational tone and explain to your audience why the content should matter to them (Hershkowitz & Lavrusik, 2013).
- Posts that start conversations by asking questions and responding receive approximately 70% above-average engagement (Hershkowitz & Lavrusik, 2013).
- Vary your post type. Users don't engage the same way with every post (Hershkowitz & Lavrusik, 2013).
- Track your results and act on them. Facebook offers analytic data that you can use to find out what posts are being "liked" or shared and which ones aren't. Focus your efforts on what is working (CDC, n.d.).

In its landmark 2005 report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, the Institute of Medicine identified four key components of quality cancer care:

1. Prevention of recurrent or new cancers that can result from cancer and its treatment
2. Surveillance for cancer spread, recurrence, or second cancers and assessing medical and psychosocial late effects
3. Intervention for side effects of cancer and its treatment, including physical and psychosocial effects as well as non-medical concerns, like employment or financial issues
4. Coordination between specialists and primary care providers

### Best Practices for Communicating about Cancer Survivorship

The first step in any communication campaign is to define your audience. According to the National Cancer Institute (NCI), "a person is considered to be a survivor from the time of diagnosis until the end of life" (NCI, n.d.). When communicating about cancer survivorship, your audience may be primary care providers, oncologists, public health professionals or patients, caregivers or families. The messaging in this toolkit is organized around these main audiences, all with their own unique strategies for outreach and framing. Remember to tailor messages to your organization, since each audience may have subgroups with different needs (for example, survivors who are undergoing active treatment vs. five-year survivors who may be out of active treatment but have distinctive screening and follow-up care needs).

## When communicating with survivors or caregivers...

### 1. Consider health literacy and numeracy

- a) Use simple language and avoid terms not often used outside of the scientific community. Explain how data impacts your audience and why it's relevant (NCI, 2011).
- b) Organize information so the most important points are first (U.S. Department of Health and Human Services, n.d.).
- c) If presenting data, use integers instead of decimals as they are more convincing and easily recalled (Witteman et al., 2011). Visual representations of data, like icon arrays are most effective.
- d) Where possible, point consumers to supporting materials, visuals and reliable, accurate sources of information such as trusted websites or physicians.

### 2. Understand the unique perspectives and needs of survivors

- a) Cancer patients and survivors often face "cancer information overload" and may feel overwhelmed by information and unable to process it (Chae, Lee & Jensen, 2015).
- b) A new study found that on average, cancer survivors maintain a less nutritious diet than those in the general population (Zhang, Liu, John, Must & Demark-Wahnefried, 2015). Messages and interventions that focus on healthy eating may be useful to correct this imbalance.
- c) Young adult cancer survivors may face unique challenges and coping strategies. Coping can include taking action, adaptation and ultimately reflecting on and giving meaning to their experiences (Miedema, Hamilton & Easley, 2007).
- d) Narratives can be an effective tool for communicating with survivors. Storytelling can overcome resistance, facilitate information processing, provide social connections and represent emotional and existential issues (Wen-Ying et al., 2007).
- e) Let patients know about specific resources they can request, like survivorship care plans or long-term recommendations about screening and follow-up.

## When communicating with providers, clinicians or public health professionals...

### 1. Make content accessible on the networks where providers are searching for information

- a) 70% of physicians reported using social media on at least a monthly basis as of 2012 (McGowan et al., 2012), and a 2009 survey found that 81% of physicians reported using a mobile device to access the web (Cooper et al., 2012).
- b) Providers often use social media daily to scan or explore medical information, while 14% of providers report contributing new information via social media on a daily basis (McGowan et al., 2012).
- c) Many providers use physician-only sites like Doximity, Sermo, Ozmosis or medical society membership sites like the American Academy of Pediatrics or the American Medical Association (McGowan et al., 2012). While this toolkit is intended for use on Facebook, Twitter, Google+, LinkedIn and email, the message strategies could easily be adapted to reach providers on other sites as well.

### 2. Emphasize the importance of communication between primary and oncology care providers

- a) In the past decade, more than 60 anti-cancer drugs have been approved by the FDA, each with their own short- and long-term side effects and potential impacts. Resources aimed at primary care providers should emphasize this information and make it more easily accessible.

- b) Decreased involvement by primary care providers is associated with worse overall care and outcomes, particularly for preventive services and non-cancer-related health conditions (Earle & Nevile, 2004; Snyder et al., 2009).
- c) Collaboration between providers can be facilitated by improving role clarity, communication and knowledge exchange between providers (Sussman & Baldwin, 2010).

### 3. Promote survivorship care resources

- a) The American College of Surgeons requires Commission on Cancer (CoC)-accredited programs to “provide a summary of treatment and a follow-up plan to all patients completing cancer treatments” (American College of Surgeons, n.d.).
- b) Providers may not be aware of the CoC requirement or may not be aware of [cancer survivorship care guidelines for cancer survivors](#) available from the National Cancer Survivorship Resource Center as well as the [Cancer Survivorship E-Learning Series for Primary Care Providers](#) that covers follow-up care for survivors of adult-onset cancers.
- c) Remind providers that patients and survivors are often looking for more information. A 1997 study found that patients reported information as their greatest need, including feedback on the progress of the cancer, information about the probable future of their illness or more information about their illness (Butow et al., 1997).

### More Tools and Resources

- [Journey Forward Survivorship Care Plan Builder](#): Helps create customizable survivorship care plans for patients.
- [American Cancer Society Survivorship Care Plans](#): Information on care plans and improving the quality of life for survivors as they move beyond their cancer treatment.
- [National Cancer Survivorship Resource Center](#): Information on treatment, clinical follow-up care and resources for patients and providers.
- [Owly](#): Link shortener from Hootsuite
- [TinyURL](#): Link shortener that allows for customization of URLs to make them more memorable
- [Goo.gl](#): Link shortener that allows for tracking of clicks
- [Hootsuite](#), [Sprout Social](#): Online platforms that allow organizations to schedule Tweets and Facebook posts, keep up with their feed (the posts of those they follow), and collect basic analytics for evaluation
- [Tweetdeck](#): Platform from Twitter that allows for pre-scheduling Tweets, including pre-loading photos
- [Thunderclap](#): Social networking tool that allows you to “crowdsource” your social media campaign to increase its impact
- [Klout](#): Service that tracks your organization’s level of online social influence
- [Canva](#): Allows users to create visually appealing graphics and photos for social media and print materials; includes a collection of low-cost or free stock photos and backgrounds
- [CDC Public Health Image Library \(PHIL\)](#): Free image library. Search “cancer,” “survivorship” or “healthy living” for relevant results on cancer survivorship.

- [CDC "photostream" on Flickr](#): Website designed for public image sharing. CDC images include public health photos and graphics developed for public health events that users can comment on and share. Search "cancer survivors" for relevant results.
- [CDC Infographics](#): Gallery of CDC-designed infographics to visually communicate data or information

## Sample Messages Aimed at Patients and Caregivers

Twitter	
Talking w/ your doc after a #cancer diagnosis can be overwhelming. These resources have symptoms & side effects to ask about: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
#DYK that [ <i>breast, colorectal, head and neck, prostate</i> ] cancer survivors have unique follow-up care needs? This checklist can help you keep track of your care: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
Going from #cancer patient to survivor can be challenging. These tools can help keep you empowered & on top of your care: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
Are you caring for someone with #cancer? This helpful toolkit can help you provide support & organize care: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
Facebook	
Talking with your doctor after a cancer diagnosis can be overwhelming. Use this handy toolkit to help you remember the treatments, symptoms and side effects to ask about: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
Did you know that breast, colorectal, head and neck and prostate cancer survivors have unique follow-up care needs? These tools and checklists can help you keep track of and organize your care: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
Navigating diagnosis, treatment and post-treatment can be difficult when you have cancer. This toolkit can help you understand your options and ways for you to advocate for your care: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
Caregivers: Supporting someone with cancer can be overwhelming. This toolkit can help you empower a loved one fighting cancer and understand what symptoms and side effects to ask about: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
LinkedIn	
Confused about follow-up care for cancer survivors? You're not alone. This National Cancer Survivorship Resource Center toolkit can help you ask the right questions and take charge of your care with the latest information from the American Cancer Society, the American Society of Clinical Oncology and the George Washington University Cancer Institute. Download it today or share with someone you love: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	
Google+	
Patients: When it comes to cancer, it's hard to keep track of treatments, symptoms and side effects. This toolkit from the National Cancer Survivorship Resource Center can help empower you or a loved one to make the most of your care. Download it today or share with someone you love: <a href="http://bit.ly/NCSRCPatients">http://bit.ly/NCSRCPatients</a>	

## Sample Messages Aimed at Primary Care Providers

Twitter	
Primary care providers: #DYK there's an e-learning series on caring for #cancer survivors? Learn more: <a href="http://bit.ly/PCPE-Learning">http://bit.ly/PCPE-Learning</a>	
Primary care providers: Keeping track of symptoms & side effects for #cancer patients can be tough. This toolkit can help: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
>60 #cancer drugs have been approved by @US_FDA in the last 10 yrs. Track follow-up care, late/long-term effects w/ this toolkit: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Coordinating #cancer care for survivors can be tough. This guide can help you communicate w/oncologists & organize care: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Facebook	
Primary care providers: Did you know there's an e-learning series on caring for cancer survivors just for you? Learn more and access the course: <a href="http://bit.ly/PCPE-Learning">http://bit.ly/PCPE-Learning</a>	
Keeping track of symptoms, late and long-term effects for cancer patients can be challenging. This toolkit provides guidance on quality clinical follow-up care for breast, colorectal, head and neck and prostate cancer survivors. Read more: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Over 60 new anti-cancer drugs have been approved by the FDA in the last 10 years, making follow-up care challenging. Get the latest recommendations and summaries of late and long-term effects here: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Care coordination is a priority for cancer patients during and after treatment. Primary care providers play a key role in follow-up care and communication with oncologists. This toolkit from the American Cancer Society and the George Washington University Cancer Institute summarizes the latest clinical care follow-up guidelines to help you provide high quality care: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
LinkedIn	
Primary care providers: Get the latest clinical care guidelines for cancer survivors with this handy toolkit from the American Cancer Society and the George Washington University Cancer Institute: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a> . Follow-up care guidelines are also covered in depth in the e-learning series for primary care providers, with CEUs available at no cost to providers. Register today: <a href="http://bit.ly/PCPE-Learning">http://bit.ly/PCPE-Learning</a>	
Google+	
Primary care providers: It can be challenging to get the latest info on caring for cancer survivors. Luckily, there's an e-learning series designed just for you. Access it today <a href="http://bit.ly/PCPE-Learning">http://bit.ly/PCPE-Learning</a> and don't miss out on the companion National Cancer Survivorship Resource Center Toolkit summarizing clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer survivors: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	



## Sample Messages Aimed at Oncologists

Twitter 	
Oncology providers: #DYK there's an e-learning series on caring for #cancer survivors? Learn more: <a href="http://bit.ly/PCPE-Learning">http://bit.ly/PCPE-Learning</a>	
Oncology providers: It's more important than ever to coordinate care w/PCPs. This toolkit can help: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Survivorship care plans are now a routine standard of care for #cancer patients. Learn more w/this toolkit: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Oncology providers: Have you seen the latest toolkit from @AmericanCancer and @GWCancerInst? Stay up-to-date on the latest in #survivorship care: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Facebook 	
Oncology providers: You play a critical role in coordinating follow-up care for cancer patients. Get the latest clinical follow-up care guidelines to inform survivorship care plans for your patients and coordinate with primary care providers. Download the American Cancer Society and the George Washington University Cancer Institute's toolkit today: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
The Commission on Cancer now requires providers to provide all patients with a survivorship care plan. This toolkit provides guidance on quality clinical follow-up care for breast, colorectal, head and neck and prostate cancer patients to inform survivorship care planning. Read more: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Cancer survivors often feel "lost in transition" after treatment. Help provide quality care for your patients and get the latest clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer patients: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Care coordination is a priority for cancer patients during and after treatment. Oncology providers play a key role in follow-up care and communication with primary care providers. This toolkit from the American Cancer Society and the George Washington University Cancer Institute summarizes the latest clinical follow-up care guidelines to help you provide high quality care and inform survivorship care planning: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
LinkedIn 	
Oncology providers: Get the latest clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer survivors with this handy toolkit from the American Cancer Society and the George Washington University Cancer Institute: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a> .	
Google+ 	
The Commission on Cancer requires survivorship care plans for cancer patients. Get the latest clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer survivors here: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	

## Sample Messages Aimed at Public Health Professionals

Twitter	
#CompCancer professionals: Looking to improve the quality of cancer #survivorship care? This toolkit can help: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Coordination→quality #cancer care. Support coordination between primary care providers & oncologists w/this toolkit: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
#DYK there's a toolkit to help improve care for #cancer survivors? Share & download today: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Quality #cancer care is a #publichealth issue. Support the latest in survivorship care w/this toolkit: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
#CompCancer professionals: #DYK there's an e-learning series on #cancer survivorship? Spread the word today: <a href="http://bit.ly/PCPE-Learning">http://bit.ly/PCPE-Learning</a>	
Facebook	
Comprehensive cancer control professionals: Are you looking to improve the quality of cancer survivorship care and support survivorship care plans as a routine standard of care? This toolkit from the American Cancer Society and the George Washington University Cancer Institute can help: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Coordination is a key part of quality cancer care. Support high quality care with these cancer survivorship care guidelines for breast, colorectal, head and neck and prostate cancer. Read more and help spread the word in your community about these new guidelines: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Did you know there's an e-learning series on cancer survivorship for primary care providers? Comprehensive cancer professionals: Spread the word and share with providers in your area: <a href="http://bit.ly/PCPE-Learning">http://bit.ly/PCPE-Learning</a>	
Cancer survivors often feel "lost in transition" after treatment. Help provide quality comprehensive cancer follow-up care for cancer survivors and promote the latest clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
Care coordination is a priority for cancer patients during and after treatment and the Commission on Cancer now requires survivorship care plans as a routine part of care. This toolkit from the American Cancer Society and the George Washington University Cancer Institute summarizes the latest clinical care guidelines so you can promote high quality care and inform survivorship care planning: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	
LinkedIn	
Comprehensive cancer control professionals: Get the latest clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer survivors and spread the word with this handy toolkit from the American Cancer Society and the George Washington University Cancer Institute: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a> .	
Google+	
The Commission on Cancer requires survivorship care plans for cancer patients. Get the latest clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer survivors and spread the word to other comprehensive cancer control professionals here: <a href="http://bit.ly/NCSRCToolkit">http://bit.ly/NCSRCToolkit</a>	

## **Sample Email Message to Primary Care Providers, Oncology Providers or Public Health Professionals**

With the number of cancer survivors expected to grow to over 18 million by the year 2020, it has never been more critical to champion quality clinical follow-up care guidelines for cancer survivors. A new Commission on Cancer Accreditation Standard requires Survivorship Care Plans (treatment summary + follow-up care plan) be given to and discussed with patients treated with curative intent who are finishing active treatment, so this practice is becoming part of the standard of care.

As primary care providers and oncology providers seek to meet this standard and coordinate follow-up care for survivors, it's important to have the latest clinical follow-up care guidelines at your fingertips. The American Cancer Society and the George Washington University Cancer Institute have released a National Cancer Survivorship Resource Center Toolkit: Implementing Clinical Practice Guidelines for Cancer Survivorship Care.

This toolkit offers summaries of the latest clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer survivors, including late and long-term treatment effects, summaries of care guidelines and checklists for primary care providers. These guidelines can inform survivorship care plans, support patient empowerment and ensure care coordination between primary care and oncology providers across the care continuum. Download the toolkit today and share with your colleagues:

<http://bit.ly/NCSRCToolkit>

## **Sample Email Message to Patients or Caregivers**

Did you know that in cancer, a person is considered to be a survivor from the time of diagnosis until the end of life? Receiving a cancer diagnosis can be overwhelming, but navigating treatment and follow-up care can be even more so. How do you navigate the transition from your cancer care team to your primary care doctor? What are potential long-term and late side effects from cancer and its treatment? These checklists from The National Cancer Survivorship Resource Center Toolkit: Implementing Clinical Practice Guidelines for Cancer Survivorship Care from the American Cancer Society and the George Washington University Cancer Institute can help you take charge of your care or the care of a loved one.

Learn more about treatment and side effects for breast, colorectal, head and neck and prostate cancers. Get checklists of questions to ask your doctor and additional tools to support patient and caregiver empowerment. Download or share the no-cost toolkit here <http://bit.ly/NCSRCPatients> and be a prepared patient today.

## Sample Press Release about the National Cancer Survivorship Resource Center Toolkit

Be sure to customize this press release—including all quotes and relevant information about your organization—before publishing.

### CONTACT:

Name

Email address

Phone:

### New Toolkit Highlights Need for Quality Follow-up Care for Cancer Survivors

*New cancer survivorship care guidelines help primary care providers coordinate care with cancer team, patients and caregivers*

WASHINGTON, DC - The American Cancer Society and the George Washington University Cancer Institute released a new toolkit on the latest clinical follow-up care guidelines for breast, colorectal, head and neck and prostate cancer survivors.

This toolkit is part of a broader effort to meet the needs of cancer survivors, a group that is projected to top 18 million in the U.S. by 2020. The American College of Surgeons' Commission on Cancer recently implemented new accreditation standards that require patients to be provided with a survivorship care plan (a treatment summary and clinical follow-up care guidelines). These guidelines, summarized in the National Cancer Survivorship Resource Center Toolkit, are intended to help primary care and oncology providers coordinate care and implement quality survivorship care plans for patients.

The National Cancer Survivorship Resource Center Toolkit: Implementing Clinical Practice Guidelines for Cancer Survivorship Care includes resources to help with implementing cancer survivorship care based on the American Cancer Society cancer survivorship care guidelines for post-treatment survivorship care in colorectal, head and neck and prostate cancers and the American Cancer Society/American Society of Clinical Oncology cancer survivorship care guideline for breast cancer. In addition to the guidelines, information is provided on training opportunities for primary care providers and patient materials to help activate cancer survivors to be full participants in their survivorship care.

"We've made significant progress in caring for cancer survivors after diagnosis, but as many survivors can attest, primary care providers and oncology providers are often uncoordinated when it comes to following up with patients," said [INSERT NAME AND TITLE]. "This toolkit fills the gap for primary care and oncology providers by helping them keep track of late and long-term treatment effects and helps support patient empowerment in their care."

The toolkit was created to be used by primary care and oncology providers, comprehensive cancer control professionals and patient navigators with summary checklists also available for patients or caregivers.

The goals of the toolkit are to:

- Educate primary care and oncology providers about clinical follow-up care needs of cancer survivors
- Provide tools primary care and oncology providers can implement to improve care for cancer survivors
- Equip patients with tools to discuss their long-term health with providers
- Highlight free continuing education resources to help improve survivorship care

“The information and free resources provided in this toolkit can be used to enhance practice and help ensure cancer survivors receive evidence-based follow-up care,” said [INSERT NAME].

For more information and to download the toolkit, visit <http://bit.ly/NCSRCToolkit>. An e-learning series for primary care providers based on the survivorship care guidelines is also available from <http://bit.ly/PCPE-Learning>.

### **About [INSERT YOUR ORGANIZATION’S NAME HERE]**

[Include general information about your organization to provide journalists with background information about the institution the news is coming from.]

###

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