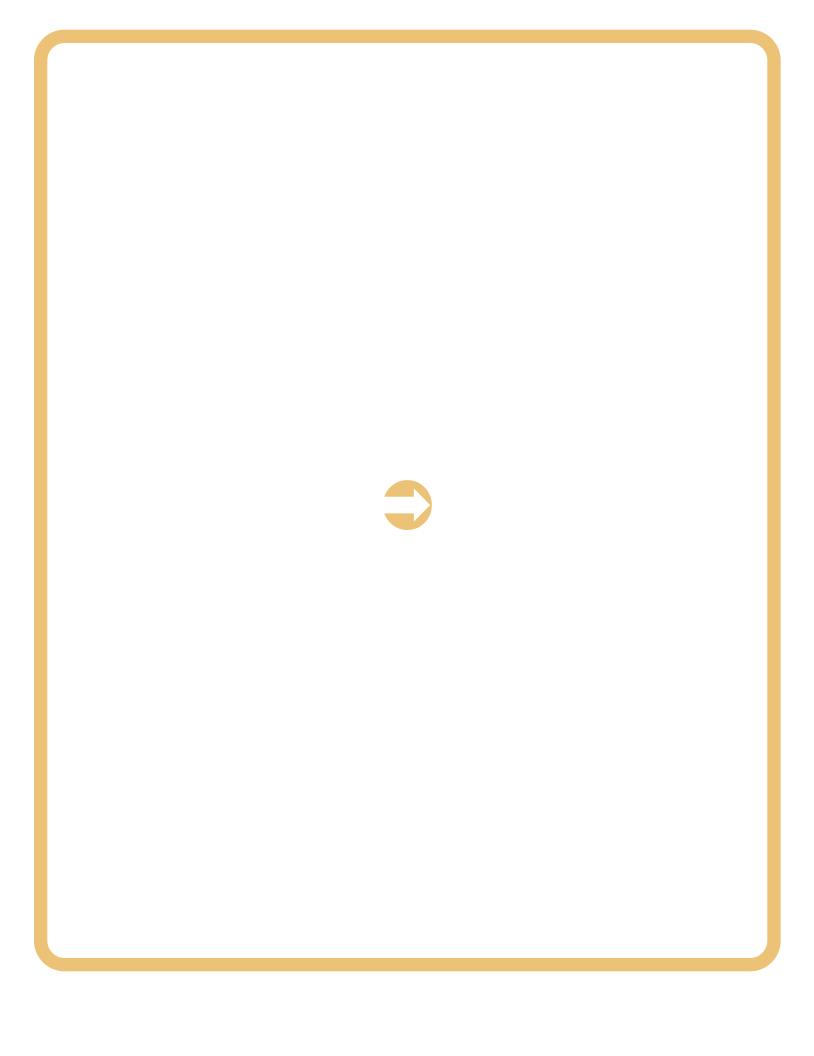


2024

Survivorship Care for Cancer-Related Late and Long-Term Effects







About the NCCN Guidelines for Patients®



Did you know that top cancer centers across the United States work together to improve cancer care? This alliance of leading cancer centers is called the National Comprehensive Cancer Network® (NCCN®).



Cancer care is always changing. NCCN develops evidence-based cancer care recommendations used by health care providers worldwide. These frequently updated recommendations are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). The NCCN Guidelines for Patients plainly explain these expert recommendations for people with cancer and caregivers.

These NCCN Guidelines for Patients are based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Survivorship, Version 1.2024 — March 29, 2024.

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Survivorship Care for Cancer-Related Late and Long-Term Effects

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Making treatment decisions

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1 About survivorship

- 5 Who is a cancer survivor?
- 5 What is survivorship care?
- 6 When should survivorship care start?
- 7 Key points

People with cancer are living longer than they did in the past. They are surviving, and their needs have changed. Survivorship care includes recovering from cancer and promoting health.

Who is a cancer survivor?

Cancer survivors are people living with cancer and those free of cancer. Survivorship starts at the time of cancer diagnosis and continues through life.

Some people do not like or identify with the term survivor. It is not meant to be a label. Its purpose is to identify the community of people with a history of cancer. Having a common term is useful for improving the care of survivors.

What is survivorship care?

Survivorship care improves health, wellness, and quality of life. Its focus is on the wide and lasting impact of cancer and its treatment. It addresses physical and mental health, health behaviors, professional and personal identity, and finances, just to name a few.

NCCN Guidelines for Patients

Many books in the library of NCCN Guidelines for Patients cover aspects of survivorship care.

- Most NCCN Guidelines for Patients focus on a type of cancer. They often describe unique details about surveillance and supportive care for that cancer type.
- The NCCN Guidelines for Patients for Adolescent and Young Adult Cancer address unique survivorship needs of people ages 15 through 39 years.
- The NCCN Guidelines for Patients for Palliative Care address patient, family, and caregiver needs for comprehensive care during cancer treatment as well as at the end of life.
- This book is part of a two-part book series on survivorship. Read the other survivorship book to get help for setting and achieving goals for healthy living.

The library of NCCN Guidelines for Patients is available at NCCN.org/ patientguidelines and on the NCCN Patient Guides for Cancer app.

Standards of survivorship care include:

- Routine testing for the return of a cancer (surveillance) and new cancers (screening)
- Routine testing for late and long-term effects of cancer and treatment
- Prevention of harmful effects of cancer and treatment
- Management of cancer-related challenges including referral to specialists
- Coordinated care between providers
- Planning for ongoing survivorship care

To plan survivorship care, your cancer or primary care provider will assess your needs. Ongoing care requires that you see one or both providers at least once a year. They will review your cancer care, health history, current abilities, and medications.

Your providers may create and review a survivorship plan with you. You will be given a schedule of follow-up visits. Possible cancerrelated late effects may be included in the plan. Your providers may refer you to other specialists and community resources.

When should survivorship care start?

Although survivorship care often begins after initial treatment ends, many care recommendations can be started during treatment to prevent or lessen cancer-related effects.

Many effects of cancer treatment, such as nausea and vomiting, quickly resolve after treatment ends. On the other hand, some effects don't go away or only start after treatment.

- Long-term effects start during treatment and persist after treatment is done.
 Cognitive problems and fatigue can be long-term effects.
- Late effects occur long after treatment has ended. Second cancers are late effects.

This book can help you get care for late and long-term effects. It is written for survivors with an onset of cancer in adulthood. It explains expert recommendations that are based on the latest science and practices at top cancer centers.

There are often many ways to get relief from cancer-related effects. Sometimes, effects can even be prevented. To get relief, there may be self-management and coping skills to learn. Professional care may include prescribed drugs and non-drug treatment.

Discuss survivorship care with your health care providers. In the last chapter, there is a list of suggested questions to ask your providers. You're more likely to get the care you want by

asking questions and making decisions with your team.

Key points

- A person with cancer is a survivor starting at diagnosis and through the balance of their life.
- Survivorship care improves health, wellness, and quality of life. Your team of care providers will work together to meet your changing needs.
- Talk to your health care providers about the effects described in this book. Early intervention is the best way to treat them!

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I told my care team right away when I noticed a side effect. This really helped. They were very good at treating it!"

2 Second cancers

- 9 Causes of second cancers
- 9 Hereditary cancers
- 10 Screening for second cancers
- 12 Preventing second cancers
- 12 Key points

As a cancer survivor, you have an increased risk of a second cancer forming. This chapter explains testing for second cancers before symptoms appear.

Causes of second cancers

A small number of cancer survivors develop second cancers. These second cancers develop years after treatment, when you may not be seeing an oncologist anymore.

Second cancers are not the return of the prior cancer. They are different. For example, a survivor may get lung cancer after being diagnosed with breast cancer. It is also possible to develop a second cancer that is the same type as a prior cancer. An example is two primary breast cancers.

Although few survivors get second cancers, more survivors develop cancers than the general public because of several reasons:

- Some causes of the first cancer may be related to getting a second cancer. These causes include genetics passed down from parents, family history, smoking, some viral infections, and exposure to cancer-causing agents.
- Some cancer treatments may increase cancer risk. Such treatments include radiation therapy, certain chemotherapies, and certain targeted therapies.

Hereditary cancers

Some second cancers occur because they are hereditary cancers. Hereditary cancer is caused by abnormal genes that are passed down from parents to children. Cancers that can be hereditary include breast, ovarian, colorectal, and prostate cancer.

Your oncologist will assess if you are at risk for hereditary cancers. The signs of hereditary cancer include:

- Having cancer at an early age
- Diagnosis of rare cancers, multiple primary cancers, or cancer related to a high-risk cancer syndrome
- Having blood relatives with the same or related cancers

At health visits, update your health care providers on any new cancers among your blood relatives. Your provider may suggest getting genetic testing. A blood sample is needed. You may talk with a genetic counselor to discuss your family's cancer history.

Screening for second cancers

Cancer screening is routine testing of cancer or pre-cancer conditions. The aim is to detect cancer at an early stage when treatment works best. Ask your health care provider what screening you need.

General screening

There are cancer screening programs for the general public. People start screening when they have either an average or high risk of cancer. The risk level that prompts screening varies between cancers. There is standard screening for breast, cervical, colorectal, lung, prostate, and skin cancers.

More information on screening for colorectal and lung cancer is available at NCCN.org/ patientguidelines and on the NCCN Patient Guides for Cancer app.





Treatment-related screening

Certain cancer treatments increase the risk of a second cancer. Risk is based on the type and intensity of the treatment.

Treatment-related second cancers are listed in **Guide 1**-

If you are at risk for treatment-related cancers, you may get screening tests. As part of

Screening vs. surveillance

What's the difference between screening and surveillance? Both involve testing for cancer but have different purposes.

Screening

Cancer screening is routine testing for a new cancer or pre-cancer conditions. The aim is to detect cancer at an early stage when treatment works best.

Surveillance

Cancer that was thought to be cured can reappear on tests. The return of cancer is called a recurrence or relapse. Survivorship care includes routine checking for a recurrence. This is called surveillance. Surveillance often includes updating your health history and a physical exam. Some survivors get blood tests or imaging like x-rays or scans.

screening, your provider will obtain your health history and do a physical exam every year. Common screening methods for second cancers are:

- Skin exams for skin cancer
- Blood tests for blood cancers
- Imaging for cancers in deep tissue, such as the brain and lungs

Prior treatment	Second cancers
Radiation therapy to the skull	Meningiomas Skin cancer
Radiation therapy to the head and neck	 Head and neck cancer Thyroid cancer Skin cancer Salivary gland cancer Soft tissue sarcoma
Radiation therapy to the chest that may extend to the neck and armpit	 Breast cancer if assigned female at birth Skin cancer Soft tissue sarcoma Lung cancer Thyroid and parathyroid cancer
Radiation therapy to the abdomen or pelvis	Colorectal cancerSkin cancerSoft tissue sarcoma
Radiation therapy to the limbs, hands, and feet	Skin cancer Soft tissue sarcoma
Hematopoietic cell transplantation	Blood and solid cancers
Alkylating agents Anthracyclines Epipodophyllotoxins	Blood cancers
Alkylating agents	Bladder cancer
Tamoxifen	Endometrial cancer
PARP inhibitors Lutetium-octreotide	Acute myeloid leukemia (AML)Myelodysplastic syndromes (MDS)

Preventing second cancers

Prevention of second (and recurring) cancers is a key part of survivorship care. You can reduce your risk of cancer with healthy living. Healthy living includes physical activity, eating well, sun protection, and not using tobacco.

Less often, medical treatments are used to prevent cancer. For example, some people do one or more of the following:

- Have surgery to remove a body part, like a breast, where cancer is likely to start.
- Take medication that lowers hormone levels to reduce the chance of getting cancer.
- Get the human papillomavirus (HPV) vaccine, which can be received up to 45 years of age.

More information on healthy living and vaccinations is available at NCCN.org/
patientguidelines and on the NCCN Patient Guides for Cancer app.



Key points

- A small number of cancer survivors develop a new cancer. The increased risk for second cancers is due in part to some causes of the first cancer and certain cancer treatments.
- Some cancers are hereditary which means the risk was passed down from parents. Your provider will assess if you're at risk for an inherited cancer.
- Cancer survivors participate in general cancer screening but may also get extra screening. Extra screening is based on prior cancer treatment and current signs and symptoms of cancer.
- Common methods of preventing second cancers include lifestyle changes and vaccines. Less often, survivors undergo surgery or receive hormone-directed drugs.

3 Hormone-related symptoms

- 14 Sex hormones and cancer
- 14 Type and timing of symptoms
- 16 Assessment of symptoms
- 16 Treatment of hot flashes
- 18 Treatment of gynecomastia
- 18 Treatment of urogenital problems
- 18 Key points

Some cancer treatments affect hormones. Hot flashes are one of many symptoms that may occur as a result. Read this chapter to learn about hormone-related symptoms and their treatment.

Sex hormones and cancer

Sex hormones play a key role in puberty, having babies, and overall health. Levels of sex hormones naturally vary between people based on their sex organs and age. Cancer treatment can cause drastic changes in sex hormones.

Estrogen and progesterone

If you have menstrual periods, your ovaries make most of the main sex hormones, called estrogen and progesterone, in your body. Levels of these hormones quickly drop when menstrual periods stop occurring.

Cancer survivors often have low estrogen and progesterone because of the following:

- Nearing or reaching the natural end of menstrual periods caused by aging
- Surgery, called oophorectomy, that removes ovaries
- Cancer drugs that stop the ovaries from working while taking them
- Chemotherapy, pelvic radiation, and surgery that damage the ovaries

Androgens

If you have testicles, they make most of the main sex hormones, called androgens, in your body. Over decades, the testicles slowly decrease making androgens.

Some cancer treatments cause a fast and large drop in androgen levels. Such treatments include:

- A surgery, called orchiectomy, that removes one or both testicles
- Cancer drugs that stop the testicles from making androgens
- Chemotherapy, pelvic radiation, and surgery that damage the testicles

Type and timing of symptoms

A big change in the amount or activity of sex hormones often causes health issues. These hormone-related health issues are listed in **Guide 2.**

Menopausal symptoms and risks

The end of menstrual cycles caused by natural aging or oophorectomy is called menopause. Health care providers identify natural menopause by an absence of menstrual periods for at least 12 months. Menopausal symptoms and risks can occur at these times:

- During the years leading up to natural menopause
- After natural or surgical menopause
- During treatment that pauses ovarian function

Androgen deprivation symptoms and risks

The slow, natural drop in androgens from testicles does not have the same effect as menopause. For example, the gradual decrease does not cause hot flashes. The sharp drop in androgens caused by cancer treatment does cause symptoms and health risks like those related to menopause.



I was on ADT for 14 months. I had hot flashes several times during the day and usually once at night. A year and a half after my ADT ended, my hot flashes were gone."

Guide 2 Hormone-related symptoms and risks

Menopausal symptoms and risks

General effects

- · Hot flashes, night sweats
- Fatigue

Mental effects

- Cognitive changes
- Mood changes, such as depression
- · Sleep disturbance

Organ effects

- · Heart disease
- · Joint pain and muscle aches
- Urogenital problems like urinary tract infections
- · Weak bones and fractures

Sexual/reproductive effects

- Sexual dysfunction
- · Vaginal dryness

Androgen-deprivation symptoms and risks

General effects

- · Hot flashes, night sweats
- Fatigue
- Hair loss

Mental effects

- Cognitive changes
- Mood changes, such as depression
- Sleep disturbance

Organ effects

- Anemia
- Diabetes
- · Heart disease or blood clots
- Joint pain and muscle aches
- Sudden kidney injury
- · Less muscle and more fat
- · Weak bones and fractures

Sexual/reproductive effects

- Enlarged breasts
- Sexual dysfunction
- Smaller penis or testicles

Assessment of symptoms

Your health care provider may ask about symptoms related to changes in sex hormones. If the symptoms cause problems, your provider will do an assessment. The cause of the symptoms will be confirmed. Be ready to give an update on your health history and medications. You may get blood tests of sex hormones and a physical exam.

There is treatment for many hormone-related symptoms:

- Read the other chapters in this book that cover heart disease, cognitive problems, sexual dysfunction, fatigue, sleep problems, pain, and mental health.
- Read NCCN Guidelines for Patients for Anemia and Neutropenia to learn about the treatment of anemia.
- The next sections in this chapter focus on hot flashes, gynecomastia, and urogenital problems.

Treatment of hot flashes

Hot flashes are a sudden feeling of warmth in the upper body. During a hot flash, many people sweat and their skin looks flushed. The intensity of hot flashes can range from mild to severe. Hot flashes are sometimes called hot flushes, night sweats and vasomotor symptoms. Treatment for hot flashes is listed in **Guide 3.**

Menopausal hot flashes

Hormones may be used to treat hot flashes but are not safe for some cancer survivors.

Estrogen by itself may be used to treat survivors whose uterus has been removed. It is given with progestin when the uterus is intact

There are medicines without hormones that reduce hot flashes. These medicines include antidepressants, anticonvulsants, blood pressure medicine, and muscle relaxers. At low doses, antidepressants and anticonvulsants treat hot flashes. Fezolinetant (Veozah) is a new treatment for hot flashes but needs to be tested among people with breast cancer.

Hot flashes may be reduced by methods other than drugs. Acupuncture, yoga, and hypnosis may help. Healthy living improves overall health and may relieve hot flashes. Avoid drinking alcohol if it is a trigger of hot flashes. Cognitive behavioral therapy (CBT) may help reduce the impact of hot flashes.

You may be taking supplements for hot flashes. However, some may interfere with cancer treatment. Tell your provider about all the medicines and supplements you take.

Androgen-deprivation hot flashes

If you're on androgen deprivation therapy (ADT), a change in the prescription may help. You may be able to take breaks from ADT to relieve side effects like hot flashes. This treatment approach is called intermittent ADT.

Hormones can be used to treat hot flashes in some survivors. Medroxyprogesterone, estrogen, and cyproterone acetate relieve hot flashes caused by ADT. Androgens treat hot flashes caused by treatment-damaged

testicles. Otherwise, androgens should not be taken by cancer survivors.

There are several non-hormonal treatments for hot flashes caused by low androgens. Venlafaxine and gabapentin are drugs that may help. Other options include acupuncture, reducing alcohol use, and CBT. You may get relief by attaining a healthy weight and exercising.

You may be taking supplements for hot flashes. However, some may interfere with cancer treatment. Tell your provider about all the medicines and supplements you take.

Guide 3 Treatment for hot flashes

Hormones

- Estrogen with progestins
- Estrogen
- Estrogen with bazedoxifene

Menopausal hot flashes

Antidepressants

- Venlafaxine (preferred antidepressant)
- Desvenlafaxine
- Escitalopram
- Citalopram
- Sertraline
- Paroxetine
- Fluoxetine

Anti-convulsants

- Gabapentin (preferred anticonvulsant)
- Pregabalin

Other medicines

- Clonidine
- Oxybutynin
- Fezolinetant

Non-drug treatment

- Acupuncture
- Healthy living
- Cognitive behavioral therapy
- Hypnosis
- Yoga
- · Limit alcohol use

Androgen-deprivation hot flashes

Hormones

- Medroxyprogesterone acetate
- · Cyproterone acetate
- Estrogen

Antidepressants

Venlafaxine

Anti-convulsants

Gabapentin

Non-drug treatment

- Acupuncture
- Healthy living
- CBT
- Limit alcohol use

Treatment of gynecomastia

Gynecomastia is an enlargement of breast tissue that sometimes happens during ADT. Breasts also enlarge because of aging and certain health conditions.

There are 3 treatments for gynecomastia. One option is radiation to the breasts before they enlarge. Another option is a medication called tamoxifen. Tamoxifen stops the action of estrogen in breast tissue. The third option is surgery that removes breast tissue. This surgery is called reduction mammoplasty.

Treatment of urogenital problems

Urogenital problems are a common menopausal symptom. They are related to the thinning of the vaginal or urinary tract wall. Such problems include:

- Urine leaks (incontinence)
- Pain when urinating
- Urinary tract infection (UTI)
- Vaginal discomfort

Treatment options include estrogen or testosterone applied to the vagina. Be aware that vaginal hormones may not be safe for survivors of estrogen-dependent cancers. You may also be referred to a specialist for care.

Key points

- A change in sex hormones may cause unwanted symptoms. If these symptoms are problematic, an assessment that may include blood tests is needed.
- Hot flashes are a sudden feeling of warmth in the upper body. The intensity of hot flashes can range from mild to severe.
- Treatment of hot flashes with hormones is safe for some survivors. There are several other drug treatments that can be used too. Some people get relief from acupuncture, healthy living, and cognitive behavioral therapy.
- Enlarged breast tissue caused by low androgens can be prevented with radiation and treated with tamoxifen and surgery.
- Urogenital problems can be treated with hormones applied to the vagina.

4

Heart disease

- 20 Heart disease and cancer
- 21 Preventing heart disease
- 23 Managing heart failure
- 25 Key points

This chapter explains how you and your care team can lower your risk for heart disease.

Heart disease and cancer

What is heart disease?

Heart disease is a group of disorders of the heart and blood vessels. It's also called cardiovascular disease. Many people think of heart attacks when they hear the term heart disease, but it's a much larger set of health problems. Some types of heart disease are listed in **Guide 4.**

What's the connection between cancer and heart disease?

Some risk factors for cancer are also risk factors for heart disease. Also, some cancer treatments increase the chance of heart disease.

A risk factor is anything that increases your chance for disease. Shared risk factors for

Arrhythmia	An abnormal rate or pattern of the heartbeat.
Atherosclerosis	A fatty buildup in the inner walls of arteries that may restrict blood flow.
Atrial fibrillation (Afib)	An abnormal beating of the top chambers of the heart.
Cardiomyopathy	Diseased heart muscle.
Cerebrovascular disease	Disorders of blood vessels in the brain.
Coronary artery disease	Disorders of the arteries that encase the heart.
Heart failure	An inability of the heart to pump enough blood. Also called congestive heart failure.
Peripheral vascular disease	Disorders of blood vessels outside the heart. Also called peripheral arterial disease.
Ventricular fibrillation	An abnormal beating of the bottom chambers of the heart.

both cancer and heart disease include age, smoking, and obesity. It's important that an assessment of heart disease be done before starting cancer treatment.

Cancer treatments that may damage the heart are described as cardiotoxic. Cardiotoxic cancer treatments kill cancer cells as well as healthy heart cells. Cancer treatments that may cause heart problems include:

- Chemotherapy called cisplatin and anthracycline
- Targeted therapy called VEGF inhibitors and HER2-directed therapy
- Hormone therapy called androgen deprivation therapy (ADT)
- > Hematopoietic cell transplant
- Radiation therapy near the heart
- Immunotherapy called immune checkpoint inhibitors

When does heart disease start after a cancer diagnosis?

The start of heart disease varies among cancer survivors. But in all cases, there is time to prevent or control heart disease with healthy living and treatment.

- Heart disease may start during or shortly after cardiotoxic drug treatment.
- Heart disease may occur years after radiation therapy in the chest.
- Heart disease that is not related to cancer treatment most often develops 5 or more years after cancer diagnosis.

Preventing heart disease

It takes teamwork to prevent heart disease. This section explains what you and your providers can do to keep your heart healthy.

Get coordinated care

Your health care providers should work together to help you. Better results are achieved when cancer and primary care providers cooperate and share care. You may also receive care from a heart specialist.

Reduce risk factors

Your care team will develop a plan to prevent heart disease. Many risk factors for heart disease can be managed:

- Health conditions that can be managed are high blood pressure (hypertension), high cholesterol, obesity, and high blood sugar (diabetes).
- Lifestyle choices that can be managed include your diet, how active you are, smoking, and drinking alcohol.

Follow the ABCDE tool

The ABCDE tool can be used to decrease the chance of heart disease. It lists important steps to follow. An adapted ABCDE tool for cancer survivors is listed in **Guide 5**.

One of the first steps of heart wellness is awareness. Learn what risk factors for heart disease you have. You might be able to lower your risk. Also, learn about the signs and symptoms of heart disease. You'll be able to tell your providers if symptoms start or worsen.

Your care team will assess if you have or are at risk for heart disease. Testing of your heart with an echocardiogram (echo), electrocardiogram (ECG or EKG), or both may be needed. An echocardiogram detects structural changes in the heart. An electrocardiogram detects abnormal heartbeats.

Ask your care team if your cancer treatment may damage your heart. Radiation near the heart may be harmful. Certain chemotherapy drugs, like anthracyclines, may also cause heart damage. Heart damage from radiation therapy or chemotherapy is related to the dosage. Doses have been standardized to treat cancer and limit heart damage.

Someone on your care team will monitor for heart disease. Your primary care provider is likely the one who will monitor you. They will measure your weight, blood pressure, and cholesterol on a regular basis. You will be screened for diabetes. Be prepared to discuss your exercise, eating, and tobacco habits.

Your health care providers will help you reduce your risk of heart disease. They can manage health conditions. They can give you recommendations for healthy living.

Taking aspirin once a day may decrease the risk of heart attack and stroke. Its benefits vary between people. It may cause unwanted effects. Ask your provider if you should take aspirin to lower your chance of heart disease.

Guide 5 The ABCDEs of heart wellness in cancer survivors				
A	 Awareness of the risk factors and symptoms of heart disease Assessment of being at risk for or having heart disease Aspirin if needed 			
В	Blood pressure management			
С	Cholesterol management Cigarettes and other tobacco products are not used			
D	 Diet and weight management Doses of anthracyclines and chest radiation are standard Diabetes prevention and treatment 			
E	Exercise Echocardiogram, electrocardiogram, or both—if needed			

Managing heart failure

Anthracycline is a type of chemotherapy that increases the risk of heart failure. It includes doxorubicin, daunorubicin, epirubicin, and idarubicin. Heart failure means that the heart can't pump enough blood. When heart failure is managed, people can have full lives.

Early heart failure screening

Heart failure is best managed when it is identified early. If you have a high risk for heart failure, get screened within 1 year after anthracycline treatment. Risk is partly based on which anthracycline was received and the total dose. A high doxorubicin dose of 250 mg/m² or above is more likely to be toxic.

An assessment of heart failure includes a review of your health history. Your provider will ask about your health problems, medicines, and lifestyle, such as alcohol use. You will also

be asked about symptoms of heart failure, which include:

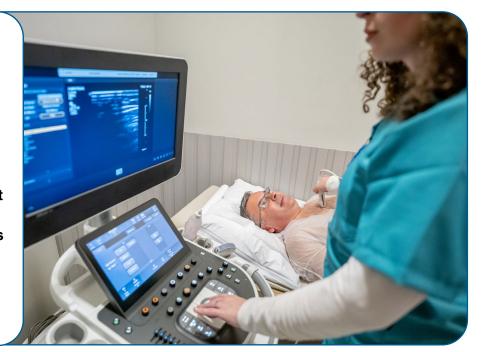
- Shortness of breath or chest pain after physical activity
- Shortness of breath when sleeping
- Waking up from shortness of breath

Your provider will examine your body. They will look for swelling caused by a buildup of blood. They will also assess your ability to do day-to-day activities.

Your care team must know your risk factors for heart failure. You may get bloodwork and heart tests. You'll likely get an echocardiogram (echo) if you had a high anthracycline dose, have other risk factors, or have symptoms of heart failure.

Echocardiogram

An echocardiogram makes pictures of the heart. A technician will move an ultrasound device on your chest and record the pictures. Your health care provider will discuss the results with you.



Prevention and early treatment

Heart failure may be prevented or managed with drug treatment. The type of care that you'll receive is based on the stage of heart failure. The 4 stages of heart failure are described in **Guide 6**.

Stage A means you're at risk of heart failure. NCCN experts encourage cancer and primary care providers to work together to manage stage A. Heart failure may be prevented by following the ABCDEs of heart wellness. Your team will keep checking for heart failure. Keep in mind that heart failure may not show until many years after cancer treatment.

Stage B is the beginning of heart failure. In this stage, there is structural heart disease, such as thinning of the heart wall. Heart failure usually worsens over time. In stage C, signs or symptoms of heart failure appear. Severe structural disease or symptoms is stage D heart failure.

A heart specialist treats stage B, C, and D heart failure. This specialist may be a cardiologist or cardio-oncologist. They may prescribe medication and other treatments to keep your heart as healthy as possible.

Guide 6 Stages o	f heart failure
Stage A	In stage A, you do not have heart failure but are at risk. This stage is treated by cancer and primary care providers. They will manage risk factors for heart failure an may refer you to a cardio-oncologist, survivorship specialist, or primary care provide for heart testing.
Stage B	In stage B, you have heart failure. There is structural heart disease but no signs or symptoms of heart failure. A heart specialist provides treatment. If needed, your cancer and primary care providers will address risk factors.
Stage C	In stage C, there is structural heart disease and signs and symptoms of heart failure A heart specialist provides treatment.
Stage D	In stage D, there is advanced structural heart disease and major symptoms of heart failure despite treatment. A heart specialist provides treatment.

Key points

- Cancer survivors are at risk for heart disease because of shared risk factors and cardiotoxic cancer treatments.
- Heart disease may be prevented by following the ABCDEs of heart wellness.
- A type of chemotherapy called anthracycline increases the risk of heart failure. Screening for heart failure should occur within 1 year after treatment ends. The four stages of heart failure are used to guide care.



Let us know what you think!

Please take a moment to complete an online survey about the NCCN Guidelines for Patients.

NCCN.org/patients/response

5 Lymphedema

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- 28 Stages of lymphedema
- 29 Early detection is important
- 30 Options for treatment
- 32 Key points

This chapter explains how lymphedema can be reversed in early stages. It also explains how to reduce symptoms of lymphedema.

Swelling of tissue

Lymphedema is swelling of body tissue that can be caused by some cancer treatments. It can start any time after treatment but most often occurs within 18 months. It can be a short-term or chronic condition.

Why is the tissue swollen?

Tissue swells because there is a buildup of lymph in fatty tissue under the skin. Lymph is

the fluid of the lymph (or lymphatic) system. This system helps fight infections in the body. Lymphedema occurs when the lymph system is damaged or blocked.

Who gets lymphedema?

Cancer survivors who had surgery or radiation therapy to lymph nodes near the armpit, collarbone, or groin may get lymphedema. Lymphedema may also occur after procedures called sentinel node biopsy and lymph node dissection.

Lymphedema

Lymphedema is a buildup of lymph fluid in a part of the body. When caused by cancer treatment, it occurs on the treated side of the body. A common symptom of lymphedema is swelling.



Stages of lymphedema

There are 3 main stages of lymphedema. Stage 0 is an early phase that has subtle or no symptoms. The main stages with clear symptoms are stage 1, stage 2, and stage 3. Symptoms of lymphedema by stage are listed in **Guide 7.**

Swelling on the treated side of the body is the key symptom of lymphedema. Swelling may impact any part of the body. It can occur in an arm or leg, the neck, trunk, or groin. Other early symptoms include a feeling of heaviness

or fatigue in a limb, fullness or tightness in the skin, or pain in the area.

As lymphedema advances, you may have a decreased range of motion or function in a limb. Your skin may thicken. Lymph buildup can cause inflammation that leads to scar tissue, infection, and fat deposits in the skin.

Guide 7 Symptoms of lymphedema by stage No swelling but there may be subtle symptoms, such as: Stage 0 A heavy feeling in a limb · Feeling of fatigue in a limb Swelling can be seen on the side of body that was treated Swelling in a limb is reduced with elevation Stage 1 An indent in the skin may occur when pressure is applied (called pitting) Area with lymphedema is larger, heavier, or stiffer · The swollen area has a spongy texture · Swelling in limb does not decrease with elevation Stage 2 • An indent in the skin (pitting) is less visible as swelling increases · Scar tissue may form making the swollen area larger and feel hard · Swelling has further increased making the area larger · Skin of swollen area is severely dry, scaly, or thickened • In the limbs, fluid leakage and blisters are common Stage 3 Moving limbs or turning your neck may be limited · Skin of swollen area may have fungal infections or benign tumors

Early detection is important

Finding lymphedema early is key to achieving the best outcomes. Stage 0 and stage 1 lymphedema may be reversed with treatment.

Screening for lymphedema

Your provider will screen for lymphedema if you are at risk. Risk is based on what treatment you had. It is also based on body mass index (BMI), skin infections, number of removed lymph nodes, and extent of cancer before treatment. Ask your care team what your risk is.

As part of screening, your care team will ask about symptoms at health visits. Look for symptoms on the treated side of your body:

- Sensations of fullness, tightness, or heaviness
- > Pain or discomfort
- Swelling
- Trouble bending, stretching, or flexing

Your provider will perform an exam. They may assess your strength, range of motion, and mobility and test your blood flow and skin sensations. You may get a test of total body water called bioimpedance spectroscopy.

Tests for lymphedema

To confirm that you have lymphedema, your care team must rule out other causes, such as cancer, infection, and a blood clot. You then may be referred to a certified lymphedema therapist. This therapist may be a physician, an occupational therapist, or a physical therapist.

The therapist may measure your limb. If not measured before treatment, the swollen limb can be compared to the normal limb. You may need to do stretches to check your range of motion. Some people need imaging of the lymph system called lymphoscintigraphy.

Lymphedema may cause or worsen distress, depression, or anxiety. Tell your provider if you feel distressed. There is help. Read Chapter 12 to learn more.

Options for treatment

Your cancer team can provide care and may also refer you to specialists. There may be a lymphedema specialist near you. You can take part in managing lymphedema as described in this section. Treatment options for lymphedema are listed in **Guide 8.**

Look for and report symptoms

You should know the symptoms of lymphedema across its stages. When you first notice symptoms, promptly tell your provider. Also tell your provider if you notice the lymphedema getting worse. Early treatment may have better results.

It's also important to know the signs of infection. Infections increase the chance

Guide 8 Treatment for lymphedema

Education about symptoms

Self-management skills

Compression

Progressive resistance training

Lymphatic massage

Range-of-motion exercises

Referral to specialists

of getting lymphedema. And lymphedema increases the chance of infections.

Infections can become serious. You may need to be hospitalized and given intravenous antibiotics. Immediately tell your provider if you notice symptoms of infection:

- Redness of the skin
- Skin that feels warm
- Red or dark streaks in the skin
- Pain

Prevent infections with good skincare

Take good care of your skin. Keep your skin clean. Moisturize to prevent skin cracking. Protect yourself from injury that would cause swelling. Use sunscreen and insect repellent.

Information on preventing infections with safe pet and gardening practices is available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



Use compression

Your provider will assess your need for compression. Two types of compression may be prescribed.

Compression garments apply pressure. The pressure helps move lymph away from the

swollen area. It's important to get garments that fit well and to use them correctly.

Compression garments can be replaced as needed

An intermittent pneumatic compression device has sleeves that wrap around the legs. It will squeezes the legs at times. Squeezing pumps lymph to a different area.

Get a massage

Manual lymphatic drainage is a type of massage. The massage moves fluid from the swollen area to where the lymph system is working. There is also a simple form of self-massage. Your provider will assess if manual lymphatic drainage is safe for you.

Move more

Movement—especially exercise—lowers the risk of lymphedema. It does not trigger or worsen lymphedema. However, you should avoid exercising if you have a new injury or infection in the affected area.

Strength training may reduce symptoms of lymphedema. Slowly increase the size of weights or strength of resistance bands. Compression garments may be needed during training.

Water exercise may also relieve symptoms. Before starting, get your skin checked for cuts and cracking.

Consult with an expert before starting exercise. A lymphedema therapist or a pain expert, called a physiatrist, is recommended. If neither is available, look for a professional trainer who knows about physical activity for

cancer survivors. See your therapist if the lymphedema worsens.

More information on physical activity for cancer survivors is available at NCCN.org/ patientguidelines and on the NCCN Patient Guides for Cancer app.

Stay flexible

Lymphedema can restrict your range of motion. See a physical or occupational therapist, certified exercise specialist, or rehabilitation specialist for help. Your provider will teach you gentle stretching and range-of-motion exercises. These movements may push the lymph to another area.

Take precautions with medical procedures

Early research suggests that air travel, venipuncture, and blood pressure measurement don't trigger lymphedema. But more research is needed to prove these results. Until there are better data, get medical procedures on the limb that is not at risk for lymphedema. If needed, procedures may be done on the at-risk limb.

Referral for surgery

Surgery may be helpful for some people. It can reroute your lymph vessels so that they bypass the blocked area.

- Lymphedema is a buildup of a fluid called lymph under the skin. It can be caused by surgery and radiation to lymph nodes.
- Stage 0 is the earliest stage of lymphedema. Swelling starts in stage 1 and worsens in stages 2 and 3.
- It's important to find lymphedema early with routine screening. Stage 0 and stage 1 can be reversed.
- You can take part in managing lymphedema. Report symptoms of infections and lymphedema. Take steps to prevent infections. Move more.
- Lymphedema is often treated with compression products, physical activity, and lymph drainage massages.

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Keeping a journal is a low-cost and practical tool to help you navigate this frightening and uncertain time. By tracking your daily symptoms, you are in a better position to see how you're doing over time, which can be clouded by one or two bad days."

6 Cognitive dysfunction

- 34 Problems with thinking
- 34 Assessment of thinking skills
- 35 Help for thinking problems
- 37 Key points

Cancer and its treatment may impair your memory or other thinking skills. Read this chapter to learn how to improve your skills and cope with these changes.

Problems with thinking

Have you noticed a change in memory or other thinking skills? It's probably not your imagination. There is growing proof from tests and scans of thinking problems reported by cancer survivors.

What is cognitive dysfunction?

Cognitive dysfunction is an impairment of one or more thinking skills. These skills include learning, reasoning, memory, problem-solving, and decision-making. Many cancer survivors report having some degree of cognitive dysfunction.

The impact of cognitive problems on life varies among cancer survivors. Problems can be long-term or short-lived. Most survivors do not have severe problems, but some do. When severe, cognitive dysfunction can impact quality of life and ability to work.

What causes cognitive dysfunction?

Cognitive dysfunction may be caused by cancer and its treatment. It most commonly occurs after chemotherapy. When related to chemotherapy, it is often called chemobrain. The causes of chemobrain are not well understood. Other cancer treatments that may cause cognitive dysfunction include endocrine therapy, radiation therapy, and surgery.

Assessment of thinking skills

At this time, there isn't one good screening tool for cancer-related cognitive dysfunction. To get help, tell your health care provider about any cognitive problems you have. Ask family or friends to share what they have observed. Your health care provider will ask questions about the nature, start, and course of the problem.

History of the problem

Your provider will obtain a history of the cognitive problem. They will review your health records. You may be asked about:

- > Trouble paying attention or multitasking
- Leaving tasks incomplete
- Trouble finding words
- Trouble remembering things and using notes or reminders more than before
- Taking longer to think through problems and slower thinking
- Not being able to do things like you used to

Causes and contributors

Your provider will assess what is causing or adding to cognitive dysfunction. Some of these factors can be changed or treated, such as:

- Pain
- Sleep problems
- Fatigue
- Depression and anxiety
- Medications, alcohol, or other agents that impair cognition
- Vitamin or hormonal deficiency
- Delirium—a short-term disturbance in mental abilities

Brain imaging

Brain imaging can show the structures of the brain or how the brain is working. Brain imaging is also called neuroimaging. Your provider will decide if brain imaging is needed based on symptoms and if there may be cancer in the brain.



By jotting down checklists of things to do, you can overcome certain minor cognitive impairments like difficulty with short-term memory."

Help for thinking problems

There are several ways your cancer or primary care provider can help you with cognitive problems. Some interventions may improve cognitive dysfunction while others will help you cope. If initial interventions don't help much, you may get a referral to an expert in cognitive dysfunction. See **Guide 9** for a list of initial interventions for people who don't have cancer in or didn't have treatment directed at the brain or spinal area.

Education and counseling

Many cancer survivors who have cognitive dysfunction benefit from education and counseling. There's also a benefit when the family understands cognitive dysfunction.

Education helps when it focuses on symptoms and the course of cognitive dysfunction. It is

Guide 9 Help for cognitive dysfunction
Education and counseling
Self-management skills
Social support
Disease and symptom management
Neuropsychological evaluation
Cognitive rehabilitation
Psychotherapy
Routine physical activity
Medications

important to know that cognitive dysfunction does not get worse over time. Instead, it may get better for cancer survivors. Counseling from your provider can support how you manage and cope with cognitive dysfunction.

Self-management skills

Self-management skills can help you cope with cognitive dysfunction and feel better.

- Get organized and use memory devices. Use notes, planners, and apps on smartphones. Also, keep items in the same place.
- Manage stress. Practice relaxation using meditation or by other means. Join a mindfulness-based stress reduction program to learn how to deal with daily stressors.
- Manage energy. Do demanding tasks when your energy levels are the highest.

Live a healthy lifestyle. Move more and exercise. Limit alcohol and other agents that alter cognition and sleep.

Your friends and family may also be able to help. Ask if they can help you complete tasks and activities.

Disease and symptom management

Get help for health conditions that limit cognitive ability. Distress and depression can make it hard to focus. Sleep problems, fatigue, and pain can affect cognitive abilities, too. Some medications and diseases impair brain function.

Neuropsychological evaluation

A neuropsychological evaluation is a report based on testing of your cognitive function. You may be tested for attention, memory,

Self-management skills for cognitive problems

There are several things you can do to cope with thinking problems. One strategy is to use memory aids. Use notes, planners, and apps tor remind yourself of your schedule and things to do.



language, perception, learning, planning, and judgment. Be aware that cancer-related cognitive dysfunction is not always detected by tests. After testing is completed, the neuropsychologist will give recommendations, such as cognitive rehabilitation.

Cognitive rehabilitation

The brain can change and adapt in adulthood. Because of the brain's plasticity, training can improve cognitive function. Cognitive rehabilitation is a set of services designed to improve cognitive function. You may work with an occupational therapist, speech-language pathologist, or neuropsychologist.

Psychotherapy

Cognitive behavioral therapy (CBT) is a type of short-term psychotherapy. Treatment goals include changing unhealthy thoughts and behaviors. CBT for fatigue or cognitive function may improve some types of cognitive function.

Physical activity

Being physically active is good for overall health. It may also improve cognitive function. Aerobic activity that improves heart health also improves cognitive function in older adults. More research is needed on physical activity and cognitive function among cancer survivors.

Medication

Your provider may prescribe medication for cognitive function. Stimulants, such as methylphenidate and modafinil, are sometimes used for treatment. Another option is donepezil, which enhances cognition in people with dementia. Your provider will choose the

best medication for you. Do not take these medications without medical oversight. More research of medications for cancer survivors with cognitive dysfunction is needed.

Key points

- Many cancer survivors report problems with thinking skills. Such problems are called cognitive dysfunction. Cancer or its treatment may be the cause.
- To get help, tell your health care provider about any cognitive problems you have. Your provider will assess what is causing or adding to the problem.
- Education, counseling, and selfmanagement skills can help survivors cope with cognitive dysfunction. It can be a relief to know that cognitive dysfunction does not get worse over time.
- Interventions that may improve cognition include cognitive rehabilitation, CBT, exercise, and medications.

7 Sexual dysfunction

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- 40 Assessment and referral
- 41 Female sexual dysfunction
- 43 Male sexual dysfunction
- 44 Key points

Many cancer survivors experience a decline in sexual function and activity. This chapter explains what causes the decline. It also describes treatments that may restore sexual function.

Sex and cancer

Sexuality includes your feelings and thoughts of people you find attractive. It also includes how you express these feelings and thoughts. Many people express their sexuality through sexual activity, but problems with sexual activity can arise.

What is sexual dysfunction?

Sexual dysfunction is an ongoing problem with desire or the ability to respond with arousal, orgasm, or satisfaction. It often causes distress and discontent with sexual activity.

Female sexual dysfunction

Female sexual dysfunction occurs in people with a vagina, uterus, ovaries, or clitoris. It includes low desire for sexual activity. Vaginal dryness is common. Other examples of female sexual dysfunctions are pain during sex and problems with orgasm.

Male sexual dysfunction

Male sexual dysfunction occurs in people with a penis, testicles, or prostate. The most common male sexual dysfunction is trouble getting or maintaining an erection, which

is called erectile dysfunction. Even with an erection, ejaculation may occur too soon, slowly, or not at all. Other examples of male sexual dysfunction are low sex drive and problems with orgasm.

Why do many cancer survivors have sexual dysfunction?

Sexual dysfunction is common because of its many causes among cancer survivors. Things that cause sexual dysfunction in everyone also cause sexual dysfunction in survivors. In addition, cancer and its treatment can cause sexual dysfunction:

- Sexual dysfunction is common when sex organs have cancer or are removed.
- Radiation therapy and surgery in the pelvis may damage sex organs.
- Androgen deprivation therapy (ADT) and endocrine therapy affect sexual activity by reducing sex hormone levels. Low levels are also caused by certain types of chemotherapy, targeted therapy, and immunotherapy.

Many cancer survivors do not feel well during and after cancer care. High levels of distress, pain, sleepiness, or fatigue reduce sexual desire and arousal. After a cancer diagnosis, mental health and relationships may decline and impact sexual functioning. Sometimes, survivors avoid sexual activity because they do not like how cancer altered their body.

Assessment and referral

Tell your health care provider if you have sexual problems or concerns. Don't be shy to speak up. Before cancer treatment, ask if any of your treatments will impact your sexual health.

If you're having sexual problems, it is common to be given a short survey on sexual health. Surveys help pinpoint the type and severity of sexual dysfunction. To plan treatment, your provider will identify the causes of sexual dysfunction. Be ready to give an update on your health history and medications. You will likely get blood tests of testosterone if your cancer treatment may have affected your testicles.

Based on an assessment, you may be referred to other providers.

- Sexual health specialists are experts in sexual function. They may have a background in primary care, gynecology, urology, oncology, psychology, or rehabilitation medicine.
- Certified sex therapists help people with the mental or emotional issues related to sex.
- Mental health professionals can provide sex and couples therapy. They also treat issues related to sexual function, such as depression, anxiety, and alcohol misuse.

- Synecologists are doctors who are experts in the female reproductive system. Urologists are doctors who are experts in the urinary tract and the male reproductive system.
- Fertility specialists help people have babies. Your care team will refer you to a fertility specialist if you want to have kids after treatment.



We want your feedback!

Our goal is to provide helpful and easy-to-understand information on cancer.

Take our survey to let us know what we got right and what we could do better.

NCCN.org/patients/feedback

Female sexual dysfunction

There is little research on treatment of female sexual dysfunction among cancer survivors. Treatment options are mostly based on research of people without cancer. See **Guide 10** for a list of treatments.

Low sex drive

If your sex drive is low, talk with your provider about medications. Androgens, flibanserin, and bremelanotide may help but need to be studied among cancer survivors. Also, androgens may increase the risk of hormone-dependent cancers. Bupropion and buspirone

are also treatment options though they are not approved for low sex drive.

Vaginal dryness

Vaginal hormones may reduce dryness and pain. Estrogen can be directly applied to the vagina with an estrogen ring, suppository, or cream. Other hormones called DHEA and testosterone are creams. Vaginal hormones may not be safe if you had an estrogendependent cancer.

Ospemifene is an oral medicine that reduces pain by acting like estrogen. Survivors of

ow sex drive	AndrogensBremelanotideFlibanserinBupropionBuspirone
aginal dryness	 Vaginal estrogen Vaginal testosterone or DHEA Lubricants for sex Vaginal moisturizers, gels, hyaluronic acid, and oils
Pain during sex	 Treatments for vaginal dryness Ospemifene Topical anesthetics Vaginal dilators Pelvic physical therapy
Problems with orgasm	VibratorPelvic physical therapy

estrogen-dependent cancers should not take ospemifene.

Lubricants also prevent painful sex but may irritate the area. More research is needed on vaginal moisturizers, vaginal gels, hyaluronic acid, and oils.

Pain during sex

Treatment for vaginal dryness may also help prevent pain during sex. Ospemifene is a non-hormonal medicine that helps improve the tissue lining of the vagina. It may reduce pain. Pain may be prevented with anesthetics applied to the vulva before sex.

Devices improve sexual function. A dilator is a tube-shaped device that stretches the vagina. It is used to prevent painful sex. More research is needed, but dilators may prevent narrowing of the vagina after pelvic radiation.

Pelvic physical therapy strengthens the pelvic floor muscles. This group of muscles supports the bladder, uterus, and rectum. Pelvic physical therapy can help reduce pain during sex.

Problems with orgasm

Stimulation devices, like a vibrator, can help people have better orgasms. Pelvic physical therapy improves orgasms by strengthening muscles involved in orgasms.

Pelvic physical therapy

Pelvic physical therapy can reduce female and male sexual dysfunction. It strengthens weak pelvic muscles. Your physical therapist will teach you strengthening exercises and may use biofeedback to check your results.



Male sexual dysfunction

Male sexual dysfunction has been the subject of research for decades. There are many good treatments. Mental causes of male sexual dysfunction can be treated with one-on-one or couples counseling or psychiatric medicines. Treatments for physical causes of male sexual dysfunction are listed in **Guide 11.**

Erectile dysfunction

PDE5 inhibitors are medicines that improve erections. The four major PDE5 inhibitors are sildenafil (Viagra), tadalafil (Cialis), vardenafil (Levitra), and avanafil (Stendra). Do not take

PDE5 inhibitors if you take nitrate drugs or have major heart failure.

Certain cancer treatments can reduce the level of testosterone and cause erectile dysfunction. Taking testosterone may improve erections but may not be safe for people with heart disease.

Healthy living can improve sexual function in men. It may be particularly helpful for erectile dysfunction. Quit smoking. Lose weight if affected by overweight. Move more and exercise. Don't drink a lot of alcohol. Good heart health is also good sexual health.

Erectile dysfunction	 PDE5 inhibitors Testosterone if levels are low Healthy living including physical activity and not smoking Pelvic physical therapy
Ejaculation problems	 Testosterone if levels are low Antidepressants called SSRIs and clomipramine Pelvic physical therapy For urine leaks, empty bladder prior to sex, do pelvic physical therapy, and use condoms to catch urine
Problems with orgasm	 Testosterone if levels are low Vibrator PDE5 inhibitors Cabergoline Pelvic physical therapy
Low sex drive	Testosterone if levels are low

Pelvic physical therapy strengthens weak pelvic floor muscles. It may help improve erections.

Ejaculation problems

Medicines called antidepressants often cause sexual dysfunction. But a group of antidepressants called SSRIs prevents premature ejaculation. And another antidepressant called clomipramine extends pleasure by delaying ejaculation.

Testosterone may be an option. Since it can affect conception, tell your provider if you're interested in having a baby.

Pelvic physical therapy may treat problems with ejaculation including urine leaks. Leaking may be lessened if you empty your bladder before sexual activity. Leaked urine can be captured in a worn condom.

Problems with orgasm

PDE5 inhibitors, testosterone, and pelvic physical therapy improve orgasms.
Cabergoline also improves orgasms by reducing the amount of prolactin in the body.
Use a vibrator to stimulate your body. It might help you have an orgasm.

Low sex drive

The treatment for low sex drive is testosterone. You may be referred to a specialist for additional help.

Key points

- Sexual dysfunction is an ongoing problem with sex drive or the body's response of arousal, orgasm, and satisfaction. Many cancer survivors have sexual dysfunction.
- Surveys help pinpoint the type and severity of sexual dysfunction.
- You may be referred to one or more specialists who help people with sexual dysfunction.
- More research is needed for treatment of female sexual dysfunction. Hormones may not be safe for survivors of hormonedependent cancers. Lubricants and other topical drugs treat vaginal dryness and pain. Devices and physical therapy can lessen pain and increase orgasms.
- There are several good treatments for male sexual dysfunction. Testosterone may help sexual dysfunction caused by damaged testes. PDE5 inhibitors improve erections and orgasms, and some antidepressants stop premature ejaculation. Other kinds of treatments are vibrators, physical therapy, and healthy living.

8Fertility

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- 47 Male fertility preservation
- 47 Female fertility preservation
- 48 Pregnancy after treatment
- 48 Key points

Cancer treatment can impair the ability to have children. Consider taking steps before treatment to be able to have children afterward. This chapter explains the steps you can take.

Fertility and cancer

Cancer can happen to anyone. Even people in their first decades of life get cancer. The impact of early cancer can be life changing. Cancer and its treatment may affect your ability to have children.

What is fertility?

Fertility is the body's ability to conceive a baby. This ability depends on the health of sex organs and supporting structures, specific parts of the brain, and sex hormones.

- Male fertility organs include the penis, testicles, and prostate.
- Female fertility organs include the vagina, uterus, and ovaries.

What impairs fertility?

Cancer may impair fertility, but more often, cancer treatment is the cause of impaired fertility. For some people, impaired fertility is permanent but for others, it can be reversed.

Impaired fertility may be caused by:

- Cancer in sex organs or cancer that indirectly affects sex organs
- Surgery that removes sex organs or removes tissue that support these organs
- Radiation therapy or surgery in the pelvis and drug treatments that damage sex organs or supporting tissue
- Androgen deprivation therapy (ADT), endocrine therapy, and certain types of chemotherapy, targeted therapy, and immunotherapy that lower sex hormone levels

Setting fertility goals

Talk to your cancer care team if there's a chance that you'll want children one day. Your team will explain if your fertility is at risk, and if so, how high of a risk. If your treatment plan changes, ask about the effects of new treatments.

Fertility preservation is about keeping your options open, whether you know or are unsure about having children later. You may be referred to a fertility specialist. A fertility specialist can explain fertility preservation options, including how procedures are done, the success rates, timing, and costs.

Tell your team what your goals for preserving fertility are. You might need to act before cancer treatment starts. Fertility preservation works best if done before cancer treatment.

More information on fertility among young adults is available at NCCN.org/
patientguidelines and on the NCCN Patient
Guides for Cancer app.



Male fertility preservation

Proven methods for preserving male fertility in adults are:

- Sperm banking (sperm cryopreservation) collects and freezes ejaculate (semen).
- Testicular sperm extraction is a procedure that removes sperm from a testicle then freezes the sperm.
- Testicular shielding is placement of a protective cover over the testicles during radiation therapy.

Female fertility preservation

Proven methods for preserving female fertility in adults are:

- Egg freezing (oocyte cryopreservation) is a 2- to 3-week procedure that makes the ovaries produce multiple eggs then removes and freezes them.
- Embryo freezing (embryo cryopreservation) is a 2- to 3-week procedure that removes and fertilizes eggs then freezes the embryo.
- Ovarian tissue freezing (cryopreservation) removes then freezes healthy tissue. The tissue is put back into the body after cancer treatment.
- Ovarian transposition (oophoropexy) moves healthy ovaries out of the radiation field to preserve fertility.
- Drugs called **GnRH agonists** preserve ovarian function when given during chemotherapy for breast cancer and should be used with other preservation methods.

Pregnancy after treatment

A follow-up visit with a fertility specialist after treatment may be helpful. You may still be fertile.

Experts think pregnancy after breast cancer treatment is safe. It is standard to wait 2 years before trying to conceive because of the risk of the cancer returning during that time.

If you become pregnant, you are not at higher risk for a recurrence due to pregnancy hormones. Your baby is not at risk for birth defects from prior cancer treatment.



My wife is pregnant and I'll be having my first child almost six years after I was first diagnosed. And it's all because my doctor and I talked about fertility on day one."

Key points

- Ask your care team how the cancer and treatment will change your fertility. Know the risks.
- A fertility specialist can explain your options for fertility preservation. You might need to act before cancer treatment starts.
- Sperm banking and testicular sperm extraction are proven methods of male fertility preservation. Testicular shielding protects testicles from radiation damage.
- Egg and embryo freezing and ovarian transposition are proven methods of female fertility preservation. Ovarian transposition and GnRH agonists protect ovaries during cancer treatment.
- After breast cancer treatment ends, it is standard to wait 2 years before becoming pregnant. Pregnancy is safe for you and the baby.

9 Fatigue

- 50 A different type of fatigue
- 50 How fatigue is assessed
- 52 Ways to manage fatigue
- 53 Key points

Cancer-related fatigue is distressing. Read this chapter to learn more about this type of fatigue and the ways to manage it.

A different type of fatigue

Most people have felt very tired or fatigued for a brief time. Cancer-related fatigue differs from the typical tiredness that follows an active or long day. It has several key features:

- Cancer-related fatigue is felt physically, emotionally, or mentally
- Cancer-related fatigue is not related to recent activity
- Cancer-related fatigue persists
- Cancer-related fatigue is distressing
- Cancer-related fatigue makes it hard to do normal day-to-day activities

Cancer-related fatigue is caused by cancer or its treatment. It sometimes occurs after surgery but is a common effect of these treatments:

- Chemotherapy, endocrine therapy, and targeted therapy
- Radiation therapy
- Hematopoietic cell transplant

Often, cancer survivors have other health problems in addition to cancer that are worsening their fatigue. More information on fatigue and cancer is available at NCCN.org/patientguidelines and on the NCCN PatientGuides for Cancer app.



How fatigue is assessed

Most cancer survivors have cancer-related fatigue. Cancer-related fatigue can last for months or years after diagnosis. Your providers need to know when fatigue starts and if it worsens.

Routine screening

There is no physical exam or lab test for fatigue. The only way for your care provider to know if you have fatigue is for you to tell them.

NCCN experts recommend that cancer or primary care providers screen for fatigue on a regular basis. Screening should start at your first visit and continue after cancer treatment ends. Screening for fatigue is done with a brief scale or survey.

In-depth assessment

Fatigue ranges from mild to severe levels. Your provider will perform an in-depth assessment if you have moderate or severe fatigue months after initial treatment. An assessment is also needed if fatigue starts or worsens after treatment ends.

Your provider will obtain a history of your fatigue. Be ready to describe when the fatigue started and whether it's changed over time. Your provider will also assess for causes of fatigue that can be treated. Some health conditions that cause fatigue are listed in **Guide 12.**

If needed, blood tests will be done. A complete blood count (CBC) with differential measures parts of the blood, such as red blood cells. A comprehensive metabolic panel can show if you have liver or kidney problems. Levels of hormones can be checked using a blood sample.

Some people may need further testing. Your provider may order imaging if you have concerning symptoms. Imaging makes pictures of the insides of your body. An echocardiogram, or echo, detects structural changes in the heart. If you have breathing problems, you may get a chest x-ray or oxygen saturation test.

Guide 12 Factors that may worsen cancer- related fatigue
Alcohol or drug use disorders
Heart problems
Low hormone levels
Digestive problems
Liver problems
Infection
Lung problems
Kidney problems
Anemia
Arthritis
Sleep aids
Pain medications
Vomiting and nausea medications
Distress
Pain
Changes in eating or weight
Physical inactivity

Ways to manage fatigue

For moderate or severe fatigue, your health care provider will make a management plan for you. It will be based on your experience of fatigue and the causes. Ways to manage fatigue are listed in **Guide 13.**

Treat causes of fatigue

The first step is to treat anything that causes or worsens fatigue. Such factors may include pain, poor sleep, distress, anemia, and diseases. You may need to have your medications adjusted.

Education and counseling

Education and counseling can help you cope with fatigue. It's important to learn about:

- Typical patterns of fatigue among cancer survivors
- How to monitor fatigue levels
- Ways to conserve energy

Conserve energy by setting priorities, being active when your energy peaks, and pacing yourself.

Physical activity

Physical activity reduces fatigue and improves energy. It also improves strength, fitness, mood, and body image.

Ask your provider about resources in your community. There may be aerobics, strength training, and yoga classes. You may be referred to a specialist. A physical therapist,

Guide 13 Ways to manage fatigue

Treat the causes of fatigue

Education and counseling

Physical activity

Cognitive behavioral therapy (CBT)

Mindfulness-based stress reduction

Supportive expressive therapies

Psychoeducational therapy

Nutrition counseling

CBT for insomnia

Acupuncture

Psychostimulants

exercise specialist, or physiatrist may help you meet your goals.

Read more about physical activity in NCCN Guidelines for Patients for Survivorship Care for Healthy Living, available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



Specialized interventions

Your provider may refer you for one or more of these interventions:

- Cognitive behavioral therapy (CBT), behavioral therapy, mindfulness-based stress reduction, or supportive-expressive therapy
- CBT for insomnia (CBT-I), which is explained in Chapter 10
- Massage therapy
- Nutrition evaluation
- Bright white light therapy
- Acupuncture

Medicines for fatigue

Psychostimulants may reduce fatigue in some survivors. More research is needed. The best dose and schedule of medicines are still unknown. Medicines for fatigue should be used with caution.

Key points

- Cancer-related fatigue is an overwhelming sense of exhaustion related to cancer or its treatment.
- Fatigue screening helps identify people with fatigue. If needed, an in-depth assessment will identify the causes of fatigue.
- Your cancer or primary care provider can help reduce fatigue by treating its causes, providing information and counseling, and prescribing medicine.
- You may be referred to one or more experts in physical medicine, mental health, sleep, acupuncture, light therapy, and massage.

10Sleep

- 55 Sleep-wake disorders
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- 57 How to sleep better
- 59 Key points

Sleep is essential for living.

Problems with sleep can greatly impact life. This chapter explains the treatments for sleep problems.

Sleep-wake disorders

Sleep is needed for good health and wellbeing. It recharges your body and mind. It helps your body to fight disease. In general, adults need 7 to 9 hours of sleep a night. Quality of sleep is important, too. Good sleep includes falling asleep easily, staying asleep, and having restful sleep.

Everyone sleeps poorly from time to time. In contrast, sleep-wake disorders are ongoing problems with sleep or daytime sleepiness. The symptoms are distressing or cause a loss of ability. Some causes of sleep-wake disorders are health conditions, medications, and poor sleep habits. Common types of sleep-wake disorders are listed in **Guide 14.**

Guide 14 Common types of sleep-wake disorders		
Circadian rhythm sleep-wake disorder	A mismaich heilween sieen-wake cycles and hay-hinni cycles	
Hypersomnia	Excessive sleepiness during the day despite getting enough sleep.	
Insomnia	An inability to fall asleep, stay asleep, or get restful sleep.	
Insufficient sleep syndrome	A chronic lack of sleep due to unhealthy sleep habits.	
Narcolepsy	An impaired ability of the brain to control states of sleep and wakefulness.	
Obstructive sleep apnea	Pauses in breathing during sleep due to blocked airflow.	
Restless legs syndrome	An intense urge to move the legs that worsens during rest and is partly relieved by movement. Also called Willis-Ekbom disease.	

Many cancer survivors have sleep problems. Sleep problems may be due to more than one reason. They can be due to changes in the body. They can also be caused by certain actions, such as drinking caffeine at bedtime.

After cancer treatment, sleep problems can persist. They can persist due to long-term treatment effects, medications, and mental health. They can also persist because of poor sleep patterns that started during treatment. You may spend a lot of time in bed, sleep during the day, or have an irregular bedtime and waketime.

Testing and referral

Your health care provider may screen for sleep problems on a regular basis. A brief survey is used for screening. An in-depth assessment is needed if you may have a sleep-wake disorder.

In-depth assessment

An assessment includes a health history and an exam of your body. You may also complete brief surveys about distress, hot flashes, pain, and fatigue. Your provider will order blood tests if you may have low red blood cell counts (anemia) or hormone levels (hypothyroidism). You may see a sleep expert for further evaluation.

Recording sleep patterns

It is common to complete a sleep diary or wear a tracking device. These tools are helpful for assessing sleep patterns. In the diary, you will record your bedtime, time you fell asleep, and the time you got up for the day. Your diary will also need to include if you woke up during the night and for how long. Diaries also capture daytime naps. Your provider will ask about any strategies you use to fall or stay asleep.

Sleep study

A sleep study is sometimes needed to measure sleep. It is also called polysomnography. It detects sleep-wake disorders like sleep apnea, narcolepsy, and restless legs syndrome (RLS). A full sleep study is often done at a sleep center. Some studies for sleep apnea can be done at home with a portable device.

Referral

Your oncologist may refer you to another provider. You may see a sleep specialist or your primary care provider for treatment. A sleep specialist is especially helpful for these sleep issues if they last at least 3 months:

- Too much time awake in the middle of sleep
- Too much time awake overall
- Too much sleep (9 or more hours)
- Narcolepsy
- Circadian rhythm sleep disorder
- Hypersomnia
- Parasomnias, which are abnormal behaviors during sleep

How to sleep better

Treatment of sleep-wake disorders often has very good results. Your provider will treat health conditions that are related to sleep-wake disorders. Such conditions include pain, obesity, anemia, heart disease, and hormone problems. Your medications will be adjusted if they affect your sleep. Specific treatments for sleep problems are listed on the next page in **Guide 15**

Sleep hygiene

Sleep hygiene is a set of healthy sleep habits. These habits will help you fall and stay asleep. They include physical activity, daytime light exposure, and regular sleep patterns. Sleep hygiene should not be used alone to treat sleep problems. It should be used with other treatments. Sleep hygiene can help treat many types of sleep-wake disorders.

CBT-I

Cognitive behavioral therapy for insomnia (CBT-I) is the preferred treatment for insomnia. It is a structured program that has very good results. Its methods include stimulus control, sleep restriction, cognitive therapy, relaxation, and sleep hygiene.

Medicines

Medicines called hypnotics are used to treat insomnia. They are also called sleep aids and sleeping pills. They should be used with caution. Hypnotics may make you do activities while sleeping, such as sleep-driving and sleep-eating. There is a risk of abusing hypnotics. Some hypnotics may cause drug dependence and withdrawal.

Central nervous depressants are used to treat insomnia. These medicines include daridorexant, lemborexant, and suvorexant.

Medicines called sedatives are used "off-label" to treat insomnia. They aren't approved by the U.S. Food and Drug Administration (FDA) for this use. Sedatives include antidepressants, antihistamines, atypical anti-psychotics, and melatonin. NCCN experts do not recommend sedatives for routine use due to a lack of data.

Gabapentin enacarbil and dopamine agonists are FDA approved and are preferred initial treatments for RLS. Other medications for RLS are opioids and clonazepam. Take iron supplements if you have low iron. Iron can improve symptoms.

CPAP machine

The most common treatment for sleep-disordered breathing is a CPAP machine. CPAP is short for continuous positive airway pressure. The machine keeps airways open with forced air. Weight loss and physical activity may also help people with sleep-disordered breathing.

Guide 15 Treatment for sleep pro	blems	
Sloop bygione combined	 During the day Be physically active in the morr Seek out bright light during the Limit caffeine intake during the If needed, take 1 nap in the after 	day, especially in the morning day
Sleep hygiene combined with other treatments for insufficient sleep syndrome, insomnia, and restless legs syndrome	 Before bedtime Don't consume caffeine at least 4 hours before bedtime Don't drink alcohol or consume nicotine before bedtime Avoid bright light at night and turn off devices near bedtime Don't eat heavy meals and limit fluids 3 hours before bedtime 	
	 During bedtime Stick to a regular bedtime and Sleep in a dark, quiet, and com Don't look at the clock during the 	fortable place
Cognitive behavioral therapy for insomnia	 Limit activities in bed to sleep and sex Limit time in bed to the amount of time sleeping Change unhelpful beliefs about sleep Calm your body and mind 	
Medication for insomnia	 Zolpidem Zaleplon Eszopiclone Ramelteon Temazepam	DoxepinSuvorexantLemborexantDaridorexant
Medication for restless legs syndrome	 Gabapentin enacarbil or dopamine agonists (preferred) Opioids 	ClonazepamIron supplement if you have low iron
Devices for sleep- disordered breathing	CPAP machine	

Key points

- Many cancer survivors have poor sleep quality. Some have a sleep-wake disorder.
- You may be asked to complete a short survey, track sleep patterns, or do a sleep study.
- Your provider may refer you to a sleep expert for treatment.
- Sleep hygiene is a set of healthy sleep habits that help treat many sleep problems.
- CBT-I is a structured program for insomnia that has very good results.
 Insomnia may be treated with medications but there are risks.
- Gabapentin enacarbil and dopamine agonists are medicines for restless legs syndrome (RLS). Iron supplements may also help improve symptoms if your iron is low.
- A CPAP machine is the most common treatment for obstructive sleep apnea.



Take our survey and help make the NCCN Guidelines for Patients better for everyone!

NCCN.org/patients/comments

11 Pain

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Read this chapter to learn about pain among cancer survivors.

There are many treatment options.

More than 1 in 3 survivors have chronic pain. Chronic pain lasts a long time and is often caused by disease. Common types of pain among survivors, known as cancer pain syndromes, are listed in **Guide 16.**

Cancer pain syndromes

Pain is a common yet diverse problem among cancer survivors. Cancer tests and treatment can cause acute pain. Acute pain starts suddenly and can often be treated.



If you are experiencing pain, discomfort, or a strange symptom, don't just assume it is supposed to be that way. Tell your doctor."

Guide 16 Cancer pain syndromes		
Neuropathic pain	Pain caused by damage to the nerves. It is often described as a shooting or burning pain. Sometimes, it is described as numbness and it can cause muscle weakness.	
Chronic pain syndromes	Pain caused by surgery including amputation, neck dissection, mastectomy, and thoracotomy.	
Arthralgias, myalgias	Arthralgias are joint pain and can be caused by aromatase inhibitors for breast cancer. Myalgias are muscle pain.	
Skeletal pain	Pain that occurs from bone damage. It includes pain caused by spinal bone collapse (vertebral compression), dead bone (osteonecrosis), and cancer in the bone.	
Myofascial pain	A type of ongoing muscle pain that is often set off by pressure on trigger points.	
Gastrointestinal pain, urinary pain, pelvic pain	Pain that occurs in the abdomen and pelvis. It is often caused by pelvic radiation.	
Post-radiation pain	Pain in an area treated with radiation. It may start soon or years after radiation therapy ends.	

Screening and assessment

Your cancer care provider will screen for pain on a regular basis. A pain screening tool consists of a brief scale. If no screening is done, tell your provider if you have pain.

An in-depth assessment is needed for pain related to cancer. Your provider will ask you to complete a pain rating scale. Rating scales help pinpoint the intensity and type of pain.

To plan pain management, your provider will identify the causes and physical pathways of the pain. If the pain is new, it may be due to the cancer returning or worsening. You may have to have tests for cancer.

If the pain is chronic, a specific pain syndrome should be identified if possible. Pain management will be based on the type of syndrome. Share your goals for pain management, such as the level of comfort you want.

Pain management plan

It's important that your pain management plan has realistic goals. The plan should set you up for success in 3 areas:

- Improve your comfort
- Improve your function
- Improve your quality of life

Be aware that pain management may relieve pain but cause other health problems. These problems are called side effects. Your pain management plan should explain how to care for side effects.

Management of pain is often done with multiple methods. For example, your management plan could include a painkiller and physical activity. Pain is distressing, so psychological support is a common part of the management plan.

Referral to specialists

Based on an assessment and follow-up visits, you may be referred to other providers. If you have pain not caused by cancer, your primary care provider may take the lead in providing pain management. For cancer-related pain, your cancer care provider may refer you to one of these specialists:

- > Pain management services
- Physical medicine and rehabilitation
- Mental health providers
- Urologist, gynecologist, orthopedics, or gastroenterology
- Palliative care

Information on pain during sex is in Chapter 7. Read this chapter to learn about experts in sexual health and help for sexual pain.

Painkillers

There are many safe medications to use for pain management. Even opioids are safe when used correctly. Medical marijuana may reduce pain, but more research with cancer survivors is needed. Pain medications for cancer pain syndromes are listed in **Guide 17.**

Adjuvant analgesic

Adjuvant analgesics are medicines that were developed for something other than pain. Over time, it was discovered that they treat pain, too. Adjuvant analgesics include:

- Antidepressants, specifically SNRIs and tricyclics
- Anticonvulsants, such as gabapentin and pregabalin

leuropathic pain	Adjuvant analgesicsCreams, gel, patches	 Opioids Dual-action opioids
Chronic pain syndromes	Adjuvant analgesicsOpioidsNerve blocks	Trigger point injectionsBotox injection
Arthralgias, myalgias	Adjuvant analgesicsNSAIDs, COX-2 inhibitors	Acetaminophen Muscle relaxers
Skeletal pain	Adjuvant analgesicsOpioidsNSAIDs, COX-2 inhibitorsAcetaminophen	Antiresorptives, bisphosphonatesMuscle relaxers
Myofascial pain	Adjuvant analgesicNSAIDs, COX-2 inhibitors	AcetaminophenOintment, patches
Chronic pelvic pain	Dorsal column stimulation	
Post-radiation pain	Pain medications for specific	cancer pain syndrome

An adjuvant analgesic can be the main treatment of pain. When taken with opioids, it may further reduce pain and allow a lower dose of opioids to be used.

Opioid medicine

Opioid medicine is sometimes necessary. It is an option for moderate to severe pain. If you have completed cancer treatment, opioid medicine is not typically the first choice.

Opioids relieve pain by affecting opioid receptors on nerve cells. A dual-action opioid that affects opioid and noradrenaline receptors is an option for neuropathic pain.

NSAIDs and acetaminophen

Acetaminophen and NSAIDs are common painkillers. They are sold over-the-counter or by prescription. NSAID is short for nonsteroidal anti-inflammatory drug. Ibuprofen, naproxen, and COX-2 inhibitors are types of NSAIDs.

Muscle relaxers

Muscle relaxers can help with some types of pain. An example is a decrease in painful muscle spasms caused by chronic pain. Muscle relaxers are an option for arthralgias, myalgias, and some types of bone pain.

Antiresorptive medicine

Your bones are living organs. New bone replaces the old bone all the time. Bone resorption is the breakdown and removal of old bone. Antiresorptive medicines slow down bone resorption and help keep bones strong. Bisphosphonates are a type of antiresorptive

Safe opioid use

Addiction to prescribed opioids can happen. But you and your provider can take preventive steps.

Your provider can create a safe management plan:

- Clearly discuss treatment goals, safety, and side effects
- Prescribe the lowest dose for the shortest period of time
- Monitor results and check if you are following the prescription
- Consider prescribing naloxone in case of overdose
- Reassess need for opioids, and if no longer needed, slowly reduce the dose to avoid withdrawal

You can use strategies to prevent misuse of opioids:

- ✓ Store opioids safetly
- Use medication diaries and pill counts
- Agree to urine testing
- Safely discard unused opioids

medicine and are commonly used. They can help treat pain from vertebral compression.

Pain relief injections

Injections to the site of pain may help. Nerve blocks are one type of injection.

- A stellate ganglion block may reduce pain from an upper-body amputation.
- A lumbar sympathetic block may reduce pain from a lower-body amputation.
- Phenol and alcohol blocks may reduce pain from a pinched nerve (neuroma).
- An intercostal nerve block may reduce pain caused by post-mastectomy or postthoracotomy syndrome.
- A medial branch block may reduce pain caused by spinal compression.

Two other types of injections are used for cancer pain:

- Trigger point injections relieve pain from muscle knots caused by post-radical neck dissection syndrome.
- Botox injections are known to reduce wrinkles but are also used for muscle pain relief caused by post-mastectomy or postthoracotomy syndrome and post-radical neck dissection syndrome.

Topical pain relief

Some pain medicines can be applied to the skin where you feel pain. Pain patches stick to the skin like a sticker. Pain creams, gels, and ointments are rubbed on the skin.

Non-drug pain relief

There are many options for non-drug pain relief. These options may be used with or instead of medications. Non-drug pain management for cancer-related pain is listed in **Guide 18** on the next page.

Psychological and psychosocial treatment

Psychological and psychosocial treatments enhance a sense of control over pain. Cognitive behavioral therapy (CBT) focuses on changing negative thoughts and learning how to relax. Other treatments include meditation, skills training, and supportive-expressive therapy. Hypnosis may help to relieve neuropathic pain.

Physical therapy and activity

It is often helpful to be physically active even when in pain. Physical activity can increase mobility and strengthen muscles. It has good results for aromatase inhibitor-induced arthralgia. But acute vertebral compression may require short-term bedrest before starting weight-bearing exercise.

Physical therapy teaches you how to do activities with less pain and increases flexibility and strength. It will help you perform your day-to-day routines, such as bathing. Aquatic therapy consists of exercises that are done in water.

Mirror therapy

Mirror therapy may relieve chronic "phantom limb" pain after amputation. It involves viewing a reflection of your intact limb in a mirror. The

Guide 18 Non-drug pain relief for	cancer pain syndromes	
Neuropathic pain	Cognitive behavioral therapyPsychosocial supportHypnosis	AcupunctureCold, heatTENS unit
Chronic pain syndromes	 Psychosocial support and behavioral treatment Physical therapy Mirror therapy after amputation 	 Massage and myofascial release for post-radical neck dissection syndrome TENS unit
Arthralgias, myalgias	AcupuncturePhysical activity, yogaPhysical therapy	Aquatic therapyMassageCold, heat, ultrasonic stimulation
Skeletal pain	 Physical activity for vertebral compression Physical therapy Back brace for acute vertebral compression 	Limited bedrest for acute vertebral compressionSurgeryAblation therapy
Myofascial pain	AcupressureAcupuncturePhysical activity	Massage Ultrasonic stimulation
Chronic pelvic pain	Physical therapySurgery	Laxatives, enemasLots of fluids
Post-radiation pain	Physical therapy	• Surgery

reflection tricks your brain into thinking the missing limb has reappeared. A therapist will guide you through a set of movements that relieve pain.

Acupuncture and acupressure

Acupuncture involves inserting very thin needles into the skin at several places on the body. It has good results for aromatase inhibitor-induced arthralgia. Acupressure uses pressure instead of needles.

Hands-on treatment

Therapists may relieve pain by manipulating body tissue. Areas with and without pain will be treated. Massage relaxes painful muscles, tendons, and joints. During myofascial release, a therapist stretches myofascial tissue. It may relieve pain caused by post-radical neck dissection.

Local treatments

Local treatments relieve pain where you feel it.

- Cold decreases inflammation and muscle spasms and relieves pain.
- Heat relaxes muscles and raises the threshold for pain. Ultrasonic stimulation is a type of heat treatment.
- A TENS unit involves placing electrodes on your skin where you have pain. A mild electric current blocks pain signals from reaching your brain.
- Radiofrequency ablation uses heat to destroy tissue for relief of spinal compression pain.

Surgery

For some people, surgery may be needed.

- Vertebral augmentation is a surgery that inserts cement into the spine to stop pain from vertebral compression.
- Core decompression drills into dead bone to relieve pressure.
- A joint replacement relieves pain caused by dead bone, or instead, you could have nerve ablation and a brace.
- Dorsal column stimulation stops pelvic pain signals with implanted electrodes.
- For severe pelvic pain, surgery to remove scar-like tissue may be needed.

Key points

- Common types of pain among survivors are called cancer pain syndromes.
- Expect to be screened for pain at health visits. If you are in pain, your provider will do a full assessment.
- You may be referred to specialists for pain management.
- Medications for pain vary based on the cancer pain syndrome. There are usually multiple options, such as antidepressants, anti-inflammatory drugs, and topical painkillers. Opioids can be safely used for moderate to severe pain.
- There are options for pain management other than medications. These options include mind and body treatments, local treatments, and surgery.

12

Mental health

- 69 Types of mental health issues
- 70 How mental health is assessed
- 71 Help for mental health
- 72 Key points

Read this chapter to learn how your health care providers can help improve your mental health.

Types of mental health issues

Cancer often takes a toll on mental health because of its many challenges. Cancer affects your body but may also affect your relationships, work, and finances, just to name a few. The challenges usually don't stop at the end of treatment.

This section describes 2 types of mental health issues. These types are often experienced by cancer survivors as well as their caregivers and family members.

What is distress?

Distress includes common feelings like sadness, worry, and anger but is much broader. It is defined as an unpleasant experience of a mental, physical, social, or spiritual nature. Distress can affect the way you think, feel, or act.

Distress is very common among cancer survivors. It ranges from mild to severe levels. Mild distress is to be expected and may reduce quality of life. An example is a normal fear of cancer recurrence. Severe distress can affect a person's self-care, social life, mood, or faith.

Information on managing distress is available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



What are mental disorders?

Mental disorders are health conditions just like heart disease is a health condition. There are many types of mental disorders. Each one is defined by a group of symptoms that are related to major problems with emotion, thinking, or behavior. The most common among cancer survivors are anxiety and depressive disorders.

- Symptoms of anxiety include severe fear or worry, panic attacks, and strong behavioral impulses.
- Symptoms of depression include feeling down or irritable and losing interest in things that you used to like.

Distress and mental disorders are sometimes connected. Distress can lead to or worsen mental disorders. And mental disorders can cause distress.

How mental health is assessed

Your cancer or primary care provider should screen for distress or mental disorders. A screening tool consists of a brief scale or short survey. After assessing your needs, your health care providers can address your concerns.

Routine screening

NCCN experts recommend routine screening for distress and mental disorders. Ongoing screening is important. Mental health issues can start any time after a cancer diagnosis. And they can persist for many years.

Your caregivers and family members may be screened too. They may be distressed at different times and for different reasons than you.

Although distress can occur at any time, there are times when distress is more likely. Distress is likely during routine health care visits, when getting health tests, or when symptoms occur. Screening for mental disorders is also very important at these times.

Your provider may not know you're struggling unless you very clearly say so. Let them know how you feel. Once your provider knows your situation, they can help.

In-depth assessment

If the mental health screener indicates you need help, your provider will ask more questions. It's important to understand the types and causes of mental issues and to rule out other health conditions. You will be asked about a range of topics.

- Emotional symptoms worry, sadness, and irritability
- Physical symptoms pain, lack of energy, and pounding heart
- Functional ability self-care, doing household duties, and lack of concentration
- Medical factors infections, diseases, medication, and fertility
- Mental health factors trauma, suicide attempts, and alcohol and drug misuse
- Social factors social support, work, health insurance, and faith

Help for mental health

Your provider will use mental health screenings and assessments to guide care. Cancer and primary care providers will treat some mental health issues and ensure your safety. For needs beyond their care, they will refer you to a specialist. Recommended steps to address mental health are listed in **Guide 19.**

Education

Your care team can provide education on cancer and mental health. It's important to know that feeling distressed is normal. Every cancer survivor is distressed at some point. Learning about cancer can help prevent high levels of uncertainty and stress. If you become anxious or depressed, these conditions can be treated.

Medical conditions

Medical conditions can cause or add to mental health issues. Such conditions include pain, hormone changes, and heart disease. Your provider will identify and treat medical conditions.

Healthy living

Healthy living can improve mental health. Work with your provider to make a plan of physical activity and healthy eating. Information on goals for heathy living is available at NCCN. Org/patientguidelines and on the NCCN Patient Guides for Cancer app.



Guide 19

Mental health care by cancer or primary care providers

Educate about cancer and mental health

Treat medical conditions that worsen mental health

Provide a plan to improve physical activity and healthy eating

Prescribe mental health medications

Develop a safety plan

Provide resources for spiritual, mental, social, or practical problems

Refer to social work and counseling services, financial navigators, or patient navigators

Refer to chaplains

Refer to mental health providers or addiction medicine specialists

Mental health medication

Your provider may prescribe medications for mental disorders. Antidepressants treat depression and anxiety. They also help treat pain and hot flashes.

It may take 2 to 6 weeks for antidepressants to work. Your provider may prescribe a benzodiazepine until an antidepressant starts working. Benzodiazepines treat anxiety.

Medication can cause unwanted effects. Tell your provider about any new or worsening symptoms. Abruptly stopping antidepressants or other medications may cause withdrawal. When a medication is no longer needed, your provider will slowly reduce the dose.

Safety plan

Sometimes, cancer survivors become a danger to themselves or others. Your care provider will assess your level of distress and resources. If you have a plan to do harm, your weapons will be secured, you will be watched, and emergency services will be contacted. If you have thoughts of death but no plans to hurt yourself, you will be referred for mental health services. You must agree to call 911 or go the emergency department if you feel close to doing harm.

Resources and referrals

Your provider or a patient navigator can put you in touch with local resources. Based on your needs, you may need help with practical problems, such as housing and food. You may benefit from educational and support groups. You may need help from a specialist. Specialists include chaplains, social workers, psychologists, psychiatrists, and advanced practice clinicians.

- Chaplains can help you with religious or spiritual concerns.
- Social workers can help with practical and psychosocial issues.
- Mental health providers can diagnose and provide treatment for mental disorders.
- Addiction medicine specialists treat problems with alcohol and drugs.

Key points

- Many survivors have mental health issues. It is normal to be distressed.
 Distress can lead to or worsen mental disorders.
- Your cancer or primary care provider may do a quick screening of your mental health. If no screening is done, tell your provider how you feel. Distress is not always obvious.
- There are many ways that your provider can help improve your mental health. Education to learn what is normal and what to expect can reduce stress. Reducing symptoms and improving physical health helps too.
- You might need to see a specialist. Your provider can make a referral.

13Work challenges

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- 74 Challenges to working
- 75 Help from your care team
- 75 Key points

Working may be beneficial yet challenging. This chapter explains how your health care providers can help you.

Why return to work?

As a cancer survivor, work can be important for your social and emotional well-being. It can bring a sense of normalcy and improve quality of life. It can serve as a distraction from the cancer.

In the United States, the workplace may be the source of your health insurance coverage. You may also need a regular paycheck. This makes work even more important so that you can afford future treatment and testing. For the reasons listed above, you may want to go back to work before you are fully recovered. Deciding to go back to work is a discussion you should have with your care team.

Challenges to working

The following challenges can be encountered as a cancer survivor in the workplace:

- Symptoms affecting work
- Employment discrimination
- Limited flexibility in schedule or tasks
- > Physical and cognitive demands

Cancer-related symptoms may increase and decrease over time. Some people start and stop working more than once because of symptoms. Other challenges may heavily weigh on your decision to work.

Deciding to return to work is a personal choice. You will likely need to think about several factors when deciding. Talk with your care team to learn your options.



Help from your care team

The best time for you and your care team to talk about work is before cancer treatment starts. Your team will take work into consideration when making treatment plans.

Your team should give you information to help you:

- Understand your likely ability to work
- Take your personal, family, and financial needs into account
- Learn employer's work policies
- Discuss work accommodations with your employer

The Americans with Disabilities Act requires many employers to make reasonable accommodations for physical or mental limitations of qualified workers with disabilities.

Your team will reassess work-related concerns at multiple timepoints. Tell them about your goals for work and any barriers to achieving goals. They can help relieve symptoms and refer you to other providers:

- Social workers
- Physical or occupational therapists
- Rehabilitation specialists
- Career counselors
- Financial counselors

Key points

- Working can improve your well-being but can also cause challenges.
- Discuss your goals for work with your care team before cancer treatment starts.
- Your team can provide education and counseling to help you achieve your goals.

66

I was overwhelmed with anxiety about my future. Imagine if you have to work to maintain yourself, plus you have extreme fatigue and then the side effects of the medication, it's very difficult to cope."

14

Making treatment decisions

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It is important to be comfortable with the health care you choose. This choice starts with having a candid conversation with your care team.

It's your choice

In shared decision-making, you and your care team share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation between you and your team.

Care decisions are very personal. What is important to you may not be important to someone else. Some things that may play a role in your decision-making:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments
- Your feelings about pain or side effects
- Cost of treatment, travel to treatment centers, and time away from school or work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from cancer care including care for late and long-term effects. Discuss openly the risks and benefits of your options. Share concerns with your care team.

Second opinion

It is normal to want to get help as soon as possible. While mental health should not be ignored, there is time to have another provider suggest a treatment plan. This is called getting a second opinion, and it's a normal part of medical care. Even doctors get second opinions!

Things you can do to prepare:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see providers who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the provider you will see for your second opinion.

Questions to ask

Possible questions to ask your care team are listed on the following pages. Feel free to use these or come up with your own. Be clear about your goals for treatment and find out what to expect from treatment.

.

Questions about cancer-related effects

1.	. What are the possible effects of the cancer I have and its treatment?						
2.	Are any effects serious or life-threatening?						
3.	Are any effects permanent?						
4.	What symptoms should I report right away, and who do I contact?						
5.	Will I need tests?						
6.	. Who should I contact with questions or concerns if the office is closed?						

Questions about prevention and relief

1.	. Is there anything that will prevent the effects of cancer and treatment?							
2.	What can I do at home to reduce symptoms?							
3.	What kinds of treatments are covered by my insurance?							
4.	Will I need opioid painkillers or can I use less intense methods of pain treatment?							
5.	Can you recommend a mental health provider that specializes in treating cancer survivors?							

Questions about resources and support

1.	Who can I	talk to	about hel	p with	housing,	food,	and	other	basic	needs?
----	-----------	---------	-----------	--------	----------	-------	-----	-------	-------	--------

- 2. What assistance is available for transportation, childcare, and home care?
- 3. Who can tell me what my options for health insurance are and assist me with applying for insurance coverage?
- 4. How much will I have to pay for my treatment? What help is available to pay for medicines and other treatment?
- 5. Who can help me with my concerns about work or school?
- 6. How can I connect with others and build a support system?
- 7. Who can I talk to if I don't feel safe at home, at work, or in my neighborhood?

Resources

AIM at Melanoma

AlMatMelanoma.org

AIM at Skin Cancer

AlMatSkinCancer.org

Be the Match

BeTheMatch.org/one-on-one

BMT InfoNet

Bmtinfonet.org

Breastcancer.org

Breastcancer.org

Breast Cancer Alliance

breastcanceralliance.org

Cancer Active, Inc. dba Throwing Bones

Throwing-bones.org

Cancer Hope Network

Cancerhopenetwork.org

DiepC Foundation

DiepCfoundation.org

FORCE: Facing Our Risk of Cancer

Empowered

facingourrisk.org

National Bone Marrow Transplant Link

(nbmtLINK)

nbmtlink.org

National Coalition for Cancer Survivorship

Canceradvocacy.org

National Ovarian Cancer Coalition

Ovarian.org/find-support

Ovarcome

Ovarcome.org

Ovarian Cancer Research Alliance

ocrahope.org

Sharsheret

sharsheret.org

The Leukemia & Lymphoma Society

LLS.org/PatientSupport

Triage Cancer

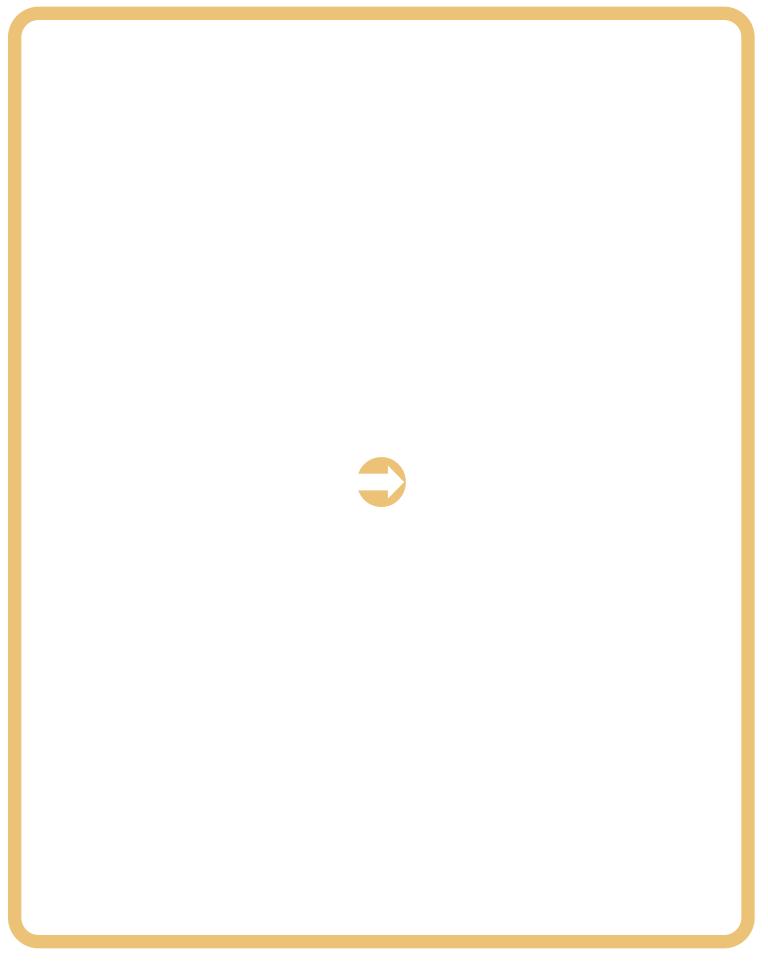
triagecancer.org

Unite for HER

Uniteforher.org

ZERO Prostate Cancer

zerocancer.org



Words to know

ADT

androgen deprivation therapy

androgen

Sex hormones made by the testicles.

anticonvulsant

A medication that treats seizures and other health conditions.

antidepressant

A medication that treats depression, anxiety, hot flashes, premature ejaculation, urine leaks, and pain.

BMI

body mass index

cancer screening

Ongoing testing to detect cancer before it causes symptoms.

cancer survivor

A person who has or had cancer.

cancer-related fatigue

An ongoing tiredness that is distressing and caused by cancer or its treatment.

cardiovascular disease

A group of disorders of the heart and blood vessels. Also called heart disease.

CBC

complete blood count

cognitive behavioral therapy (CBT)

A short-term "talk therapy" that focuses on changing thoughts and behaviors to improve health.

cognitive rehabilitation

A set of services designed to improve thinking skills.

CBT-I

cognitive behavioral treatment for insomnia

cognitive function

A set of brain-based thinking skills.

compression garment

A wearable piece of material that applies pressure.

CPAP

continuous positive airway pressure

CT

computed tomography

distress

An unpleasant experience of a mental, physical, social, or spiritual nature.

echo

echocardiogram

ECG/EKG

electrocardiogram

FDA

Food and Drug Administration

fertility

The ability to have a baby.

heart failure

A condition in which the heart muscle can't pump enough blood.

hereditary cancer

Cancer that is caused by abnormal genes passed down from parents to children.

hormone

A chemical in the body that triggers a response from cells or organs.

hot flashes

A sudden feeling of warmth in the upper body. Also called night sweat and vasomotor.

HPV

human papillomavirus

immune system

The body's natural defense against disease.

intermittent androgen deprivation therapy (ADT)

Alternating periods of time on and off medications that reduce androgen.

late effect

A cancer- or treatment-related health issue that occurs long after diagnosis or treatment.

lymphedema

A buildup of a bodily fluid called lymph.

manual lymphatic drainage

A type of massage that moves fluid out of the swollen area.

menopause

The end of menstrual cycles.

NSAID

nonsteroidal anti-inflammatory drug

neuropsychological evaluation

A report based on testing of brain-based thinking skills.

pelvic physical therapy

A type of treatment that strengthens muscles in the pelvis.

physical therapy

A type of treatment that improves movement.

polysomnography

A sleep study.

RLS

restless legs syndrome

sexual function

Feelings of desire and the body's ability to respond with arousal, orgasm, and satisfaction.

sleep hygiene

A set of healthy sleep habits.

sleep-wake disorders

Ongoing problems with sleep or daytime sleepiness that cause distress or a loss of function.

surveillance

Ongoing testing for the return or a worsening of cancer.

survivorship care

Interventions to improve the health and wellbeing of people who have or had cancer.

sexual dysfunctions

Ongoing problems with desire or the ability to respond with arousal, orgasm, or satisfaction.

sleep disorder

Ongoing problems with sleep that causes distress or loss of function.

UTI

urinary tract infection

NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Survivorship, Version 1.2024. It was adapted, reviewed, and published with help from the following people:

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NCCN Cancer Centers

Abramson Cancer Center at the University of Pennsylvania Philadelphia, Pennsylvania 800.789.7366 • pennmedicine.org/cancer

Case Comprehensive Cancer Center/ University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute Cleveland. Ohio

UH Seidman Cancer Center

800.641.2422 • uhhospitals.org/services/cancer-services

CC Taussig Cancer Institute

866.223.8100 • my.clevelandclinic.org/departments/cancer

Case CCC

216.844.8797 • case.edu/cancer

City of Hope National Medical Center

Duarte, California

800.826.4673 • cityofhope.org

Dana-Farber/Brigham and Women's Cancer Center | Mass General Cancer Center

Boston, Massachusetts

617.732.5500 • youhaveus.org

617.726.5130 • massgeneral.org/cancer-center

Duke Cancer Institute

Durham, North Carolina

888.275.3853 • dukecancerinstitute.org

Fox Chase Cancer Center

Philadelphia, Pennsylvania 888.369.2427 • foxchase.org

Fred & Pamela Buffett Cancer Center

Omaha, Nebraska

402.559.5600 • unmc.edu/cancercenter

Fred Hutchinson Cancer Center

Seattle, Washington

206.667.5000 • fredhutch.org

Huntsman Cancer Institute at the University of Utah

Salt Lake City, Utah

800.824.2073 • healthcare.utah.edu/huntsmancancerinstitute

Indiana University Melvin and Bren Simon Comprehensive Cancer Center

Indianapolis, Indiana

888.600.4822 • www.cancer.iu.edu

Mayo Clinic Comprehensive Cancer Center

Phoenix/Scottsdale, Arizona Jacksonville, Florida

Rochester, Minnesota 480.301.8000 · Arizona

904.953.0853 • Florida

507.538.3270 • Minnesota

mayoclinic.org/cancercenter

Memorial Sloan Kettering Cancer Center

New York, New York

800.525.2225 • mskcc.org

Moffitt Cancer Center

Tampa, Florida

888.663.3488 • moffitt.org

O'Neal Comprehensive Cancer Center at UAB

Birmingham, Alabama

800.822.0933 • uab.edu/onealcancercenter

Robert H. Lurie Comprehensive Cancer

Center of Northwestern University

Chicago, Illinois

866.587.4322 • cancer.northwestern.edu

Roswell Park Comprehensive Cancer Center

Buffalo, New York

877.275.7724 • roswellpark.org

Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

St. Louis. Missouri

800.600.3606 • siteman.wustl.edu

St. Jude Children's Research Hospital/

The University of Tennessee Health Science Center

Memphis, Tennessee 866.278.5833 • stjude.org

901.448.5500 • uthsc.edu

Stanford Cancer Institute

Stanford, California

877.668.7535 • cancer.stanford.edu

The Ohio State University Comprehensive Cancer Center -James Cancer Hospital and Solove Research Institute

Columbus. Ohio

800.293.5066 · cancer.osu.edu

The Sidney Kimmel Comprehensive

Cancer Center at Johns Hopkins

Baltimore, Maryland

410.955.8964

www.hopkinskimmelcancercenter.org

The UChicago Medicine Comprehensive Cancer Center

773.702.1000 • uchicagomedicine.org/cancer

The University of Texas MD Anderson Cancer Center

Houston, Texas

844.269.5922 • mdanderson.org

UC Davis Comprehensive Cancer Center

Sacramento, California

916.734.5959 • 800.770.9261

health.ucdavis.edu/cancer

NCCN Cancer Centers

UC San Diego Moores Cancer Center

La Jolla, California

858.822.6100 • cancer.ucsd.edu

UCLA Jonsson Comprehensive Cancer Center

Los Angeles, California

310.825.5268 • uclahealth.org/cancer

UCSF Helen Diller Family

Comprehensive Cancer Center

San Francisco, California

800.689.8273 • cancer.ucsf.edu

University of Colorado Cancer Center

Aurora, Colorado

720.848.0300 • coloradocancercenter.org

University of Michigan Rogel Cancer Center

Ann Arbor, Michigan

800.865.1125 • rogelcancercenter.org

University of Wisconsin Carbone Cancer Center

Madison, Wisconsin

608.265.1700 • uwhealth.org/cancer

UT Southwestern Simmons

Comprehensive Cancer Center

Dallas, Texas

214.648.3111 • utsouthwestern.edu/simmons

Vanderbilt-Ingram Cancer Center

Nashville, Tennessee

877.936.8422 • vicc.org

Yale Cancer Center/Smilow Cancer Hospital

New Haven, Connecticut

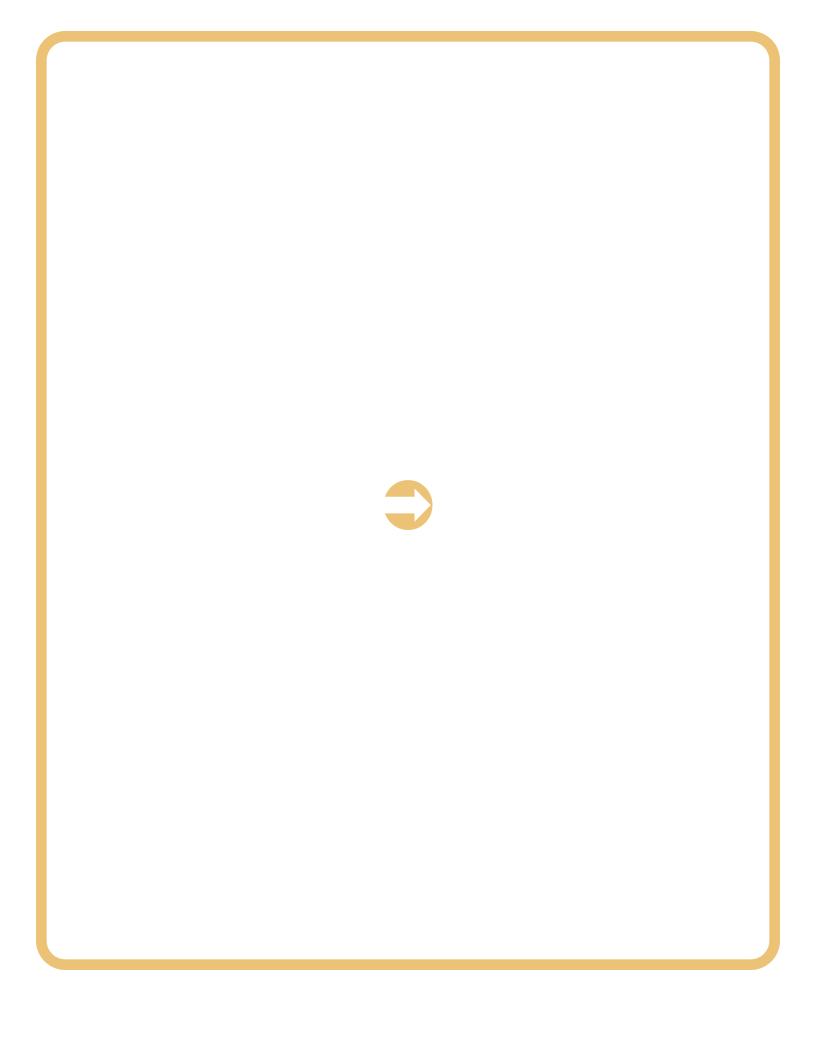
855.4.SMILOW • yalecancercenter.org

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Survivorship Care for Cancer-Related Late and Long-Term Effects

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