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NCCN GUIDELINES FOR PATIENTS®

2020

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

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- ✓ Step-by-step guides to the cancer care options likely to have the best results
- ✓ Based on treatment guidelines used by health care providers worldwide
- ✓ Designed to help you discuss cancer treatment with your doctors

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NCCN

- ✓ An alliance of leading cancer centers across the United States devoted to patient care, research, and education

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These NCCN Guidelines for Patients are based on the NCCN Guidelines® for Survivorship (Version 2.2020, July 14, 2020).

NCCN Foundation seeks to support the millions of patients and their families affected by a cancer diagnosis by funding and distributing NCCN Guidelines for Patients. NCCN Foundation is also committed to advancing cancer treatment by funding the nation's promising doctors at the center of innovation in cancer research. For more details and the full library of patient and caregiver resources, visit NCCN.org/patients.

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Good Days is proud to support this educational resource for patients and their families and offers unwavering commitment to those who struggle with chronic disease, cancer, and other life-altering conditions. mygooddays.org

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American Lung Association

The American Lung Association strongly supports efforts to help ensure all patients facing lung cancer get the highest standard of treatment and care. Helping patients understand treatment guidelines is one important step in empowering them to get the care they want and need. That is why we are pleased to endorse NCCN's efforts to provide accessible treatment guidelines and information to patients through the NCCN Guidelines for Patients. lung.org

Be The Match®

National Marrow Donor Program® (NMDP)/Be The Match® is the global leader in providing a possible cure to patients with life-threatening blood and marrow cancers, as well as other diseases. Our Be The Match Patient Support Center provides support, information, and resources for patients, caregivers, and families. BeTheMatch.org/one-on-one

Cancer Hope Network

As an organization committed to providing peer mentorship and ensuring that no one faces cancer alone, Cancer Hope Network is proud to endorse the informative, straightforward NCCN Patient Guidelines. These guidelines are a valuable tool for patients, caregivers and survivors, empowering them to live the best version of their lives while facing cancer. cancerhopenetwork.org

Save Your Skin Foundation

Save Your Skin Foundation (SYSF) is a Canadian patient-led not-for-profit group dedicated to the fight against non-melanoma skin cancers, melanoma and ocular melanoma. By using and sharing the valuable and thorough NCCN Guidelines, SYSF is confident in their provision of solid patient support with accurate and current information on these cancers and related topics such as skin cancer treatment with immunotherapy. saveyourskin.ca

The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is dedicated to developing better outcomes for blood cancer patients and their families through research, education, support and advocacy and is happy to have this comprehensive resource available to patients. lls.org/informationspecialists

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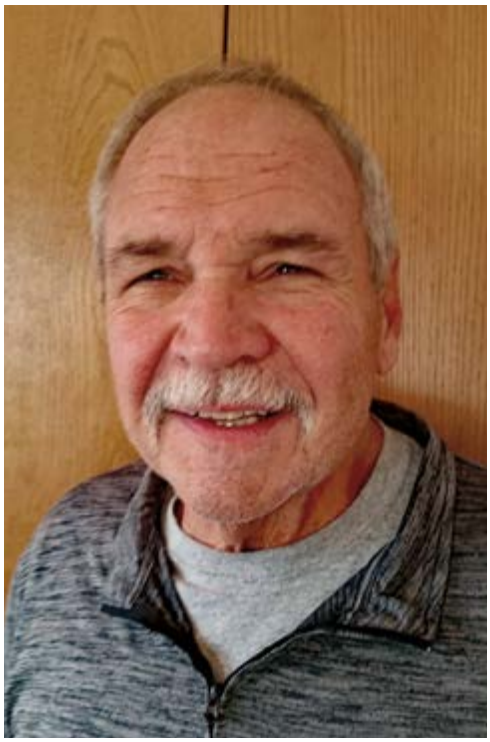

Contents

1
Survivorship

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.

Cancer survivors

Over the past 40 years, cancer care has greatly improved. Cancer screening is finding cancer at early stages when it can be fully removed. Newer treatments are more precise and better at stopping cancer growth.

With better cancer care, people with cancer are living longer. As a result, the needs of the cancer community have changed. More people need help to recover from cancer and its treatment and to be healthy.

The term “cancer survivor” was proposed in the 1980s. The intent of the term was to raise awareness of better outcomes and changing needs. A person with cancer is a survivor:

- starting at the time of diagnosis,
- during and right after treatment, and
- through the balance of their 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.

Survivorship care

The large and rising number of cancer survivors need survivorship care. Survivorship care improves health, wellness, and quality of life. Standards of survivorship care are listed in Guide 1.

Prevention

Prevention of a new or recurring cancer is a key part of survivorship care. You can reduce your risk of cancer with healthy living. Healthy living includes physical activity, eating well, and not using tobacco.

Less often, medical treatments are used to prevent cancer. Some people have surgery to remove a body part, like a breast, where cancer is likely to start. Some people take medication

Guide 1
Standards for survivorship care

Prevention of new and recurrent cancers
Prevention of late effects of cancer and treatment
Routine testing for the return of a cancer (surveillance)
Routine testing for new cancers (screening)
Assessment and treatment of late effects of cancer and treatment
Coordinated care between providers
Planning for ongoing survivorship care

that lowers hormone levels to reduce the chance of getting cancer.

Besides cancer, other unwanted effects of treatment and cancer can occur after treatment. A goal of survivorship care is to lower your chance of having these late effects. If detected early, treatment for a late effect may reduce its impact on your life.

Cancer 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 for cancer

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. There is screening for prostate, breast, cervical, skin, lung, and colorectal cancers. Screening is started when there is an average or high risk of cancer. Ask your health care provider what screening, if any, you need.

Survivors have a higher risk of a new (second) cancer. Ask your health care provider about your chance of getting a second cancer.

- Some causes of a first cancer may be related to getting a second cancer.
- Some cancer treatments may increase cancer risk. Such treatments include radiation therapy, certain chemotherapies, and certain targeted therapies.
- Excess radiation from a lifetime of computed tomography (CT) scans slightly increases cancer risk. Ask your provider if these scans are needed and for how long.

Some survivors are at risk of 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.

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.

Late effects

Many effects of treatment quickly resolve after treatment ends. An example is nausea and vomiting. Long-term effects start during treatment and persist after treatment is done. Less often, effects start long after treatment has ended. During health visits, your health care providers will assess for such late effects. They will provide treatment for late or long-term effects as needed.

Coordinated care

Cancer survivors often receive care from multiple providers. You may receive care from oncologists, a primary care provider, and non-cancer specialists. Your providers will work together and clarify their roles to address all your needs. Over time, your primary care provider will resume charge over your health care. You'll see your cancer doctor less often or if new symptoms arise.

Ongoing planning of care

A key part of survivorship care is ongoing planning of your health care. Your cancer or primary care provider will assess your needs. See one or both of them at least once a year. They will review your cancer care, health history, current abilities, and medications.

Your provider will review the plan with you. You will be given a schedule of follow-up visits, such as cancer surveillance and screening. Possible late effects may be included in the plan. Your providers may refer you to other specialists and community resources.

Survivorship guidelines

There have been challenges to putting survivorship care into practice. One of the strategies to overcome these challenges is practice guidelines.

Practice guidelines include recommendations by experts of the best options for care. They are based on health research, such as clinical trials. Providers use practice guidelines to tailor health care to each person.

NCCN has practice guidelines on survivorship for health care providers. The guidelines:

- Pertain to survivors with an onset of cancer in adulthood
- Apply whether treatment is ongoing, paused, stopped, or completed
- Address general survivorship issues, late and long-term effects, and healthy living
- Include screening, testing, and treatment options
- Complement treatment guidelines for cancer

NCCN has a two-part book series for survivors that are based on the practice guidelines. This survivorship book addresses late and long-term effects of cancer and treatment. Read about preventing poor health in *NCCN Guidelines for Patients: Survivorship Care for Healthy Living,* available at NCCN.org/patientguidelines.

Review

- A person with cancer is a survivor starting at diagnosis and through the balance of their life.
- Survivorship care is needed for the large and rising number of survivors. It improves health, wellness, and quality of life.
- Prevention of new and recurrent cancers is part of survivorship care. One way to lower your chance of cancer is through healthy living.
- Survivorship care includes routine testing, called surveillance, for a recurrence.
- Survivors are at higher risk for a second cancer. Follow cancer screening recommendations. If needed, genetic testing can confirm if you are at risk for hereditary cancer.
- Your health care providers will assess for late effects of cancer and its treatment. They will prescribe care to relieve or treat late effects.
- Your team of care providers will work together to meet your needs. They will clarify their roles in your care. Over time, your primary care provider will resume charge of your health care.
- Planning of survivorship care is ongoing. Survivorship plans often include follow-up visits, possible late effects, and referrals to specialists.
- There have been challenges to putting survivorship care into practice. To address these challenges, NCCN produces practice guidelines on survivorship for health care providers.
- NCCN practice guidelines have been adapted into a two-part book series intended for cancer survivors. This survivor book addresses late and long-term effects of cancer and treatment.

“

I decided that I am a survivor; I have to call myself one. Once I did, it changed my mental focus.

– Mike
Cancer survivor

2
Hormones and hot flashes

Some cancer treatments cause levels of sex hormones to drop. Hot flashes are one of many symptoms that may occur as a result. Read this chapter to learn about hormone-related symptoms and treatment for hot flashes.

Sex hormones

Sex hormones play a key role in puberty, having babies, and overall health. Testosterone is the main male sex hormone and is made by the testicles (or testes). Estrogen and progesterone are the main female sex hormones. The ovaries produce the most estrogen and progesterone.

The level of sex hormones declines as people age. The pattern of decline differs between the sexes. Testosterone made by the testes slowly drops over many years. During a menstrual cycle, estrogen and progesterone levels rise and fall. They quickly drop when a person stops having menstrual cycles.

The end of menstrual cycles is called menopause. Menopause caused by aging is called natural menopause. Health providers identify natural menopause by an absence of menstrual periods for 12 months. There is a transition time to menopause called perimenopause. During perimenopause, menstrual periods may start sooner or later than normal.

Causes of low sex hormones among cancer survivors include aging and cancer treatment. Certain cancer treatments reduce hormone levels or block hormone effects.

- Hormone therapy for prostate cancer targets male sex hormones. The most common form is called androgen deprivation therapy (ADT).
- Orchiectomy is a surgery that removes one or both testicles. It is a type of ADT and also treats testicular cancer.
- Chemotherapy, pelvic radiation, and surgery may damage testes and ovaries. When damaged, these organs may not make hormones.
- Endocrine therapy for breast cancer targets female sex hormones. It is also called hormone therapy.
- Oophorectomy is a surgery that removes ovaries. It is a type of endocrine therapy and also treats ovarian cancer.

A drop in sex hormones may cause unwanted symptoms. Low female sex hormones caused by aging or cancer treatment often causes menopausal symptoms. Sudden drops of male sex hormones caused by cancer treatment often causes symptoms. Symptoms as well as signs and health risks of low sex hormones are listed in Guide 2.

Guide 2
Symptoms, signs, and health risks of low levels of sex hormones

Low female sex hormones	Low male sex hormones
Hot flashes, night sweats	Hot flashes, night sweats
Urogenital problems like urinary tract infections	Enlarged breasts
Vaginal dryness	A size decrease of the penis, testicles, or both
Sexual dysfunction	Sexual dysfunction
Sleep disturbance	Sleep disturbance
Mood disorders, such as depression	Mood disorders, such as depression
Cognitive changes	Cognitive changes
Joint pain and muscle aches	Joint pain and muscle aches
Fatigue	Fatigue
Weak bones and fractures	Weak bones and fractures
Heart disease	Heart disease
Parkinson’s disease	Sudden kidney injury
	Blood clots
	Less muscle and more fat
	Anemia
	Diabetes
	Hair loss

Assessment

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

There is treatment for many hormone-related symptoms.

- Read **chapter 3** for treatment of heart disease.
- Read **chapter 5** for treatment of cognitive problems.
- Read **chapter 6** for treatment of sexual dysfunction, vaginal dryness, and urogenital complaints.
- Read **chapter 7** for treatment of fatigue.
- Read **chapter 8** for treatment of sleep problems.
- Read **chapter 9** for treatment of joint and muscle pain.
- Read **chapter 10** for treatment of depression and anxiety.
- This chapter focuses on treatment of hot flashes.

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. Other names of hot flashes are night sweats and vasomotor symptoms. Treatment for hot flashes is listed in Guide 3.

For prostate cancer survivors taking 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 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.

Medroxyprogesterone, estrogen, and cyproterone acetate relieve hot flashes caused by ADT. Androgens are used to treat hot flashes caused by treatment-damaged testicles but should not be taken by prostate and breast cancer survivors.

There are medications without hormones that reduce hot flashes. Antidepressants treat hot flashes at lower doses and faster than they treat depression. Anticonvulsants also treat hot flashes at lower doses than they treat seizures. Anticonvulsants can cause sleepiness, so they may be most helpful for night sweats. Clonidine is a blood pressure medicine that also treats hot flashes.

Hot flashes may be reduced by methods other than drugs. Acupuncture, yoga, and hypnosis may help. Healthy living improves overall health and may help with 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.

Compounds that don't work or aren't safe include phytoestrogens, botanicals, dietary supplements, and black cohosh.

Guide 3
Treatments for hot flashes

Hormones	Options for females: • Estrogen with progestins • Estrogen • Estrogen with bazedoxifene	Options for males: • Medroxyprogesterone • Cyproterone acetate • Estrogen
Antidepressants	• Venlafaxine (preferred) • Desvenlafaxine • Escitalopram • Citalopram • Sertraline • Paroxetine • Fluoxetine	
Anticonvulsants	• Gabapentin (preferred) • Pregabalin	
Alpha-agonist hypertensives	• Clonidine	
Integrative therapy and lifestyle changes	Options for females: • Acupuncture • Healthy living including physical activity and maintaining a normal weight • Cognitive behavioral therapy • Hypnosis	Options for males: • Acupuncture • Healthy living including physical activity and maintaining a normal weight • Cognitive behavioral therapy

Gynecomastia

Gynecomastia is an enlargement of male breast tissue. Male breasts enlarge as a result of aging. Certain health conditions and medications can also increase breast size. Cancer treatments that reduce male sex hormones may enlarge breasts.

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.

“

Knowing there is treatment available gave me hope at diagnosis and for the future.

– Margaux
Cancer survivor

Review

- Sex hormones play a key role in puberty, having babies, and overall health.
- A drop in sex hormones may cause unwanted symptoms.
- Cancer survivors may be screened for symptoms related to a decrease in sex hormones. If the symptoms cause problems, an assessment is needed. You may get blood tests of hormones.
- There are treatments for many hormone-related symptoms.
- Hot flashes are a sudden feeling of warmth in the upper body. The intensity of hot flashes can range from mild to severe.
- If on ADT nonstop, taking breaks may provide relief from hot flashes.
- Treatment for hot flashes includes hormones, antidepressants, and anticonvulsants. Acupuncture, healthy living, and cognitive behavioral therapy may also help treat hot flashes.

3
Cardiovascular disease

Cancer survivors are at risk for heart disease. Read this chapter to learn how you and your health care providers can lower your risk.

Cancer and heart health

Cardiovascular disease is a group of disorders of the heart and blood vessels. It is often simply called heart disease. Some types of cardiovascular disease are listed in Guide 4.

Cardiovascular disease causes the most deaths around the world. It can cause disabling and fatal events.

- Heart attack (myocardial infarction)
- Stroke (cerebrovascular accident)
- Blocked blood vessel (embolism)

Cancer survivors are more likely to develop heart disease than people who never have had cancer. Cardiovascular disease causes more deaths among survivors than many types of cancer. Some of the causes of cancer can also cause cardiovascular disease. Some cancer treatments increase the chance of cardiovascular disease.

- Chemotherapy such as anthracyclines
- Targeted therapy such as HER2-targeted therapy
- Hormone therapy such as androgen deprivation therapy (ADT)
- Radiation therapy delivered near the heart
- Immunotherapy such as immune checkpoint inhibitors

The onset of cardiovascular disease varies among cancer survivors. Except for radiation, cardiovascular disease that is related to cancer treatment starts during or shortly after therapy. Radiation-related cardiovascular disease may occur years after treatment ends. Cardiovascular disease that is not related to cancer treatment most often develops 5 or more years after diagnosis. There is time to prevent or control cardiovascular disease with healthy living and treatment.

> “Stay in contact with family, friends and neighbors. Let them know you want to hear from them via text. My family and friends sent me daily songs, inspirations and humor. You will see that it is really helpful to re-read them when you are alone.
>
> – Judith
> Cancer survivor

Guide 4
Types of cardiovascular disease

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.

Preventing heart disease

A risk factor is anything that increases your chance for cardiovascular disease. Your risk of cardiovascular disease increases as the number of risk factors increase. Some risk factors can't be changed, such as your age. Other risk factors can be managed, such as:

- High blood pressure (hypertension)
- High cholesterol
- High blood sugar (diabetes)
- Tobacco use
- Obesity

Work with your health care providers to learn about and lower your risk of cardiovascular disease. Your cancer and primary care providers will work together to coordinate your care. You may see other specialists as needed. Steps to prevent heart disease among cancer survivors are listed in Guide 5.

ABCDEs of cardiovascular wellness

One of the first steps of cardiovascular wellness is awareness. Learn about the risk factors of cardiovascular disease. Also, learn about its signs and symptoms. Signs and symptoms differ between the types of heart disease. They also differ between sexes. See **Chapter 11**

Guide 5
The ABCDEs of cardiovascular 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 use as needed
B	• Blood pressure management
C	• Cholesterol management • Cigarette and tobacco cessation (quit smoking)
D	• Diet and weight management • Doses of anthracylines, radiation to the heart, or both • Diabetes prevention and treatment
E	• Exercise • Echocardiogram, electrocardiogram, or both—as needed

for informational resources on cardiovascular disease.

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

Ask your cancer doctor if your 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 dose. Doses have been standardized to treat cancer and limit heart damage.

One or more of your health care providers will monitor for cardiovascular disease. Often, it is the primary care provider who monitors. Your weight, blood pressure, and cholesterol will be measured 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 cardiovascular disease. Medication can help control diabetes, high blood pressure, and cholesterol. Exercise, healthful eating, and not using tobacco can also reduce your risk. Read about preventing poor health in *NCCN Guidelines for Patients: Survivorship Care for Healthy Living*, available at NCCN.org/patientguidelines.

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 cardiovascular disease.

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.

Anthracycline-induced heart failure

Anthracyclines are a type of chemotherapy. They increase the risk of heart failure—a condition in which the heart can't pump enough blood. Heart failure ranges from mild to severe.

The risk of heart failure from anthracyclines differs between people. It is partly based on which anthracycline was received and the total dose. A high doxorubicin dose of 250 mg/m^2 or above is more likely to be toxic.

Screening of heart failure

Get screened for heart failure within 1 year after anthracycline treatment. Your cancer doctor will examine your body and ask about symptoms of heart failure.

Symptoms of heart failure include:

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

Your doctor will assess for all risk factors of heart failure. You will get an echocardiogram if you had a high anthracycline dose, have other risk factors, or have symptoms of heart failure.

Prevention and early treatment

After screening, your care providers will keep checking for heart failure. Heart failure may not show until many years after treatment. Read Guide 6 to learn about the 4 stages of heart failure.

Guide 6
Stages of heart failure

Stage A	Your heart appears healthy but you are at risk for heart failure.	Your cancer and primary care providers will manage risk factors. They may refer you to a cardiologist.
Stage B	Tests show structural heart disease but you do not have signs or symptoms of heart failure.	A cardiologist will provide treatment. As needed, your cancer and primary care providers will address risk factors.
Stage C	You have structural heart disease and signs and symptoms of heart failure.	A cardiologist will provide treatment.
Stage D	You have advanced structural heart disease and major symptoms of heart failure.	A cardiologist will provide treatment.

The 4 stages are partly based on heart defects called structural heart disease. Structural defects may be detected before you have symptoms. Defects in the heart's main pumping chamber (left ventricle) or to heart valves may occur, such as:

- Enlargement of the left ventricle
- Thinning of left ventricle wall
- Weakened contractions of the left ventricle
- Heart valve disease

To prevent severe heart failure, follow the ABCDEs of cardiovascular wellness. Your cancer and primary care providers will manage risk factors. An expert in heart disease, called a cardiologist, treats stage B, C, and D heart failure. This doctor may prescribe medication and other treatment to keep your heart as healthy as possible.

Review

- Cardiovascular disease is a group of disorders of the heart and blood vessels.
- Cancer survivors are more likely to develop cardiovascular disease than people who never have had cancer.
- A risk factor is anything that increases your chance for cardiovascular disease. Reducing risk factors can help prevent cardiovascular disease and events. Risk factors that can be managed include high blood pressure, high cholesterol, and obesity.
- To reduce your risk, follow the ABCDEs of cardiovascular wellness. To start, learn about your risk factors of cardiovascular disease. Your care providers will monitor and help manage risk factors that can be changed.
- Anthracyclines are a type of chemotherapy. They increase the risk of heart failure.
- Screening for heart failure within 1 year after anthracycline treatment is needed. You may get an echocardiogram. An echocardiogram detects structural changes in the heart.
- After anthracycline treatment, it is important to lower your risk of cardiovascular disease including heart failure. You may take medication, live more healthfully, or see a cardiologist.

"

Survivorship is HOPE.

– Nigel
Cancer survivor

4
Lymphedema

Lymphedema is a buildup of fluid called lymph. This chapter explains how lymphedema can be reversed in early stages. It also explains how to reduce symptoms of lymphedema.

Stages of lymphedema

The lymph (or lymphatic) system is a network of fluid and tissues in your body. It transports fluid called lymph to the bloodstream. It also helps fight infections and disease.

The space between cells in body tissue is filled with fluid. When tissue fluid increases, some of it drains into ducts called lymph vessels. Lymph vessels transport the fluid, now called lymph, to the bloodstream. As lymph travels, it passes though lymph tissue that filters out germs and cell waste. Lymph tissue includes the tonsils, spleen, and lymph nodes.

Lymphedema is a buildup of lymph in fatty tissue under the skin. It occurs when the lymph system is damaged or blocked. Lymph buildup causes inflammation that can lead to scar tissue, infection, and fat deposits.

Swelling is the key symptom of lymphedema. Lymph may amass in a limb, neck, trunk, genitals, or other part of the body. Swelling occurs on the side of the body that was treated. Symptoms of lymphedema by stage are listed in Guide 7.

Guide 7
Symptoms of lymphedema by stage

Stage 0	No swelling but there may be subtle symptoms, such as • A heavy feeling in a limb • Feeling of fatigue in a limb
Stage 1	• Swelling can be seen on the side of body that was treated • Swelling in a limb is reduced with elevation or compression • An indent in the skin may occur when pressure is applied (called pitting) • Area with lymphedema is larger, heavier, or stiffer
Stage 2	• The swollen area has a spongy texture • Swelling in limb does not decrease with elevation • An indent in the skin (pitting) is less visible as swelling increases • Scar tissue may form making the swollen area larger and feel hard
Stage 3	• 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 • Moving limbs or turning your neck may be limited

Lymphedema may get worse over time without treatment. Stage 0 lymphedema is the earliest stage when there are subtle or no symptoms. Swelling starts in stage 1 and gets worse in stages 2 and 3.

Lymphedema is common among cancer survivors. It may occur after surgery or radiation to lymph nodes near the armpit, collarbone, or groin. It may also occur after procedures called sentinel node biopsy and lymph node dissection.

Sometimes no matter how tough the journey, there were beautiful days. No cars on the road, and a clear sky. This is how I felt later on in my journey. I started seeing that there is hope.

– Michael
Cancer survivor

Assessment and referral

If you are at risk for lymphedema, your cancer doctor will ask about symptoms at health visits. Lymphedema can occur any time after cancer treatment but most often occurs within 18 months. If symptoms are present, your doctor will ask questions about:

- How often and severe is the swelling
- Pain or discomfort
- Loss of strength, range of motion, or mobility
- Ability to do things you usually do

To confirm that you have lymphedema, tests are needed to rule out a return or worsening of cancer. You then may be referred to a certified lymphedema therapist. This therapist may be a physician, an occupational therapist, or 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.

Lymphedema may cause or worsen distress, depression, or anxiety. Tell your provider if you feel distressed. There is help. Read **chapter 10** to learn more.

Management and treatment

For the best results, detecting lymphedema at early stages is needed. Lymphedema can be reversed in stages 0 and 1, but treatment doesn't work as well in stages 2 and 3. Self-management strategies and treatment of lymphedema are listed in Guide 8.

Education

It is important that you learn about lymphedema. Learn the risk factors of lymphedema, such as older age, being overweight, and cancer treatment. Know the signs and symptoms of lymphedema. When you first notice symptoms, promptly tell your care provider.

Infections

Infections are more likely to happen in the swollen area. Infections can occur even before swelling begins. Prevent infections by taking good care of your skin. Keep your skin clean. Moisturize to prevent skin cracking. Protect yourself from injury that would cause swelling.

Immediately tell your provider if you notice symptoms of infection. Symptoms include redness, pain, skin streaking, and feeling of warmth in the area. You may need to be hospitalized to receive intravenous (IV) antibiotics for infections.

Physical activity

Physical activity and strength training do not trigger lymphedema. In fact, strength training may reduce symptoms of lymphedema. Water exercise may be an option, too. Consult with a lymphedema therapist before starting physical activity. Read about physical activity in *NCCN Guidelines for Patients: Survivorship Care for Healthy Living*, available at NCCN.org/patientguidelines.

Medical procedures

Early research suggests that air travel, venipuncture, and blood pressure measurement don't trigger lymphedema. 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. But, if needed, procedures may be done on the at-risk limb.

Guide 8
Self-management and treatment of lymphedema

Learn about lymphedema
Promptly report any symptoms of lymphedema to your care provider
Prevent infections at the site of lymphedema
Promptly report any symptoms of infection to your care provider
Consult with a lymphedema specialist before starting physical activity
Find a trainer for water exercise or progressive resistance training, which may improve lymphedema symptoms
Get medical procedures done on the limb that doesn't have lymphedema
Talk to a lymphedema specialist about wearing compression garments
Talk to a lymphedema specialist about manual lymph drainage
See a physical therapist for range-of-motion exercises

Compression garments

Compression garments apply pressure to the area with lymphedema. The pressure helps move lymph away from the swollen area. Your therapist will assess your need for these garments. If needed, it's important to get garments that fit well and to use them correctly. At follow-up visits, tell your therapist if the garment is not fitting right. Compression garments can be replaced as needed.

Manual lymphatic drainage

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.

Physical therapy

Lymphedema can restrict your range of motion. See a physical therapist for help. The therapist will teach you gentle stretching and range-of-motion exercises. These movements may push the lymph to another area. At follow-up visits, your provider will check your range of motion again.

Compression garments

Compression garments apply pressure that helps move lymph away from a swollen area.

Review

- Lymphedema is a buildup of a fluid called lymph under the skin.
- Stage 0 is the earliest stage of lymphedema. Swelling starts in stage 1 and worsens in stages 2 and 3.
- Causes of lymphedema include surgery and radiation to lymph nodes.
- Lymphedema can occur any time after cancer treatment but most often occurs within 18 months.
- You may be referred to a lymphedema therapist if you have lymphedema.
- To plan treatment, you will be asked about symptoms of lymphedema. You may have your limbs measured and your range of motion checked.
- Self-management of lymphedema starts with learning about lymphedema. Promptly tell your care provider if you notice symptoms of lymphedema or infection. Do strength training if your lymphedema specialist says it's safe.
- Wearing compression garments, having lymph drainage massages, and physical therapy may help relieve symptoms.

5
Cognitive dysfunction

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

Cognitive function is a set of brain-based thinking skills. These skills include learning, reasoning, memory, problem solving, and decision-making. Cognitive dysfunction is an impairment of one or more thinking skills.

Many cancer survivors report having some degree of cognitive dysfunction. Common problems occur with memory, attention, planning, processing, and learning. Cognitive dysfunction may be caused by cancer and its treatment. It may be more severe when cancer starts in or spreads to the brain.

Cognitive dysfunction 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.

Cognitive dysfunction differs between cancer survivors. The type of problem varies. 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.

Assessment

At this time, there isn’t one good screening tool of 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, onset, and course of the problem.

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

- Pain
- Sleep problems
- Fatigue
- Depression
- Medications or supplements

Some people may need imaging. Your provider may prescribe brain imaging based on your symptoms. Imaging may also be done to assess for cancer in the brain.

> “Anxiety and depression were real during my cancer treatments.
>
> – Judith
> Cancer survivor

Interventions

Cognitive dysfunction among cancer survivors does not get worse over time. Instead, it may get better. For bothersome problems, there are ways to improve or cope with cognitive dysfunction. See Guide 9 for a list of interventions.

Education and counseling

Many cancer survivors who have cognitive dysfunction benefit from education and counseling. Survivors also benefit when their family understands cognitive dysfunction. Education focuses on symptoms and the course of cognitive dysfunction. Counseling focuses on management and coping strategies of cognitive dysfunction.

Guide 9
Interventions for cognitive dysfunction

Education and counseling
Self-management strategies
Neuropsychological evaluation
Cognitive rehabilitation
Psychotherapy
Routine physical activity
Medications

Self-management strategies

You may improve your cognitive ability through brain training. Brain training may include cognitive rehabilitation or cognitive behavioral therapy. Both are described later in this section.

If you're forgetful, get organized and use memory devices. Also, keep items in the same place. Use notes, planners, and apps on smart phones.

Manage stress and energy. Practice relaxation using meditation or by other means. Develop stress management skills. Mindfulness-based stress reduction is a program that teaches how to deal with daily stressors. 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.

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 can impair brain function.

Neuropsychological evaluation

A neuropsychological evaluation is based on testing of your cognitive function. It may include tests of attention, memory, language, perception, learning, planning, and judgment. Cancer-related cognitive dysfunction is not always detected by tests. Based on the results, the neuropsychologist will give recommendations, such as cognitive rehabilitation.

Cognitive rehabilitation

The brain has the ability to 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 health care provider may prescribe medication. 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.

Review

- Cognitive function is a set of brain-based thinking skills. Cognitive dysfunction is an impairment of one or more thinking skills.
- Among cancer survivors, cognitive dysfunction can be caused by the cancer or treatment.
- 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 cognitive dysfunction.
- Many cancer survivors benefit from education on cognitive dysfunction. It can be a relief to know that cognitive dysfunction does not get worse over time.
- Counseling can help survivors manage and cope with cognitive dysfunction. You may benefit from memory tools, stress management, and living healthfully.
- A neuropsychological evaluation may detect specific types of cognitive dysfunction. Based on results, a neuropsychologist can make recommendations.
- Interventions that may improve cognition include cognitive rehabilitation, CBT, exercise, and medications.

6
Sexual dysfunction

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.

Symptoms and causes

Sexuality is part of who you are. It 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. Normal sexual function includes feelings of desire, becoming aroused, orgasm, and feeling satisfied. As people age, changes in sexual activity and function are common.

Sexual dysfunctions are ongoing problems with desire or the ability to respond with arousal, orgasm, or satisfaction. Sexual dysfunction often causes distress and discontent with sexual activity. Some symptoms of sexual dysfunction are listed in Guide 10.

Besides aging, sexual dysfunctions can occur because of one or more reasons.

- Illness or disease
- Low levels of sex hormones
- Medication
- Poor mental health and well-being
- Relationship issues

Sexual dysfunction is common among cancer survivors. It may be caused by cancer and its treatment. Tell your health care provider if you are having sexual problems. Ask if your problems are related to cancer or treatment.

The impact of cancer treatment on sexual function varies. Sexual dysfunction is common when organs in the pelvis have cancer or are removed. Radiation and surgery in the pelvis may damage sex organs. Androgen deprivation therapy (ADT) and endocrine therapy lower the level of sex hormones. Certain types of chemotherapy, targeted therapy, and immunotherapy reduce hormone levels, too.

Guide 10
Symptoms of sexual dysfunction

Male and female symptoms
Low desire for sexual activity
Trouble getting or staying aroused
Trouble having an orgasm
Pain during sex
Female symptoms
Vaginal dryness
Tight vaginal muscles
Male symptoms
Trouble getting or maintaining an erection
Ejaculation occurs too soon, slowly, not at all
Backward flow of semen into bladder

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. You may want to avoid sexual activity because you do not like your body.

Assessment and referral

Your health care providers will ask about your sexual functioning. Don't be shy to share any concerns or problems. If you are younger, your provider will also talk to you about having children and birth control.

Your health care provider may ask you to complete a short survey. 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 testes were affected by cancer treatment.

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.
- Mental health professionals can provide sex and couples therapy. They also treat issues related to sexual function, such as depression, anxiety, and alcohol abuse.
- Gynecologists 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 cancer doctor will refer you to a fertility specialist if you want to have kids after treatment.

> "Anxiety? You are not alone, especially for the newly diagnosed. It will get better! You will be able to think clearer and develop questions that you want more info on.
>
> – Steve
> Cancer survivor

Female sexual dysfunction

There is little research on treatment of female sexual dysfunction. Treatment options for female cancer survivors are mostly based on research of non-cancer patients. See Guide 11 for a list of treatments.

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 estrogen-dependent cancer.

For vaginal dryness and pain, there are treatments without hormones. Ospemifene is an oral medicine that reduces pain by acting like estrogen. Survivors of estrogen-dependent cancers should not take ospemifene. Pain may be prevented with anesthetics applied to the vulva before sex. Lubricants also prevent painful sex but may irritate the area. More research is needed for vaginal moisturizers, vaginal gels, and oils.

Guide 11
Treatment for female sexual dysfunction

Low sex drive	• Androgens • Bremelanotide • Flibanserin • Bupropion • Buspirone
Vaginal dryness	• Vaginal estrogen • Vaginal testosterone or DHEA • Lubricants for sex • Vaginal moisturizers, gels, and oils
Pain during sex	• Treatments for vaginal dryness • Ospemifene • Topical anesthetics • Vaginal dilators • Pelvic physical therapy
Problems with orgasm	• Vibrator • Pelvic physical therapy

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. Stimulation devices, like a vibrator, can help people have better orgasms.

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 and problems with orgasm.

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. Androgens may increase the risk of hormone-dependent cancers. Bupropion and buspirone may be used for a low sex drive although they are not approved for this use.

Urogenital complaints

Urogenital complaints are female health problems 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

Urogenital complaints are a common menopausal symptom. They may affect sexual function.

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 management.

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

The most common male sexual dysfunction is erectile dysfunction (ED). Erectile dysfunction has been the subject of research for decades. There are many good medical and surgical treatments.

There are often mental causes of male sexual dysfunction. These causes can be treated with one-on-one or couples counseling or medication. See Guide 12 for other treatments of male sexual dysfunction.

PDE5 inhibitors are medications that improve erections and orgasms. 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 made by the testes. Low testosterone may cause erectile dysfunction, ejaculation problems, or problems with orgasm. Taking testosterone may relieve these problems.

Medications called antidepressants often cause sexual dysfunction. Most commonly, they make having orgasms difficult. In contrast, a group of antidepressants called SSRIs may prevent premature ejaculation. Clomipramine is another antidepressant that may also delay ejaculation. The antidepressant imipramine is used to treat

Guide 12
Treatment for male sexual dysfunction

Low sex drive	• Testosterone if levels are low
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 • Antidepresants called SSRIs and clomipramine • Pelvic physical therapy • For urine leaks, empty bladder prior to sex and try imipramine
Problems with orgasm	• Testosterone if levels are low • Vibrator • PDE5 inhibitors • Pelvic physical therapy

bedwetting and may help stop urine leaks during sexual activity.

Pelvic physical therapy and vibrators may improve orgasms. The goal of physical therapy is to strengthen weak pelvic floor muscles. Vibrators stimulate the body and may help you achieve orgasm.

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

Review

- Sexual dysfunction is an ongoing problem with feelings of desire or your body's response of arousal, orgasm, and satisfaction.
- Cancer or its treatment may cause sexual dysfunction among cancer survivors.
- 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. These specialists include sexual health specialists, mental health professionals, gynecologists, urologists, and fertility specialists.
- More research is needed for treatment of female sexual dysfunction. Treatment options vary by type of sexual dysfunction. They include over-the counter and prescriptive drugs, devices, and physical therapy. Some treatments may not be safe for survivors of hormone-dependent cancers.
- Treatment for male sexual dysfunction often focuses on physical and mental causes. Testosterone may help sexual dysfunction caused by damaged testes. PDE5 inhibitors improve erections and orgasms. Certain antidepressants may help with premature ejaculation and urine leaks. Other treatments include vibrators, physical therapy, and healthy living.

7
Fatigue

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

Cancer-related fatigue

Most people have felt tired or fatigued for a brief time. This fatigue can be caused by being overworked, poor sleep, worry, stress, inactivity, and medications. Most cancer survivors have cancer-related fatigue, which differs from common fatigue.

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

Cancer-related fatigue is related to the cancer or its treatment. It is a common effect of chemotherapy, radiation therapy, blood stem (hematopoietic) cell transplant, and biological therapy. It sometimes occurs after surgery. Cancer survivors may have mild to moderate fatigue for months or years after diagnosis.

Screening and assessment

Your health care provider may screen for fatigue on a regular basis. Fatigue screening tools consist of a brief scale or survey. There is no exam or lab test for fatigue. Fatigue screening helps identify people with fatigue and assess treatment results.

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 ask you questions. 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 13.

Your provider will order blood tests if needed. 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 (ECHO) detects structural changes in the heart. If you have breathing problems, you may get a chest x-ray or oxygen saturation test.

Guide 13 Conditions that add to cancer-related fatigue
Alcohol or drug abuse
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
Sleep problems
Pain
Changes in eating or weight
Physical inactivity

Cancer can temporarily rob you of your energy, but it can't steal your burning desire to get it all back.

– Joe
Cancer survivor

Strategies that work

For moderate or severe fatigue, your health care provider will tailor a management plan for you. It will be based on your experience of fatigue and the causes. Strategies to reduce fatigue are listed in Guide 14.

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 can help you cope with fatigue. Learn about typical patterns of fatigue among cancer survivors. Monitor your fatigue and find ways to conserve energy. You can conserve energy by setting priorities, being active when your energy peaks, and pacing yourself.

Physical activity reduces fatigue and improves energy. It also improves strength, fitness, mood, and body image. A physical therapist or exercise specialist may help you meet your goals. Read about physical activity in *NCCN Guidelines for Patients: Survivorship Care for Healthy Living*, available at NCCN.org/patientguidelines..

Psychosocial interventions reduce fatigue. Cognitive behavioral therapy (CBT) helps people change unhelpful thinking and behaviors. Reducing stress may in turn reduce fatigue. Supportive expressive therapies help people find support and express emotions. Such therapies include support groups, counseling, and journal writing.

CBT for insomnia improves sleep and may also improve fatigue. Read **chapter 8** for more information. Acupuncture and healthful eating may also reduce fatigue.

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

Guide 14
Strategies 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

Review

- Cancer-related fatigue is a distressing, ongoing tiredness that limits one's ability to do day-to-day tasks.
- Many cancer survivors have fatigue as a result of cancer or its treatment.
- Fatigue screening helps identify people with fatigue and assess treatment results.
- Your health care provider will identify and treat the causes of your fatigue.
- Learn about patterns of fatigue among cancer survivors. Monitor your fatigue and learn ways to conserve your energy.
- Physical activity, psychosocial treatments, and CBT reduce fatigue. Acupuncture, acupressure, and psychostimulants may improve fatigue, but more research is needed.

8
Sleep

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 well-being. 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 15.

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.

Guide 15
Common types of sleep-wake disorders

circadian rhythm sleep disorder A mismatch between sleep-wake cycles and day-night 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.
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.
sleep apnea Pauses in breathing during sleep due to blocked airflow. Also called obstructive sleep apnea.

Screening and assessment

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

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.

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.

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. 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.

Treatment that works

Treatment of sleep-wake disorders often has very good results. Your cancer doctor 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 in Guide 16.

Polysomnography

A polysomnography is a sleep study. Sensors will be placed on your body to detect brain waves, heart rate, blood oxygen, breathing, and movement. While you sleep, a technician will monitor and record your data. At the end of the study, the sleep center doctor will write a report about your results.

Guide 16
Treatments for sleep problems

Sleep hygiene	• Stick to a regular bedtime and waketime • Be physically active in the morning, afternoon, or both • Seek out bright light during the day • Avoid bright light at night and turn off devices near bedtime • Don't eat heavy meals and limit fluids 3 hours before bedtime • Limit caffeine intake during the day and don't consume caffeine at least 4 hours before bedtime • Don't drink alcohol or consume nicotine before bedtime • Sleep in a dark, quiet, and comfortable place • Schedule a time to think about worries well before bedtime • Don't look at the clock during the night • If needed, take 1 nap a day for less than 30 minutes
Devices	• CPAP machine • Oral appliance
Cognitive behavioral therapy	• Limit activities in bed to sleep and sex (stimulus control) • Limit time in bed to the amount of time sleeping (sleep restriction) • Change unhelpful beliefs about sleep (cognitive therapy) • Calm your body and mind (relaxation)
Medication for insomnia	• Zolpidem • Zaleplon • Eszopiclone • Ramelteon • Temazepam • Doxepin • Suvorexant
Medication for restless legs syndrome	• Gabapentin enacarbil or dopamine agonists (preferred) • Opioids • Clonazepam • Iron supplement if you have low iron

Your cancer doctor may refer you to another provider. You may see a sleep expert or your primary care provider for treatment. A sleep expert 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

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.

Losing weight may help people with obstructive sleep apnea. It can improve breathing during sleep and reduce daytime sleepiness. Breathing is also improved with a CPAP machine. CPAP is short for continuous positive airway pressure. For mild obstructive sleep apnea, mouthpieces (oral appliances) may help.

Read about physical activity and weight management in *NCCN Guidelines for Patients: Survivorship Care for Healthy Living*, available at NCCN.org/patientguidelines.

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

Medications 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.

Medications 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 restless legs syndrome (RLS). Other medications for RLS are opioids and clonazepam. Take iron supplements if you have low iron. Iron can improve symptoms.

Review

- Sleep-wake disorders are ongoing problems with sleep and excessive daytime sleepiness.
- Many cancer survivors have poor sleep quality. Some have a sleep-wake disorder.
- Cancer, treatment, and related stress may cause or worsen sleep quality.
- You may be asked to complete a short survey as part of an evaluation of sleep-wake disorders.
- To diagnose a sleep-wake disorder, you may complete a sleep diary or do a sleep study.
- Treatment of sleep-wake disorders often has very good results.
- You may be referred to a sleep expert for treatment.
- Sleep hygiene is a set of healthy sleep habits that help treat many sleep problems.
- Weight loss, CPAP machines, and mouthpieces may help reduce obstructive sleep apnea.
- 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.

You don't have time to dwell on things when you're in it. It changed me and it was borne out of survival.

– Yvonne
Cancer survivor

9
Pain

Read this chapter to learn about pain among cancer survivors. There are many treatment options.

Cancer pain syndromes

Pain is the body's alarm system that something is wrong. It alerts people to act and teaches people what to avoid. Pain usually stops when its cause ends or the body heals.

Pain is either acute or chronic. Acute pain starts suddenly and can often be treated. Chronic pain lasts a long time and is often caused by disease. It is managed to reduce problems, such as:

- Distress, depression, anxiety
- Inactivity, disability
- Poor quality of life

Many cancer survivors have pain. The type and severity of pain differs among them. More than 1 in 3 survivors have chronic pain after treatment. For many, pain management is needed. Causes of pain among survivors include the cancer and treatment. Pain syndromes among cancer survivors are listed in Guide 17.

Guide 17
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.

Assessment and referral

Your health care provider will screen for pain on a regular basis. A pain screening tool consists of a brief scale. There is no exam or lab test for pain. If you have pain, tell your health care provider. Your provider will do a full pain assessment.

Your provider will ask you to complete a survey on pain. Surveys help pinpoint the intensity and type of pain. To plan treatment, your provider will identify the causes and physical pathways of the pain. Share your goals for pain management, such as the level of comfort you want.

Based on an assessment and follow-up visits, you may be referred to other providers.

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

> Never give up, fight a good fight, keep the faith, and believe you will conquer this. You are not alone.
>
> – Judith
> Cancer survivor

Pain medications

The goals of pain management are to improve your comfort, function, and quality of life. Management of pain often is done with multiple methods. Examples are pain medication and different types of therapy. Pain medications for cancer pain syndromes are listed in Guide 18.

Opioids

Opioids relieve pain by affecting opioid receptors on nerve cells. They are a treatment option for moderate to severe pain. If you have completed cancer treatment, opioids are not typically the first choice for pain management. A dual-action opioid that affects opioid and noradrenaline receptors is also an option for neuropathic pain.

Ask your provider about the benefits and risks of opioid use. Addiction to prescribed opioids can happen. Your provider will take the following steps to prevent addiction.

- Discuss the goals of treatment
- Educate about side effects
- Create a treatment contract
- Prescribe the lowest dose for the shortest period of time
- Monitor results and reassess need for opioids
- Slowly reduce the amount of opioids to avoid withdrawal

Learn how to safely use opioids. Strategies to prevent misuse of opioids include medication diaries, pill counts, psychological interventions, and urine drug testing. Also, learn how to safely discard unused opioids. Opioids should not be

taken by people who don't have a prescription. You should never use someone else's prescription.

Adjuvant analgesics

Adjuvant analgesics may be taken with opioids but can also be used alone. When taken with opioids, they may further reduce pain. They also allow a lower dose of opioids to be used.

Adjuvant analgesics include antidepressants called SNRIs and tricyclics. SNRIs have good results for arthralgia that is caused by a breast cancer treatment called aromatase inhibitors.

Adjuvant analgesics include anticonvulsants. The most commonly used anticonvulsants are gabapentin and pregabalin. More research on anticonvulsants for pain among cancer survivors is needed.

NSAIDs and acetaminophen

NSAIDs and acetaminophen are sold over-the-counter or by prescription. NSAID is short for nonsteroidal anti-inflammatory drug. Acetaminophen is a very common pain reliever. High doses can hurt the liver.

NSAIDs reduce inflammation and pain, but can hurt your stomach. For some people, they can hurt the kidneys. Ibuprofen and naproxen are types of NSAIDs. COX-2 inhibitors are also NSAIDs and are less likely to cause stomach ulcers.

Guide 18
Pain medications for cancer pain syndromes

Neuropathic pain	• Opioids • Dual-action opioids	• Adjuvant analgesics • Creams, patches
Chronic pain syndromes	• Opioids • Adjuvant analgesics • Nerve blocks	• Trigger point injections • Botox injection
Arthralgias, myalgias	• Adjuvant analgesics • Muscle relaxers	• NSAIDs, COX-2 inhibitors • Acetaminophen
Bone (skeletal) pain	• Opioids • Adjuvant analgesic • NSAIDs, COX-2 inhibitors • Acetaminophen	• Antiresorptives, bisphosphonates • Muscle relaxers
Myofascial pain	• Adjuvant analgesic • NSAIDs, COX-2 inhibitors	• Acetaminophen • Ointment, patches
Chronic pelvic pain	• Dorsal column stimulation	
Post-radiation pain	• Pain medications for specific cancer pain syndrome	

Muscle relaxers
Muscle relaxers can help 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 medications
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 medications slow down bone resorption and help keep bones strong. Bisphosphonates are a type of antiresorptive medication and are commonly used. They can help treat pain from vertebral compression.

Pain killing 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 help pain caused by post-mastectomy or post-thoracotomy syndrome.

There are two types of injections that may help post-radical neck dissection syndrome. Trigger point injections relieve pain from muscle knots. Botox is short for botulinum toxin injection. It is known to reduce wrinkles but is also used for muscle pain relief.

Topical pain relief
Some pain medications can be applied to the skin where you feel pain. Pain patches stick to the skin like a band aid. Pain creams and ointments are rubbed on the skin. Medications from patches, creams, or ointments pass through the skin and into the body.

Non-pharmaceutical pain management

There are many options for non-pharmaceutical pain management. These options may be used with or instead of medications. A list of non-pharmaceutical pain management for cancer-related pain is in Guide 19.

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 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. 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 routine, such as bathing. Aquatic therapy consists of exercises that are done in water.

Guide 19 Non-pharmaceutical management of cancer pain syndromes		
Neuropathic pain	• CBT • Psychosocial support • Hypnosis	• Acupuncture • Cold, heat • TENS unit
Chronic pain syndromes	• Psychosocial support and behavioral treatment • Physical therapy for post-amputation (mirror therapy) or post-radical neck dissection pain syndrome	• Massage for post-radical neck dissection syndrome • Myofascial release for post-radical neck dissection syndrome • TENS unit
Arthralgias, myalgias	• Acupuncture • Physical activity, yoga • Physical therapy	• Aquatic therapy • Massage • Cold, heat, ultrasonic stimulation
Bone (skeletal) pain	• Physical activity for vertebral compression • Physical therapy • Back brace for acute vertebral compression	• Limited bedrest for acute vertebral compression • Surgery
Myofascial pain	• Acupressure • Acupuncture • Physical activity	• Massage • Ultrasonic stimulation
Chronic pelvic pain	• Physical therapy • Surgery	• Laxatives, enemas • Lots of fluids
Post-radiation pain	• Physical therapy	• Surgery

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 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, 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.

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. Dorsal column stimulation stops pelvic pain signals with implanted electrodes. For severe pelvic pain, surgery to remove scar-like tissue may be needed.

Review

- Pain is the body's alarm system that something is wrong.
- Many cancer survivors have pain caused by the cancer or treatment.
- Survivors will 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.
- Pain is often managed with multiple methods.
- Medications for pain vary based on the specific pain syndrome. Opioids can be safely used for moderate to severe pain. They are often not the first pain medication used. Other pain medications include antidepressants, anti-inflammatory drugs, acetaminophen, nerve blocks, and topical pain killers.
- There are options for pain management other than medications. These options include mind and body treatments, local treatments, and surgery.

10
Distress and mental health

Many cancer survivors are distressed at some point. Read this chapter to learn how to take care of your mental health.

Distress is normal

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress is normal during cancer care, but it may make it harder to cope with cancer.

Distress ranges from mild to severe levels. Many survivors have a normal fear of a cancer recurrence. Mild distress may reduce quality of life. Severe distress can affect a person's self-care, social life, mood, or faith. Survivors with severe distress may not go to health visits or have a healthy lifestyle.

Distress can lead to or worsen mental disorders. Mental disorders are health conditions just like heart disease is a health condition. There are many types of mental disorders. Each mental disorder is a group of symptoms that are related to major problems with emotion, thinking, or behavior. Anxiety and depressive disorders are common among cancer survivors.

- 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.

Screening and assessment

Your cancer or primary care provider may screen for distress or mental disorders on a regular basis. Ongoing screening is important. Mental health issues can start any time after a cancer diagnosis. Also, your provider may not know you're struggling unless you very clearly say so.

Distress can occur at any point in time, but there are times when distress is more likely. Distress is likely during routine health care visits, when getting health tests, or when symptoms occur. Mental health screening is very important at these times.

A mental health screening tool consists of a brief scale or short survey. If you're struggling with a mental health issue, your provider will ask more questions. It's important to understand the type and cause of distress and to rule out other health conditions. You will be asked about a range of topics.

- Emotional symptoms like worry, sadness, and irritability
- Physical symptoms like trouble sleeping, lack of energy, heart pounding
- Cognitive symptoms like trouble concentrating and mind going blank
- Loss of ability to do normal life activities
- Medical factors like illness, medication, and alcohol or drug abuse

Initial steps of care

Your provider will use the mental health screening and follow-up questions to guide care. Cancer and primary providers will treat some mental health issues and ensure your safety. For needs beyond their care, they will refer you to a specialist. Initial steps of mental health care are listed in Guide 20.

Education

Your care team can provide education on cancer and cancer survivorship. 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 care 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. To learn more, read *NCCN Guidelines for Patients: Survivorship Care for Healthy Living*, available at NCCN.org/patientguidelines.

Mental health medication

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

SSRIs and SNRIs are two common types of antidepressants.

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.

Guide 20
Initial steps of mental health care by cancer or primary care providers

Educate on cancer and its treatment to prevent confusion and distress
Educate on distress and mental health among cancer survivors
Treat medical conditions that add to mental health issues
Provide a plan for physical activity and healthy eating
Prescribe mental health medications
Develop safety plan
Provide resources for spiritual, mental, social, or practical problems
Refer to social work and counseling services or patient navigators
Refer to chaplains
Refer to mental health providers

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 care provider 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.

Your cancer or primary care provider may refer you to 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.

Review

- Distress is normal during cancer care. Many survivors have a normal fear of a cancer recurrence.
- Distress can lead to or worsen mental disorders. Anxiety and depressive disorders are common among cancer survivors.
- Tell your provider if you are distressed. Distress is not always obvious. You may not look or sound distressed.
- One of the first steps of mental health care is education. Knowing what is normal and what to expect can reduce stress.
- Medical conditions can contribute to mental health issues. Your cancer or primary care provider will treat contributing conditions. Living a healthy lifestyle can also improve mental health.
- Your cancer or primary care provider may prescribe medications for mental disorders. If you may harm yourself or others, your provider will work with you to ensure people's safety.
- You may need care from a specialist. Your provider may refer you to a chaplain, social worker, or mental health specialist.

I have mixed emotions on a regular basis. On one hand, I'm so happy and grateful because I found a treatment that is working, but on the other hand I have to live with the fear and anxiety for the rest of my life. It's always in the back of my mind.

– Danika
Cancer survivor

11
Resources

There are many resources to help you improve your health. Learn more about survivorship through the organizations listed in this chapter. Get help and use supportive tools to achieve your health goals.

Survivorship

American Institute for Cancer Research
aicr.org/cancer-survival

American Society of Clinical Oncology
cancer.net/survivorship

American Society of Clinical Oncology tracking form
cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans

Be the Match®
bethematch.org/survivorship

Cancer Hope Network
cancerhopenetwork.org/get-support

Cancer Survivors Network
csn.cancer.org

Centers for Disease Control and Prevention
cdc.gov/cancer/survivors/index.htm

Children's Oncology Group
survivorshipguidelines.org

Leukemia & Lymphoma Society
lls.org/managing-your-cancer/follow-up-care-and-survivorship

National Cancer Institute
cancercontrol.cancer.gov/ocs/resources/survivors

National Cancer Survivorship Resource Center (The Survivorship Center)
cancer.org/SurvivorshipCenter

National Coalition for Cancer Survivorship
canceradvocacy.org

Save Your Skin
saveyourskin.ca/self-care-after-cancer

Survivor.net
survivornet.com/

> "In time you breathe a little easier, you have less scans, then less appointments and transition to survivorship. I became a survivor when I could buy long term car insurance as opposed to six months at a time.
>
> – Kathy
> Cancer survivor

Cancer-related effects

American Cancer Society
cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html

National Cancer Institute
cancer.gov/about-cancer/treatment/side-effects

Heart and vascular effects

American Cancer Society, Heart rate calculator
cancer.org/healthy/eat-healthy-get-active/get-active/target-heart-rate-calculator.html

CardioOnc.org
cardioonc.org/patients

CardioOnc.org, Heart Risk Calculator
cvriskcalculator.com

Million Hearts
millionhearts.hhs.gov/learn-prevent/index.html

Immunotherapy effects

NCCN Guidelines for Patients: Immunotherapy Side Effects: CAR T-Cell Therapy
NCCN.org/patients/guidelines/cancers.aspx#immunotherapySECarTCell

NCCN Guidelines for Patients: Immunotherapy Side Effects: Immune Checkpoint Inhibitors
NCCN.org/patients/guidelines/cancers.aspx#immunotherapySEICI

Mental health effects

Anxiety and Depression Association of America
adaa.org/

Anxiety and Depression Association of America (ADAA) Reviewed apps
adaa.org/finding-help/mobile-apps

NCCN Guidelines for Patients: Distress During Cancer Care
NCCN.org/patients/guidelines/cancers.aspx#distress

Oral effects

National Institute of Dental and Craniofacial Research
nidcr.nih.gov/health-info/cancer-treatments/more-info

Sexual and fertility effects

Livestrong
livestrong.org/we-can-help/livestrong-fertility

OncoLink
oncolink.org/support/sexuality-fertility/sexuality

The Oncofertility Consortium
oncofertility.northwestern.edu/for-patients

Sleep effects

National Cancer Institute
cancer.gov/about-cancer/treatment/side-effects/sleep-disorders-pdq

National Heart, Lung, and Blood Institute
nhlbi.nih.gov/health-topics/education-and-awareness/sleep-health

Healthy living

Food

American Cancer Society, Calorie Counter
cancer.org/healthy/eat-healthy-get-active/take-control-your-weight/calorie-counter-calculator.html

American Institute for Cancer Research
aicr.org/cancer-prevention/healthy-eating/new-american-plate

Cancer Nutrition Consortium
cancernutrition.org

Livestrong, MyPlate Calorie Tracker
cancernutrition.org

Memorial Sloan Kettering Cancer Center
mskcc.org/cancer-care/diagnosis-treatment/symptom-management/integrative-medicine/herbs/about-herbs

MyPlate app
choosemyplate.gov/startsimpleapp

Oncology Nutrition
oncologynutrition.org/erfc

Physical activity

American Cancer Society
cancer.org/treatment/survivorshipduringandaftertreatment/stayingactive/physical-activity-and-the-cancer-patient

American Cancer Society, Exercise calculator
cancer.org/healthy/eat-healthy-get-active/get-active/exercise-counts-calculator.html

Cancer Supportive and Survivorship Care
cancersupportivecare.com/whyexercise.html

LIVESTRONG at the YMCA
livestrong.org/ymca-search

SilverSneakers
tools.silversneakers.com

Tobacco

American Cancer Society
cancer.org/healthy/stay-away-from-tobacco.html

American Lung Association
lung.org/quit-smoking

American Lung Association
freedomfromsmoking.org

American Society of Clinical Oncology
asco.org/practice-policy/cancer-care-initiatives/prevention-survivorship/tobacco-cessation-control

Livestrong MyQuit Coach
apps.apple.com/us/app/livestrong-myquit-coach-dare/id383122255

National LGBT Cancer Network
cancer-network.org/tobacco-related-cancer-project

North American Quitline Consortium
naquitline.org

Smokefree.gov
smokefree.gov

Weight management

American Society of Clinical Oncology
cancer.net/sites/cancer.net/files/weight_after_cancer_diagnosis.pdf

CA: A Cancer Journal for Clinicians Patient Page
acsjournals.onlinelibrary.wiley.com/doi/pdf/10.3322/caac.21146

Centers for Disease Control and Prevention, Adult BMI Calculator
cdc.gov/healthyweight/assessing/bmi/adult_bmi/english_bmi_calculator/bmi_calculator.html

National Heart, Lung, and Blood Institute
nhlbi.nih.gov/health/educational/lose_wt

National Institute of Diabetes and Digestive Kidney Diseases Body Weight Planner
niddk.nih.gov/bwp

Support programs

Cancer Hope Network Get Matched Program
cancerhopenetwork.org/get-support/get-matched

Good Days
mygooddays.org/patients

Leukemia & Lymphoma Society
lls.org/support-resources

Save Your Skin
saveyourskin.ca/patient-support-webinars

Help lines

American Cancer Society
1.800.227.2345

American Lung Association
1.800.LUNGUSA

American Psychosocial Oncology Society
1.866.276.7443

Be the Match®
1.888.999.6743

Cancer Support Community
1.888.793.9355

Leukemia & Lymphoma Society (LLS)
1.800.955.4572

Livestrong
1.855.220.7777

National Cancer Institute
1.800.4.CANCER

National Suicide Prevention Lifeline
1.800.273.TALK

Words to know

ADT
androgen deprivation therapy

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.

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

ED
erectile dysfunction

EKG
electrocardiogram

FDA
Food and Drug Administration

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 a child.

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 symptom.

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.

IV
intravenous

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 well-being 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.

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NCCN Cancer Centers

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

Fred & Pamela Buffett Cancer Center
Omaha, Nebraska
402.559.5600 • *unmc.edu/cancercenter*

Case Comprehensive Cancer Center/
University Hospitals Seidman Cancer
Center and Cleveland Clinic Taussig
Cancer Institute
Cleveland, Ohio
800.641.2422 • UH Seidman Cancer Center
uhhospitals.org/services/cancer-services
866.223.8100 • CC Taussig Cancer Institute
my.clevelandclinic.org/departments/cancer
216.844.8797 • Case CCC
case.edu/cancer

City of Hope National Medical Center
Los Angeles, California
800.826.4673 • *cityofhope.org*

Dana-Farber/Brigham and
Women's Cancer Center |
Massachusetts General Hospital
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*

Huntsman Cancer Institute
at the University of Utah
Salt Lake City, Utah
800.824.2073
huntsmancancer.org

Fred Hutchinson Cancer
Research Center/Seattle
Cancer Care Alliance
Seattle, Washington
206.606.7222 • *seattlecca.org*
206.667.5000 • *fredhutch.org*

The Sidney Kimmel Comprehensive
Cancer Center at Johns Hopkins
Baltimore, Maryland
410.955.8964
www.hopkinskimmelcancercenter.org

Robert H. Lurie Comprehensive
Cancer Center of Northwestern
University
Chicago, Illinois
866.587.4322 • *cancer.northwestern.edu*

Mayo Clinic 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*

The Ohio State University
Comprehensive Cancer Center -
James Cancer Hospital and
Solove Research Institute
Columbus, Ohio
800.293.5066 • *cancer.osu.edu*

O'Neal Comprehensive
Cancer Center at UAB
Birmingham, Alabama
800.822.0933 • *uab.edu/onealcancercenter*

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*

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 • *cancer.ucla.edu*

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*

The University of Texas
MD Anderson Cancer Center
Houston, Texas
844.269.5922 • *mdanderson.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

2020

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