



Survivorship Handbook

Everything you need to know to create a more
confident cancer journey.

Brought to you by PearlPoint Cancer Support

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Introduction

Welcome to the Survivorship Handbook presented by PearlPoint Cancer Support.

About The Survivorship Handbook

You've just finished cancer treatment, but you may be asking yourself what comes next? Survivorship brings with it new challenges and questions. Use PearlPoint Cancer Support's Survivorship Handbook as your guide.

The "new normal" is a phrase used by many cancer survivors to describe life after cancer treatment as they create and settle into new routines that no longer revolve around treatment and appointments. Once your treatment plan is complete, you might expect life to return back to the way it was before you were diagnosed with cancer. However, your cancer journey doesn't always end when treatment ends. It takes time for you and your family to recover, physically and emotionally.

In this handbook, you'll learn how to stay healthy and well during survivorship through follow-up care and make healthy lifestyle changes. You will learn strategies to help prevent recurrence and secondary tumors. You will also learn how to care for your emotional needs such as managing fear of recurrence.

Even after treatment ends, you may experience new or long-term side effects, but most side effects are manageable. It's important to know what to expect. This handbook will walk you through the possible side effects and tips for managing them.

The Survivorship Handbook also addresses the practical issues of life after cancer treatment such as health insurance, financial issues, returning to work, and personal relationships.

Make the handbook your own! Ask your survivorship navigator or another member of your survivorship team to highlight the sections that most apply to your specific cancer journey. Use the worksheets in the back to keep track of all your information such as medical history and appointments. Use the "Additional Resources" section at the end of the handbook to find any additional assistance you may need or ask your healthcare team to add more.

We hope you find the Survivorship Handbook to be a valuable, frequently consulted tool as you navigate survivorship and create your own "new normal."

Survivorship Navigation Team

What does the survivorship navigation team do?

The survivorship navigation team works directly with cancer patients to help guide them through their life after cancer treatment. Survivorship navigators serve as a constant point of contact for patients to coordinate care, answer questions, and provide resources.

As a cancer patient, your healthcare team may have included a large number of people including:

- A medical oncologist
- A radiation oncologist
- Surgeon
- Pharmacist
- Dietitian
- Physical therapist
- Nurse navigator
- Nurse practitioner/ Physician’s assistant
- Nurses
- Other healthcare professionals
- Your caregiver, family, and friends

Your survivorship navigator will continue work closely with every member of your healthcare team to keep the lines of communication open.

Your survivorship team understands the medical, practical, and emotional needs of cancer patients. If you have questions about treatment, medications, appointments, or anything else, ask a member of your survivorship team.

Who is my survivorship navigator, and how do I contact him or her?

My Survivorship Navigator	
Name	
Phone Number	
Email	

My Survivorship Team	
Name	
Role	
Phone Number	
Email	

My Survivorship Team	
Name	
Role	
Phone Number	
Email	

Survivorship and Wellness

Even after treatment ends, your cancer journey continues. It may take you a while to readjust to life after treatment. You may wish to make changes in your nutrition and lifestyle to help prevent recurrence. Use these sections to help you navigate your “new normal” and to promote wellness during survivorship.

Follow-Up Care

Follow-up care after completing cancer treatment is very important. Your healthcare team will help you manage long-term side effects and watch for any changes such as the cancer spreading or coming back. Here are some things to remember about follow-up care:

- Always go to your follow-up appointments.
 - You will probably have follow-up exams every 3-6 months following treatment depending on the type of your cancer.
 - After some time goes by without a recurrence, your healthcare team will probably recommend checkups only once or twice a year.
- Follow your recommended screening schedule.
 - Your screening schedule will depend on the type and stage of your cancer and other aspects of your medical history.
 - Typically a few months after treatment your doctor may order an imaging scan such as a CT scan, PET scan, or MRI to set a new baseline. Your doctor will use this image to compare with future scans to check for recurrence.
 - At most appointments with your oncologist, you will first have a lab visit to do blood tests. Your oncologist uses these blood tests to check for tumor markers, protein levels, blood cell counts, and general health.
- If you change your primary care physician, make sure your new doctor has all your medical records and history. You can do this by:
 - Contacting your oncologist’s office to send the medical records to your new primary care physician.
 - Obtaining your own copy of your records to take to your primary care physician.
 - Keeping a copy of your medical records at home to make copies for any medical team.
- Tell your doctor about any side effects.
 - Some side effects occur after treatment ends. Let your healthcare team know of any and all changes so they can help you manage them effectively.
 - Some side effects are delayed and can present months after treatment ends.
- Keep your health insurance, if at all possible.
 - Follow-up care, especially imaging, can be very expensive if you do not have health insurance.

Recommended Screenings, Tests, and Exams

Follow-up cancer care involves regular medical checkups that include a review of the patient's medical history and a physical exam. These checkups help find recurrence, secondary cancers, and other medical issues. Your follow-up care may include any of the following:

Physical exam: Your doctor will examine your body to check your general health. He or she will look for lumps or anything else unusual. Your doctor will feel your neck, under your arms, and your abdomen to check for swollen lymph nodes.

Blood work: At most appointments with your oncologist you will have a lab visit first to do blood tests. Your oncologist uses these blood tests to check for tumor markers, protein levels, blood cell counts, and general health.

CT scan: Computerized Tomography (CT) scans (sometimes called CAT scans) may be used to determine a baseline for comparing later scans. They may also be used after treatment to check for change or recurrence.

A CT scan is an imaging test. CT scans take multiple images from different angles to capture “slices” of the inside of the body. These slices are then reassembled on a computer to create a 3-D image of organs and tissues. Before a CT scan, you may be asked to drink contrast, a milky liquid that helps certain organs show up better in the pictures. You may also receive contrast through an IV in your arm or hand during the scan.

PET scan: Positron Emission Tomography (PET) scans may be used after treatment to check for change or recurrence.

A PET scan is an imaging test involving an injection of radioactive glucose (sugar). A PET scan takes images of areas of the body that pick up the radioactive glucose. Cancer cells take up more glucose than normal cells, so cancer cells can be seen on the image.

MRI scan: Magnetic Resonance Imaging (MRI) (sometimes called nuclear magnetic resonance imaging or NMRI) may be used after treatment to check for change or recurrence.

An MRI is an imaging test. Unlike CT scans or PET scans, MRIs do not use x-rays to take these images. MRIs use a powerful magnet and radio waves to create images of the inside of the body. MRIs are often used for imaging the breasts, brain, spine, joints, and soft tissues, but they can be used in other ways also.

During an MRI, you may also receive contrast through an IV in your arm or hand during the scan. You have to stay very still during an MRI. Some people say this is the most difficult part. If you are claustrophobic, let your healthcare team know. There are medications that you can take to help you relax during the scan.

Breast Self-Exam: Breast self-exams are to be performed monthly beginning at age 20. Begin by examining the appearance of the breasts in the mirror, first with arms down then with arms raised. Check for dimpling of the skin, redness, change in color, or discharge from the nipples. Feel your breasts while standing or sitting with the opposite arm raised. Check the entire breast and armpit for lumps or other changes. The best way to ensure you check your entire breast is to start at the nipple with the pads of your fingers and work your way around the breast in a circular motion. Next, lie down and follow the same process of checking your breasts for lumps. Let your doctor know if you see or feel any lumps or changes.

Mammogram/mammography

Traditionally, health care professionals have recommended annual mammograms for women to be done beginning at age 40—or earlier if there is a family history of breast cancer. A mammogram is an X-ray image of your breasts. It does not hurt but may feel uncomfortable. During a mammogram, the technician presses your breasts between two firm surfaces. This spreads out the breast tissue and allows the X-ray machine to get good pictures of your breasts. Your doctor will use these pictures to check for changes in your breast tissue and also to check for cancer. Mammograms are also done once a lump is detected—to show a more detailed picture of the mass.

A new advancement in mammography is breast tomosynthesis, which creates a three-dimensional (3D) image of the breast. Tomosynthesis can be done along with a traditional digital mammogram, but it is not a replacement.

Colonoscopy: A colonoscopy is usually recommended every ten years starting at age 50. A colonoscopy is used to examine the bowel's interior surface for abnormalities like polyps. In this procedure, the doctor inserts a flexible tube into the bowel. The tube contains a camera. The colonoscopy lets the doctor examine the inside of the entire colon and rectum. If the doctor discovers a polyp or abnormal tissue, it may be removed and sent for further testing. Removal of a polyp is called polypectomy. You will be sedated during the procedure so you are comfortable. The night before the exam you will have to cleanse your colon by drinking a liquid or taking a medication given to you by your healthcare team. You will also not be allowed to eat before a colonoscopy. Follow your doctor's instructions closely.

Sigmoidoscopy: A sigmoidoscopy is usually recommended every five years starting at age 50. A sigmoidoscopy is similar to a colonoscopy. A sigmoidoscopy checks the rectum and lower (sigmoid) colon for polyps that may be cancerous. A sigmoidoscope is a thin tube with a light and small camera at the end. Your doctor will insert the tube into the bowel. If any polyps need to be biopsied, your doctor can take a sample during the procedure. You will be sedated during the procedure so you are comfortable.

Pap smear: In this procedure for women, the doctor uses a cotton swab or small brush to collect cells from your vagina and the surface of your cervix. The doctor views the cells under a

microscope to see if they are abnormal. Pap smears are used to screen for cervical cancer. In the past, Pap smears were recommended for women annually. However, for women with no other risk factors for cervical cancer, Pap smears every three years are sufficient.

Pelvic Exam: This is an examination of a woman’s entire pelvic region, including your vagina, cervix, uterus, fallopian tubes, ovaries and rectum. Here’s what you can expect: first, the doctor will insert an instrument called a speculum into your vagina. This enables your doctor to look for lumps or changes in the shape or size of your uterus, vagina, and nearby tissues. Your doctor will also insert a gloved, lubricated finger into your rectum to check for lumps or abnormal signs.

Prostate exam/ Digital rectal exam: Digital rectal exams are used to screen for prostate cancer or abnormalities in men and also to check for colon and anal cancer. Your doctor inserts a lubricated, gloved finger into the rectum. This is a way to feel the prostate through the rectal wall. The prostate and rectum are checked for hard or lumpy areas that may indicate cancer.

Prostate Specific Antigen (PSA): Your blood may be tested to obtain its PSA level. In men, the prostate makes PSA. PSA can be elevated due to reasons other than cancer. These include benign hypertrophy (enlarged prostate), infection, or inflammation.

Skin checks: Your doctor or a dermatologist will check all of you skin for signs of skin cancer, such as suspicious moles. If your doctor suspects a malignancy, he or she will biopsy the mole to check for cancer. Signs of irregular moles include: asymmetry, uneven border, dark color, large size, and/or changes.

Testicular Self-Exam: Testicular self-exams are recommended for men monthly. Check each testicle separately. Roll your testicle gently between your fingers checking for lumps or other changes. Let your doctor know if you see or feel any changes.

Scheduling Your Exams

Your healthcare team will determine the best course of action for your screening schedule and follow-up care. Remember to always follow your recommended screening schedule. Usually, the earlier a recurrence or secondary cancer is found, the more treatable it is. The following are the current screening recommendations for some common cancer types. Due to your cancer history you may need screenings more often.

Breast Cancer			
Population	Age 40-49	Age 50-74	Age ≥ 75
Mammogram*	Baseline at 40	Annually	Annually
Breast Self-Exam	Monthly	Monthly	Monthly

* Subsequent mammograms should be obtained every six to twelve months for surveillance of abnormalities.

Colorectal Cancer		
Population	Age 50-59	Age ≥ 60
Colonoscopy*	Baseline at 50	Every 10 years
Sigmoidoscopy	Baseline at 50	Every 5 years
Hemoccult Blood Test	Annually	Annually

* A surveillance colonoscopy should be performed one year after the initial surgery to treat colon cancer then every five years, dictated by the findings of the previous test.

Lung Cancer	
Population	Age 55-80 with 30 pack years* smoking history, currently smoke, or only quit within last 15 years
CT Scan	Annually**

* Pack years is equal to the number of packs smoked per day times the number of years smoking.

** Scanning may differ for patients with a history of lung cancer.

Cervical Cancer		
Population	Age 20-29	Age ≥ 30
Pelvic Exam	Annually	Annually
Pap Smear	Annually	Every 1-3 Years

Testicular Cancer	
Population	All Ages
Testicular Self-Exam	Monthly

Prostate Cancer	
Population	Age ≥ 50
Prostate Specific Antigen	Annually
Digital Rectal Exam	Annually

Source: United States Preventative Task Force

Maintenance Therapy/ Adjuvant Therapy

Sometimes small cancerous cells remain in your body even after chemotherapy or radiation treatments. Maintenance therapy is the use of single drugs or a combination of drugs at low doses on a long-term basis for patients who are in complete remission or to stop the growth of any remaining cancer cells. Adjuvant chemotherapy is often given to destroy tiny cancer cells that may be left over after the known tumor is removed by surgery. For cancers affected by hormones (such as breast, gynecological, testicular, or prostate), hormonal therapies are often used as maintenance therapies.

Maintenance therapy delivers one hit after another to fight off any cancer cells that might remain in the body after the initial therapy session. Maintenance therapy is used in a number

of cancers, including breast, lung, colorectal, ovarian, and blood cancers. New maintenance therapies are also being studied in a number of clinical trials.

For patients who have advanced-stage cancer, maintenance therapy can help slow the progression of the disease. Ongoing treatment can also help control certain disease-related symptoms, like bone pain and shortness of breath.

You may or may not be a candidate for maintenance treatment. Doctors typically recommend ongoing treatment for patients whose cancer may respond to maintenance therapy or for patients whose bodies can tolerate additional chemotherapy.

Is maintenance or adjuvant therapy right for you?

If you're deciding whether maintenance or adjuvant therapy is right for you, you might want to discuss the following issues with your doctor.

- What treatments are you considering? Learn exactly what will be expected of you during therapy. For instance, will you have to see your doctor for injections or will you take pills at home?
- What are the side effects? What side effects are you willing to live with? Which ones will be too much for you to tolerate? Do you plan to work or stay active during treatment? Could side effects interfere with your plans?
- What are the odds you'll stay cancer free? It's important to know how likely it is that your cancer will return if you decide not to go through further therapy and how much improvement you might experience if you undergo additional therapy. Your doctor can estimate how well your treatment will work based on studies of other patients with your same type of cancer who received the same treatment.
- How is your overall health? People who are otherwise healthy may experience fewer side effects during maintenance therapy and are more likely to benefit. People with more serious health problems may be more likely to experience side effects during therapy and may see fewer positive results.
- What do you prefer? Some people are willing to try everything possible to reduce the chance that their cancer will return, regardless of the side effects. Others don't want the extra side effects if there is likely to be little benefit. Share your desires with your doctor.

Your doctor can help you weigh these factors and decide whether the benefits of maintenance or adjuvant therapy outweigh the risks for you.

Risk Factors for Recurrence and Secondary Tumors

Many survivors worry about their cancer coming back (recurrence), secondary tumors (metastasis), or a new, different cancer diagnosis (second primary cancer) developing, which can cause stress and anxiety.

Your chance of recurrence, secondary tumors, or a second primary cancer depends on a number of things including:

- Type of cancer
- Stage
- Treatment received
- Family history
- Lifestyle
- Age when treated

Type of Cancer

Some cancers are more aggressive than others. Your healthcare team will have kept your specific diagnosis in mind when they helped you create your treatment plan. If your cancer was more aggressive or your tumor had certain genetic mutations, you may be at a higher risk for recurrence.

The type of original cancer you had may affect your risk for a second primary cancer. Researchers are still not sure if the cancer is caused by chemotherapy, radiology, the original cancer, or even a combination of the three. It's also possible that both the original cancer and a second cancer share certain risk factors like an underlying cause, environmental exposure, or family history.

Stage

If your cancer was a later stage (III or IV) or if lymph nodes or blood vessels were affected, you are at a higher risk for metastasis or secondary tumors. Talk to your healthcare team to learn more about your risk.

Type of Chemotherapy

High doses of chemotherapy medicines have been associated with a small number of second cancers in some survivors. Types of chemotherapy that may make you more likely to have a second primary cancer include:

- Anthracyclines
- BCNU (bischloroethylnitrosourea)
- Chlorambucil
- Cyclophosphamide
- Epipodophyllotoxins
- Ifosfamide

- Mechlorethamine
- Nitrogen mustard
- Procarbazine

Type of Radiation

The risk of getting a second primary cancer from radiation depends on the amount of radiation given during treatment and the area being treated. The risk of a second primary cancer from radiation is low; however, radiation therapy is the main risk factor for second primary cancers for survivors of childhood cancer.

Surgery

When performing curative surgery for solid tumors, the surgeon tries to achieve clear margins. When a cancerous tumor is surgically removed, some of the healthy tissue surrounding the tumor is removed as well. After removal, this border of healthy tissue is examined for cancer cells. If no cancer cells are found in the healthy tissue, then you have “clear margins,” which means all of the cancer was most likely removed. However, if there are cancer cells, in the border of healthy tissue, then there are not clear margins, and there may have been some cancer cells left behind. If this is the case, you may have received chemotherapy or radiation after the surgery to try to kill the remaining cancer cells. If a clear margin was not achieved during surgery, the risk of recurrence or secondary tumors increases.

Bone Marrow Transplant

Some survivors have developed a second primary cancer after hematopoietic stem cell transplant (SCT). This could be related to the transplant or additional chemotherapy and radiation treatments and their effects on the immune system.

Family History

If cancer "runs in your family," you may have a higher chance of recurrence, secondary tumors, or a second primary diagnosis. It's important to know your family history. Make sure your healthcare team knows your full family history because it may affect your recommended screening schedule for both recurrence and second primary cancers. See the “Genetic Counseling for You and Your Family” section of the handbook to learn more about genetics and cancer.

Lifestyle

Smoking, excessive alcohol use, lack of exercise, poor diet, and sun exposure without proper sunscreen all increase your risk of recurrence and secondary cancers. Try to lead a healthy and active lifestyle by following the tips and suggestions throughout the handbook.

Age When Treated

Children, teens, and adults in their 20's have a higher risk of receiving a second primary cancer diagnosis following treatment with radiation or chemotherapy than older adults.

Younger survivors have more years ahead of them for a second primary cancer to develop, and some treatments increase the risk for second diagnosis.

As we age, the risk of cancer increases. This is true even for those who have never had cancer. A healthy lifestyle may help minimize this risk. This includes eating right and exercising, as well as cutting out unhealthy habits like smoking. Following your recommended screening schedule is also important. The earlier cancer is found, usually the more treatable it is.

Signs of Recurrence and Secondary Tumors

Below are the types of symptoms that may indicate a recurrence, metastasis, or second primary cancer. Remember, just because you experience one of these symptoms, it does not mean your cancer has returned or you've developed a new cancer. These symptoms could be caused by other issues as well. Alert your healthcare team to any changes in your health.

Symptoms include:

- Changes in bowel or bladder habits
- A sore that does not heal
- Unusual bleeding or discharge
- Thickening or lump in the breast or other parts of your body
- Indigestion or difficulty swallowing
- Noticeable change in a wart or mole
- Nagging cough or being hoarse
- Fatigue
- Bone pain
- Changes in vision
- Constant or severe headaches

Lower the Risk of Recurrence and Secondary Tumors

One of the most important things you can do to manage your risk is to follow-up with your healthcare team. Good medical care and screening can help detect second cancers early.

Another key factor in lowering your risk is to enjoy a healthy lifestyle. Eat right, exercise, and cut out unhealthy habits. If you feel something unusual or painful, note it and make sure you let your healthcare team know about any changes as soon as possible. Learn more about lowering your risk of recurrence and secondary tumors and how to lead a healthy lifestyle in the “Healthy Behaviors for Prevention and Recovery” section of the handbook.

No matter how long it has been since your last treatment, the fear of recurrence is likely to be a concern every now and then, especially at checkup time. Ask your doctor to help you understand your risk factors based on your cancer type, your treatment plan, and your general

medical history. For tips on managing the anxiety associated with recurrence, read the “Fear of Recurrence” section of the handbook.

Genetic Counseling for You and Your Family

What is genetic counseling?

Genetic counseling helps people determine their risk for hereditary cancers. Genetic counselors are medical specialists who help people identify their risk for the types of cancer that are passed from one generation to the next. They also help develop a personalized plan to manage risk.

What happens during genetic counseling?

First, you’ll provide your family medical history. Your genetic counselor will use that information to determine the likelihood of any hereditary forms of cancer in your family. Your counselor will discuss the following:

- Your need for genetic testing
- Any inheritance patterns in your family
- Your surveillance and risk-reduction options

Your genetic counselor will coordinate the testing if you choose to do it. After testing, your counselor will interpret the results to come up with the best plan to detect cancer and lower the risks of getting it. Your genetic counselor will also let you know if other members of your family should be tested.

What are the most common hereditary cancers?

Genetic testing for hereditary breast and ovarian cancer, such as the BRCA gene, and Lynch syndrome are the most common reasons for referrals to genetic counselors.

What are the BRCA mutations?

The BRCA1 and BRCA2 gene mutations make up the majority of hereditary breast and ovarian cancers.

Women who carry mutations in the BRCA genes have an increased risk of developing breast cancer and ovarian cancer. Men who carry mutations in the BRCA genes have a slightly increased risk for prostate cancer. Men who carry BRCA2 mutations have an increased risk for male breast cancer, pancreatic cancer, and perhaps melanoma.

What is Lynch syndrome?

Lynch syndrome is also known as hereditary non-polyposis colorectal cancer. Lynch syndrome can be due to mutations in one of five different genes. People with Lynch syndrome are at an increased risk for the following cancers:

- Colon
- Uterine
- Ovarian
- Urinary tract
- Gastrointestinal
- Brain
- Sebaceous adenomas or carcinomas

The risks for each of these cancers vary depending on which gene carries the mutation.

Should I do genetic testing?

If one or more of these apply to you, talk to your healthcare team about genetic testing.

- Multiple family members on the same side of the family with the same cancer or related cancers
- Cancer at an early age (under age 50)
- More than one diagnosis of cancer in the same family member
- Rare cancers
- A known family history of altered genes that increase cancer risk
- Triple negative breast cancer diagnosis before 60
- Jewish ancestry
- A personal or family history of breast, ovarian, or pancreatic cancer
- A pheochromocytoma or a paraganglioma tumor

Where can I find a genetic counselor?

You can find a genetic counselor using the National Society of Genetic Counselors website at www.nsgc.org. You can also ask your healthcare team or insurance company for a referral.

Will my insurance cover genetic testing?

Most insurance companies now cover genetic testing for people with a family history that suggests a hereditary cancer syndrome. Your genetic counselor can help you verify your coverage.

If you don't have insurance or genetic testing is not covered by your insurance, your genetic counselor can help you find local and national resources to help cover the cost of genetic testing.

Healthy Behaviors for Prevention and Recovery

As you probably already know, a healthy lifestyle helps to prevent cancer and other diseases. There are two types of prevention:

- Primary prevention helps prevent disease from occurring in the first place. Examples of primary prevention include immunizations, a healthy lifestyle, and avoiding carcinogens in daily life and in the workplace. Some examples of carcinogens are pollution, radon gas, infectious agents, and ultraviolet light.
- Secondary prevention helps halt or slow disease in its earliest stage. Examples of secondary prevention include screenings such as CT scans to check for lung tumors or mammograms to detect breast cancer. When diseases, like cancer, are caught early they are usually easier to treat.

Learn more about methods of primary and secondary prevention and the steps you can take to lead a healthy life in the following sections.

Survivorship Nutrition

Once cancer treatment is complete, it is time to restore and rejuvenate the body by feeding it with the best foods for optimal nutrition. Nutrition status, physical activity, and body weight all play a role in preventing cancer recurrence. Here are some guidelines to follow while adopting a new lifestyle now that cancer treatment is over.

Eat a wide variety of colors of fruits and vegetables every day.

- Fruits and vegetables contain phytochemicals that fight cancer. Each color contains a different phytochemical. A wide variety of colors introduces more types of these cancer fighting chemicals into the body.
- Choose organic varieties when available to limit exposure to chemicals and pesticides. Wash all fruits and vegetables very well.
- Frozen fruits and vegetables are a great alternative to fresh and are easy to have available when time for shopping is limited.

Choose complex carbohydrates for increased energy.

- Select complex carbohydrates like whole grains (oats, wheat, brown rice, whole grain pasta) and whole fruits and vegetables.
- Complex carbohydrates are digested slowly due to their high fiber content, providing sustained energy.
- Choose grain products that have whole wheat or a whole grain flour listed as one of the first 3 ingredients.
- Avoid highly processed and refined grains (white enriched flour, baked goods, snack foods, sweets).
- One serving of whole grain is one slice of bread, ½ cup of cooked rice or pasta, and ½ cup of whole grain cold cereals and oatmeal.

Choose lean protein most of the time.

- Choose lean proteins that include beans, eggs, white meat chicken and turkey, and fresh fish (not farm raised). When available, select organic and locally farmed. Other good sources of protein are nuts and tofu.
- Limit red meat to less than 18 ounces per week. Red meat includes beef, pork, and lamb. For reference, one ounce of meat contains 7 grams of protein. To make sure that you are getting enough protein, aim to eat a source of protein at every meal.

Incorporate good fats into meals and snacks.

- Eliminate fried foods and eat foods that are high in omega-3 fatty acids such as avocados, fish, and nuts.
- Avoid trans fats and avoid foods containing partially hydrogenated oils.

Limit sweets and simple sugars. Avoid artificial sweeteners.

- Choose fruit to satisfy cravings for sweets. Sweets provide our body with empty calories and no nutritional value.
- Stevia is a plant-based natural sweetener that is an acceptable alternative to sugar or artificial sweeteners like aspartame, sucralose, and saccharin.

Drink plenty of water.

- Staying hydrated is essential to rejuvenating the body. Too much caffeine may lead to dehydration.
- Green tea and white tea are also good beverage options for staying hydrated.
- Aim for 80 ounces of caffeine-free fluids per day. If you are not drinking any water, start slowly and gradually increase water intake.

Eat consistently throughout the day to avoid overeating.

- Five to six small meals per day eaten every 2-3 hours help to keep blood sugar levels more stable.
- Smaller, more frequent meals help with weight management by encouraging metabolic rate to increase and better absorption of nutrients.

Achieve and maintain a healthy body weight for your height.

- Consult with a registered dietitian to determine individual energy needs and a realistic goal weight.
- Measure portion sizes.
- Begin to track food intake in a journal.

Exercise

- If not currently exercising, gradually work toward 45-60 minutes 5-6 days a week. This can be split up into 10-minute increments or longer to make it more possible when time is a factor.
- Be realistic and start slowly. A regular exercise program may help to minimize stress and depression.
- Choose an enjoyable activity. Enlist a friend or relative as an accountability partner.

Nutrition Supplements

- Choose food as the primary source for vitamin and minerals. Ask a registered dietitian for guidance on vitamins, minerals, and other nutrition supplements.
- Do not rely on supplements for cancer prevention.

Drink alcohol in moderation, if at all.

- Alcohol is a contributing factor to many types of cancer.
- Alcohol provides the body with calories but no nutrients.

Food Safety

The immune system is weakened during all types of cancer treatment. Unfortunately, chemotherapy medications are not able to tell the difference between healthy cells and cancer cells. For this reason, perfectly healthy red and white blood cells are damaged or killed during treatment and shortly thereafter. The result is that the body is not as good at fighting illness and infection. A common term used to refer to a very low neutrophil (white blood cell) count is **neutropenia**. Paying special attention to food safety during or after cancer treatment to reduce the risk of exposure to food borne illness may also be referred to a **neutropenic diet**. The following are some simple tips to reduce exposure and avoid unnecessary infection and/or illness during the time the immune system is compromised.

Keep EVERYTHING Clean

- Wash hands often and thoroughly especially before and after handling any food. Be sure to wash hands with warm water and soap for at least 20 seconds. Pay special attention to finger nails and the backs of the hands.
- Keep raw and cooked foods separate. Do not reuse any utensils, cutting boards, plates, dishes, etc. once they have been touched by raw meat or eggs. Utensils, cutting boards, plates, dishes, etc. that have been used for preparing raw meats or eggs should be washed in hot, soapy water. It is best to keep separate cutting boards for meat and fruits/vegetables. Have an extra clean cutting board available for additional preparation as well.
- When shopping for and storing raw meats, keep them away from other foods and cover the packages with extra plastic wrap or use plastic bags. This will prevent any liquids

from leaking onto other foods or surfaces. Store meats and eggs toward the bottom of the refrigerator to prevent any dripping on other foods below.

Cook Food Thoroughly

- Avoid raw foods such as sushi, undercooked eggs (make sure eggs are at least “over easy” and not “sunny side up”), and other meats that have not been cooked to a proper internal temperature.
- Cook all eggs until both the white and the yolk are firm.
- Use a meat thermometer to make sure that all meats are cooked to the proper internal temperature prior to eating. Here is a chart for reference:

<i>Meat</i>	<i>Internal Minimum Temperature</i>
Ground Beef	165° F
Turkey	165° F
Chicken	165° F
Steak or other cuts of beef	160° F
Whole chicken, turkey, duck, or goose	180° F
Pork	170° F
Egg dishes	160° F
Casseroles	165° F
Reheated leftovers	165° F

Foods To Avoid

- Raw or undercooked meats
- Unpasteurized milk and juices
- Soft cheeses made with unpasteurized milk such as feta, blue cheese, Roquefort, Stilton, brie, or farmer’s cheese
- Processed meats such as luncheon meats as well as anything else from a deli counter
- Refrigerated meat spreads or paté
- Smoked fish or precooked shrimp or crab meat
- Sprouts such as bean sprouts, alfalfa sprouts, or broccoli sprouts
- Pre-cut fresh fruit and vegetables. Buy them whole, wash, and cut them yourself using proper sanitary techniques as outlined above.
- Unwashed fresh fruits and vegetables
- Unroasted or raw nuts and seeds
- Raw tofu or tempeh
- Food from salad bars or buffets

- “Fresh” salad dressings, salsas, sauces, etc. sold in the refrigerated section of the grocery store.
- Raw apple cider
- Raw honey
- Unrefrigerated cream-filled pastries

The guidelines above were created with those who have severely weakened immune systems in mind. Consult your physician or healthcare team for regular updates on your blood counts and the status of your immune system.

Smoking Cessation

Why is smoking bad?

Smoking increases your risk for heart disease, stroke, and emphysema. Smoking also increases your risk for a number of cancers, including:

- Lung
- Oral
- Nasal and Paranasal
- Throat
- Esophageal
- Bladder
- Kidney
- Pancreatic
- Ovarian
- Cervical
- Colorectal
- Stomach

If you already have a cancer diagnosis, smoking can increase your risk of recurrence. Smokeless tobacco also increases your cancer risk.

Why should I quit?

Quitting smoking has almost immediate benefits. Here are some of the benefits of quitting smoking:

Time Since Quitting	Benefit
20 minutes	Blood pressure and heart rate drop
12 hours	CO ₂ levels in blood stream return to normal*
3 months – 9 months	Circulation and lung function improve
1 year	Risk of heart disease cut in half
5 years	Risk of mouth, throat, esophageal, and

	bladder cancer cut in half
10 years	One-half as likely to die from lung cancer, and risk of laryngeal and pancreatic cancer decreases
15 years	Risk of heart disease is the same as a non-smoker's

Source: smokefree.gov

*If the CO₂ (carbon dioxide) levels in your bloodstream are high, your lungs have to work harder to return these levels to normal. When you exhale, CO₂ leaves your body.

How can I quit?

The first step is to talk to your healthcare team about the best quitting strategies for you.

With smoking, your body builds up a dependence on nicotine, a chemical found in tobacco. As you quit smoking, your body will go through withdrawals from nicotine. Some common symptoms and side effects of withdrawal include:

- Cravings
- Feelings of sadness
- Stress and anxiety
- Difficulty sleeping
- Restlessness
- Weight gain

Here are some tips to help you manage the side effects of withdrawal:

- With your doctor's permission, you may wish to use Nicotine Replacement Therapies (NRT).
 - NRTs give you a small, decreasing dose of nicotine without smoking to help you wean yourself off nicotine and minimize withdrawal symptoms.
 - NRTs come in many forms such as gum, lozenges, inhalers, and patches.
 - Some NRTs are available without a prescription, but always talk to your healthcare team first.
 - Other prescription medications are available to help you quit. Check with your doctor to see if these may be right for you.
- Tell your friends and family that you are trying to quit.
 - They can support you and hold you accountable.
 - Ask a friend or family member you trust to be your "sponsor." If you feel the urge to smoke, you can call them to talk until the craving passes.
 - If your friends or family members smoke, ask them not to smoke around you and not to offer you cigarettes. This will only make achieving your goal harder.

- Join a support group or online support group to connect with other people trying to quit.
- Change your routine.
 - For example, if you always have a cigarette with your coffee, find a new morning routine. Try watching the news with your coffee, or replace your cigarette with a healthy snack.
- Know your triggers and have a plan.
 - What triggers your cravings—stress, food, other people smoking?
 - Avoid triggers if at all possible.
 - If you encounter a trigger, have a plan to keep yourself from smoking such as chewing gum, counting to 10, or calling a friend.
- If you have a setback, don't be too hard on yourself. Get back on track as soon as possible. However, do not use a slip as an excuse to start smoking regularly again.
- Do not use other tobacco products or e-cigarettes as a replacement for smoking.
 - Other tobacco products can also increase your risk for cancer and diseases.
 - E-cigarettes have not been studied enough to know their safety. The chemicals inhaled with e-cigarette use may have their own risks.

Resources for Quitting

Smokefree.gov or call (800) QUIT-NOW to connect with your state's helpline.

Immunizations for Cancer Survivors

What are immunizations?

Immunizations help your body build a resistance to specific diseases. Most immunizations work by introducing a small, safe amount of the disease to your immune system. This way if you are ever exposed to the disease, your body's immune system already knows how to fight it. Most immunizations are vaccines given as a shot or series of shots.

Many people receive one-time immunizations when they are children for diseases such as chickenpox. Some immunizations, such as tetanus shots, need boosters to keep them effective. Other immunizations, such as flu vaccines, need to be received annually.

What are the risks of vaccines?

As with any treatment or medication, vaccines can cause side effects. Each vaccine carries risk for different side effects. Most side effects are minor such as pain where you receive the shot or mild fever. There are risks for serious side effects, but vaccines are carefully tested for safety. In most cases, the great benefits of vaccines outweigh the minor risks. To learn more, visit the Centers for Disease Control and Prevention (CDC) at www.cdc.gov. Talk to your healthcare team about the risks and benefits of vaccines to determine what is best for you.

I'm a cancer survivor; what immunizations do I need?

For cancer survivors, immunizations are especially important because cancer treatments weaken the body's immune system. Below is the immunization schedule recommended by the CDC for people with weakened immune systems, such as cancer survivors.

Vaccine	Schedule
Influenza (flu)	Annually
Tetanus, diphtheria, pertussis (Td/Tdap)	One Tdap vaccine with Td booster every 10 years.
Varicella (chickenpox)*	Should NOT get vaccine**
HPV vaccine (women and men)*	3 doses through age 26
Zoster (shingles)	Should NOT get vaccine**
Measles, mumps, rubella (MMR)*	Should NOT get vaccine**
Pneumococcal (PCV13)	1 dose
Pneumococcal (PPSV23)	1 or 2 doses
Meningococcal	1 or more doses
Hepatitis A*	2 doses
Hepatitis B*	3 doses

Source: Center for Disease Control

* These vaccines are only for adults who did not get them as children.

** If you received these vaccines before your cancer diagnosis, there is no harm done. In fact, it is good that you are protected from these diseases. If you have not received these vaccines, it is not safe to receive them with a weakened immune system.

If you are planning to travel outside of the United States, check the recommended vaccines for where you are going. You may need additional immunizations.

Always consult with your oncologist before receiving any vaccine.

What else do cancer survivors need to know about immunizations?

Influenza (Flu)

If you are a cancer survivor, the CDC recommends getting the annual flu vaccine. However, only get the flu shot; do NOT get the nasal spray version. The nasal spray version contains live viruses so it is not safe for people with a compromised immune system.

Caregivers or anyone living with a cancer survivor should also receive the flu vaccine to lower the risk of infection.

Pneumococcal

There are two pneumococcal vaccines: PCV13 and PPSV23. For cancer survivors, doses of each may be needed. Ask your healthcare team about the best pneumococcal schedule for you.

Meningococcal, Hepatitis A and B

These vaccines are recommended for adults with certain jobs, lifestyles, or other health factors that increase their risk of these diseases. Your healthcare team can tell you if you are at a higher risk.

Varicella, Zoster, and MMR

As shown in the chart above, people with a compromised immune system, such as cancer survivors currently or recently out of treatment, should NOT receive these vaccines.

Sunscreen

If you've had skin cancer, sunscreen is very important to prevent a recurrence. Even if you've never had skin cancer, you should still be wearing sunscreen every day. If you received radiation treatment as part of your cancer treatment, radiated skin is very sensitive to sun damage. Make sure to take special care of radiated skin if you are going to be in the sun. Certain medications may also increase your risk of sun damage.

How To Take Care of Your Skin

Choose a sunscreen with a sun protection factor (SPF) of at least 30 for UVA and UVB protection. Apply it liberally each time you use it. You need more sunscreen than you think to cover your skin properly. Use about a shot glass full or handful of sunscreen. Apply sunscreen even to the skin that's covered by clothing, and apply it every 30 minutes to an hour. Reapply after swimming or excessive sweating. Don't just use sunscreen on sunny days. Exposure to dangerous, cancer-causing ultraviolet (UV) rays can occur even when skies are cloudy. Along with protecting your skin from recurring or secondary cancer, using sunscreen also helps prevent brown spots and discoloration, as well as slows down the development of premature wrinkles.

To be on the safe side, make these additional safety habits part of your daily health care routine to protect your skin:

- Avoid tanning and never use UV tanning beds.
- Avoid smoking.
- Wear a long-sleeved shirt, brimmed hat, and UV-blocking sunglasses outside.
- Avoid the sun between 10:00 a.m. and 2:00 p.m.
- Seek the shade, especially between the hours listed above.
- Examine your skin head-to-toe every month to check for any new or changing moles.
- Alert your healthcare team to any changes in your skin.

Emotional Health

After cancer treatment, caring for your emotional health is just as important as caring for your physical health. A cancer diagnosis can make you feel anxious and depressed. These feelings can last long after you've completed your treatment plan. Remember, feeling sad or anxious is

normal and understandable after an event like cancer. Don't be too hard on yourself, and take time to emotionally heal. Share your worries with your close family and friends.

In the following section, "Emotional Support Programs" learn about your different options for emotional support including support groups, peer counseling, and individual counseling. In the next section, learn more about managing "Fear of Recurrence," a common source of anxiety among cancer survivors.

If you are struggling with your emotional health, talk to your healthcare team. If your emotional health is preventing you from accomplishing your daily activities, let your healthcare team know. If you are having trouble enjoying things you once loved or your feelings of anxiety and sadness are persistent, meaning they do not come and go, you may need medical intervention. You may benefit from speaking to a professional.

Signs and symptoms of emotional issues that need professional medical help:

Depression	Anxiety	Post-Traumatic Stress Disorder (PTSD)
Losing interest in usual activities and pastimes	Feeling tense or nervous	Having flashbacks
Feeling irritable	Having trouble relaxing	Startled by loud noises or sudden movements
Crying frequently	Feeling unusually tired	Trouble sleeping
Feeling hopeless	Muscle aches	Difficulty concentrating
Poor appetite	Feeling restless or jittery	Nightmares
Significant weight loss	Being scared or fearful	Anger or irritability
Sleeping poorly or sleeping too much	Sweaty or shaky hands	
Feeling unusually tired	Racing heart	
Feeling worthless or guilty	Stomachaches	
Thoughts of dying or suicide	Fainting or dizzy spells	
	Feeling like you are choking or smothering	

Emotional Support Programs

If you are feeling anxious and depressed, it may help to talk to someone. It can be especially helpful to connect with other patients and survivors. You are not alone in your fight. You may find it helpful and inspirational to hear others' stories. You may also be able to help someone else by sharing your story. Here is some information about available emotional support:

Support groups

- Connect you with a group of people in a similar situation.
- Support groups meet on a regular basis.
- Support groups meet online, over the phone, or face-to-face.
- Ask your healthcare team about local support groups.
- Licensed social workers or other medical professionals facilitate most support groups.
- Support groups can be for current cancer patients, survivors, or family members.
- Some groups are defined by diagnosis, age, or sex.
- A support group is meant to help you through your cancer journey. The first support group you go to may not be the right fit for you. If you do not enjoy the first group, try another.
- Where can you find support groups?
 - Your hospital or treatment center
 - Your local American Cancer Society chapter
 - Visit cancer.org or call (800) 227-2345.
 - Cancer Support Community
 - This includes The Wellness Community and Gilda's Club.
 - Visit cancersupportcommunity.org or call (888) 793-9355.
 - CancerCare
 - Visit cancercare.org or call (800) 813- HOPE (4673).
 - These support sites also have resources and one-on-one support for caregivers and family members in addition to survivors.

Connect with a Fellow Survivor

- One-on-one partnering programs will match you with a fellow cancer survivor. This person may have a similar diagnosis.
- These allow for a more personal connection.
- Most programs are for family members as well as patients.
- Usually these programs are run through phone or email.
- How can you connect with a fellow survivor?
 - Imerman Angels
 - Visit imermanangels.org or call (877) 274-5529.
 - Cancer Hope Network
 - Visit cancerhopenetwork.org or call (800) 552-4366.

Individual Counseling from a Medical Professional

- If you find it difficult to function in your daily life because of anxiety or depression, you may need individual counseling from a medical professional.
 - Ask your healthcare team for a recommendation.
 - Visit *CancerCare* for more information.

Fear of Recurrence

Many believe that once treatment ends, the cancer journey is over, but that's not the case. Many cancer survivors struggle with the fear of recurrence. What if my cancer comes back? What if my cancer spreads? For some, these fears can become overwhelming even years into remission. These fears are completely normal, but there are things you can do to try to manage them.

Take charge of what you can.

You may feel afraid because of the lack of control you have over the situation. To take back some control in your life, try making positive changes.

- Talk to a registered dietitian about developing a survivorship nutrition plan. Good nutrition can reduce your chance of recurrence and make you healthier all around.
- Start an exercise program. Exercising is not only good for your body; it is also good for your mind. Exercising releases endorphins, natural chemicals that make you feel happier. Many people also say exercising helps clear their minds and lower stress. Always talk to your doctor before starting any exercise program.
- Stay on top of your screenings and checkups. At the end of your treatment, work out a screening and checkup plan with your oncologist. What kind of scans or tests do you need? How often do you need them?

Take a deep breath.

If you feel yourself starting to get worked up, close your eyes, take a deep breath, and count to ten. This may seem like silly or old advice, but taking a second to gather your thoughts can make you feel a lot better.

Try meditation or visualization. Find a quiet, comfortable spot in your home. Take a few moments to yourself to breathe deeply and reflect on the positive things in your life. Think about some of your goals, even simple ones, and imagine yourself reaching them. In the rush of everyday activities, we sometimes forget to just breathe.

Find a hobby.

Hobbies can be a great source of entertainment and can also take your mind off of negative things. Try one of the hobbies listed below or make up one of your own. Find something that you enjoy and are passionate about.

- Knitting
- Cooking
- Painting
- Hiking
- Photography

- Writing
- Yoga

Volunteer.

Volunteering can be a worthwhile way to pass your free time and make a difference in your community. Is there a cause you are passionate about? To find a variety of volunteer opportunities in your neighborhood, visit VolunteerMatch.org or Volunteer.gov.

A quick word of caution: For some, volunteering for a cancer support organization may hit too close to home. Consider how it may affect you to be in this environment with constant reminders of your experience. You need to do what is best for you. If you are unsure how it may affect you, volunteer once before committing more time.

Talk about it.

You may find it helpful to talk to someone. It can be especially comforting to connect with other survivors. Hearing other survivors' stories can show you what you are feeling is normal, and you are not alone. You may also be able to help someone else by sharing your story. Here are some options for connecting with other survivors:

- Support Groups
 - Cancer Support Community hosts support groups around the country.
 - Visit cancersupportcommunity.org or call (888) 793-9355.
 - Ask your healthcare team about other groups in your area or at your hospital.
- One-on-One Partnering Organizations
 - These organizations connect you with a fellow survivor. Usually the connections happen via phone.
 - Imerman Angels
 - Visit imermanangels.org or call (877) 274-5529.
 - Cancer Hope Network
 - Visit cancerhopenetwork.org or call (800) 552-4366.
 - Cancer Connection
 - Visit thecancerconnection.org or call (512) 459-5883.
- Survivor Retreats
 - Epic Experience offers outdoor adventure retreats to adults with a past cancer diagnosis. Activities are based on the season.
 - Visit epicexperience.org or call (855) 650-9907.
 - First Descents hosts retreats for young adults (18-39) to learn to rock climb, kayak, or surf.
 - Visit firstdescents.org or call (303) 945-2490.

Educate yourself.

Knowledge is power. Talk to your oncologist about your fear of recurrence. Here are some questions to ask:

- What are my chances of recurrence?
- What can I do to lower my risk?
- What signs do I need to look for to know if my cancer has returned?

Armed with the answers to these questions you can better understand your situation and minimize fear of the unknown.

If you do face a recurrence, remember that every survivor's situation is different. With clinical trials and new medications, there may be many treatment options available. Not all recurrences are the same.

Know what triggers your emotions and avoid it.

Do movies or TV shows that address cancer upset you? Don't watch them. Does the sight of the sweatshirt you wore on treatment days bother you? Throw it out or donate to a clothing bank. Do you get especially anxious around scan days? Ask a friend to go to lunch with you.

If you can identify the objects or activities that trigger negative feelings, you can make a special effort to avoid them.

Don't dismiss your fear.

It is normal and understandable to fear recurrence. A cancer diagnosis is a scary thing. If you've already been through treatment, you know how difficult it can be. Don't be too hard on yourself. It is okay to be scared. It is okay to be upset. Admitting your feelings can be an important first step to managing your emotions.

Remember what works for other people may not work for you. Try a few different things. Once you find an activity that makes you feel at ease, be sure to include it in your schedule. Take time for yourself.

If your fear of recurrence becomes overwhelming or interferes with your day-to-day activity, talk to your doctor. You may need individual counseling from a medical professional. Your doctor can make a recommendation for you.

Side Effect Management

Learn how to manage the possible long-term side effects of cancer treatment.

Introduction to Treatment Toxicities

Many cancer treatments can cause toxic side effects. The side effects you experience depend on your treatment, cancer type, and overall health. While many side effects go away after treatment ends, some side effects are longterm or can show up in the months or years following cancer treatment. If you do experience side effects, there are ways to manage them. In the following sections, learn about the common side effects that can occur or linger after cancer treatment. Talk to your healthcare team about which side effects you may experience and plans for managing them. Always let your doctor know if you have any new or worsening problems.

Bowel and Bladder Control Problems

Bowel and bladder control problems may happen after treatment for bladder, prostate, colorectal, gynecological, or other cancers. You may have no control over your bladder or bowel or you may need to make extra, sudden trips to the bathroom. Another problem you may be facing is not being able to have a bowel movement or constipation. Here are some tips for dealing with bowel and bladder control problems:

- Talk to your healthcare team about any changes in your bowel or bladder control. There may be medications that can help.
- If you are having trouble with bladder control, try Kegel exercises.
 - These exercises help strengthen the muscles in the genital area by tightening and relaxing the muscles repeatedly.
 - You can also strengthen these muscles by stopping the flow of urine when you are in the bathroom.
- You may wish to wear pads or underwear liners to help with accidents.
- If you have no control over your bowel or bladder you may have a colostomy, an ileostomy, or a urostomy. If you are having trouble caring for your ostomy, talk to your healthcare team.
- For tips on dealing with constipation, see the “Gastrointestinal Issues” section of the handbook.

Cardiac Issues

Though rare, heart damage is a possible side effect of cancer treatment. Radiation, medications, and certain chemotherapy treatments have been found to increase the chances of cardiac issues and heart disease.

Some forms of cancer require radiation therapy. If your heart is in the area receiving radiation, you have an increased risk of developing a weakened heart muscle which impacts how the heart pumps (cardiomyopathy), scarred or blocked blood vessels (coronary artery disease), and heart attack. The protective covering of the heart may also become inflamed (pericarditis) or scarred (pericardial fibrosis). It's also important to note that combining radiation and chemotherapy can further increase the risk of heart damage.

Chemotherapy treatments may also increase the risk of heart disease, including the weakening of the heart muscle and irregular heartbeat. An irregular heartbeat may occur after you begin treatment, but your heartbeat will typically return to normal when treatment ends. Certain types of chemotherapy may also increase the risk of high blood pressure and even heart attack.

If you experience any of the following symptoms in the months following your chemotherapy, please tell your doctor or healthcare team.

- Chest pain
- Shortness of breath
- Light-headed or dizzy
- Feel abnormally tired
- Swollen feet or ankles
- Coughing or wheezing that doesn't stop
- Heart racing

Take heart! Though these risk factors are real, they are rare. Your doctor is aware of these risks and will take steps to reduce these risks as much as possible. Not all chemotherapy drugs carry the possible side effect of heart damage. Your doctor will monitor the amount of chemotherapy drugs you receive, and the potential impact on your heart. In recent years, radiation has become more targeted so less healthy tissue is damaged. Ask you healthcare team about your risk of heart damage.

Other Causes of Heart Damage

Chemotherapy and radiation therapy aren't the only factors that increase the risk of heart problems. Others include:

- Obesity
- High blood pressure
- High cholesterol or triglyceride levels in the blood
- Diabetes
- Family history of heart problems
- Smoking

- Being inactive or not exercising regularly

To lower your risk of heart damage, eat a well-balanced, healthy diet with a variety of fruits and vegetables, lean protein, and whole-grains. Try to lead an active lifestyle. Ask your healthcare team what kind of exercise program is best for you. If you smoke, quit as soon as possible. Talk to your healthcare team about ways to quit. See the “Smoking Cessation” of the Handbook.

“Chemo Brain” (Cognitive Issues)

Many cancer patients report issues during and after cancer treatment including:

- memory loss
- forgetfulness
- loss of concentration
- confusion

These side effects result from changes in the cognitive (thinking) processes of the brain. Even though these side effects are commonly referred to as “chemo brain,” factors other than chemotherapy can lead to cognitive side effects such as:

- brain cancer or brain metastasis
- brain surgery
- radiation to the brain
- medications
- fatigue
- anemia
- hypothyroidism
- stress and anxiety

Cognitive side effects can be short term or long term. This depends on the cause of the side effects, the age of the patient, and the overall health of the patient. If the cause is medication, once the medication is stopped, cognitive issues should improve. If surgery or radiation damages the brain or nervous system, the side effects may not improve over time. Delirium is a severe cognitive issue indicated by loss of awareness and memory, drastic changes in behavior and judgment, and lack of muscle control. Delirium can be dangerous if the person is left alone. Delirium is most likely to occur in advanced cancer patients or near end of life.

Cognitive issues present many challenges. Because the direct cause of cognitive issues can be unclear, they are difficult to treat. Healthcare professionals are still researching cognitive issues as they relate to cancer and cancer treatment. Changes in memory and brain function can be distressing, but many patients share the same experience. Below are some things you can do to help manage cognitive side effects.

- Plan ahead.
 - Write to-do lists.
 - Keep a detailed calendar of appointments and other important dates.
 - Leave notes around the house to remind you to do things.
 - Track your medications and use a weekly pill box organizer.
 - Lay out everything you need for the next day the night before.
 - Use your phone to set reminders.
- Get organized.
 - De-clutter your home and your workspace.
 - Make sure everything has a place.
 - Put keys in bowl by the door every day.
 - Leave your cell phone on your nightstand.
 - Use labels for storage areas and boxes.
- Minimize distractions.
 - Avoid multitasking; focus on one task at a time.
 - Put your phone and other unnecessary electronic devices away when working.
- Exercise your brain.
 - Do “brain exercises” by taking free online quizzes or playing along with game shows.
 - Try Sudoku or crossword puzzles.
 - Read.
 - Learn a new hobby such as painting or writing.
- Exercise your body.
 - Exercise is not only good for your body; it can make you feel better mentally, too. Exercising releases mood-boosting endorphins.
 - Exercise also combats fatigue, which can contribute to cognitive issues.
 - Try going for a daily walk or taking an exercise class.
 - Ask your healthcare team before beginning any exercise program.
- Eat well.
 - Choose foods that promote healthy brain functioning such as fish (omega-3 fatty acids), dark, leafy greens, fresh fruits and vegetables, and whole grains.
 - Avoid alcohol and other substances that alter cognition.
- Get plenty of rest.
 - Being tired can make you less focused.
 - Fatigue and insomnia are common side effects of cancer treatment.
- Check red blood cell counts.
 - Anemia is a condition that occurs when the body does not have an adequate amount of red blood cells.
 - Anemia can cause cognitive issues.
 - Ask your healthcare team to check your red blood cell counts if they are not doing so already.
- De-stress.
 - Anxiety and stress can cause or worsen cognitive issues.
 - Try to relax in a way that works for you. Consider trying:
 - Deep breathing

- Meditation
 - Taking a warm bath
 - Your doctor may be able to prescribe medication to help with anxiety and depression.
 - Try seeking emotional support from a support group or one-on-one partnering organizations.
- Ask for Help.
 - Be honest with your friends and family about your “chemo brain.”
 - If you explain what you are going through, they can be more understanding.
 - They can also help you manage your side effects by sending you friendly reminders or helping you organize your space.
 - As always, talk to your healthcare team about your side effects and ways to manage them.

Dry, Itchy Skin

When cancer treatments fight cancer cells, they can also affect healthy cells. This can result in certain side effects including skin changes. Side effects of the skin commonly occur with two cancer treatments: external beam radiation therapy and new targeted therapies.

External Beam Radiation Therapy

With external beam radiation therapy, high-energy radiation rays from outside the body are used to kill and shrink cancerous tumors. The radiation is targeted at a specific area of the body. This therapy usually consists of daily treatments over several weeks.

Skin side effects, such as the following, do not usually appear until about the third week of treatment and may continue after finishing treatment:

- The skin at the treatment area may become red, dry, and tender like a mild to moderate sunburn.
- The skin may also become very itchy, which is a condition called pruritus.
- In some cases, the skin may even darken, swell, blister, or peel away.
- If the skin becomes too moist or cracked, you are at risk for an infection.

If side effects become too severe, your radiation oncologist may stop or delay treatment to allow your skin to rest.

Targeted Therapies

Targeted therapies focus on or “target” a specific type of cell or molecule. Common types of targeted therapy drugs attack the epidermal growth factor receptor (EGFR) to stop cancer cells from continuing to grow. Because EGFRs are also important to normal skin cell growth, this may cause skin side effects.

The most common skin side effects with targeted therapies are rashes, dry and itchy skin, hair loss, redness, and inflammation around fingernails and toenails. These side effects most commonly appear after the second or third treatment.

The following are targeted therapies (drugs) that commonly cause skin changes:

Drug	Type of Cancer
Erlotinib, Gefitinib, Cetuximab, Panitumumab	Colorectal, Head and Neck, Lung, Pancreatic
Sorafenib, Sunitinib	Kidney, GIST, Liver
Ipilimumab	Melanoma
Vemurafenib	Melanoma
Everolimus and Temsirolimus	Kidney, Pancreatic

Source: American Society of Clinical Oncology

How can I manage my skin side effects?

First, always tell your healthcare team about any skin changes you notice. Some side effects can be easily managed with prescription creams or oral medications. Here are some tips to help take care of your skin.

- Avoid irritants.
 - Use unscented bath and household products including soap, shampoo, lotion, deodorant, detergent, and dryer sheets.
 - Do not use bath products containing alcohol. Alcohol dries the skin, making irritation worse.
 - If your facial skin is affected, avoid using makeup, or switch to a sensitive skin brand.
 - Always wear gloves when cleaning, and avoid skin contact with cleaning products.
 - Do not shower or bathe with extremely hot or extremely cold water.
 - Stay out of the sun, or wear protective clothing and sunscreen if you must be outside.
 - Do not use tanning beds.
 - Do not use chlorinated pools or hot tubs.
- Let your skin rest.
 - Do not scratch or pick at your skin.
 - Do not pop blisters.
 - Wash skin with care.
 - Use a mild, fragrance-free soap.
 - Do not scrub the skin.
 - Let warm (not hot) water gently run over the affected area.
 - Do not wear tight clothing over the affected areas.
 - Do not use adhesive bandages.
- Moisturize.
 - Keep skin well moisturized.
 - Use petroleum-based skin protectants or unscented lotions.
 - Look for moisturizers specifically for sensitive skin.
 - Ask your doctor which over-the-counter moisturizer is best for you.
 - Use a humidifier while you sleep, and keep the temperature cool.

- If you are having radiation treatment, do not apply moisturizers right before treatment. It's better for your skin to be clean and clear during actual treatments.
- Watch for signs of infection.
 - Signs of infection include:
 - swelling, redness, or warmth
 - cloudy drainage or pus instead of clear
 - fever
 - bad smells
- Tell your doctor immediately if you notice signs of infection because you may need an antibiotic. If left untreated, infections can become very serious and spread to other parts of the body.

Fatigue

Fatigue impacts quality of life and can make it hard to eat healthy meals. The body needs proper nutrition to function. Improper nutrition can make other side effects worse. These tips can help manage fatigue.

- Cancer-related fatigue primarily occurs because the body requires additional energy to heal.
 - Other side effects, medications, and stress can make fatigue worse.
- While rest is important, too much rest can make you feel more tired so stay as active as possible.
 - Try going for a daily walk.
 - Talk to your healthcare team before beginning any exercise program.
- Go no longer than 4-5 hours without eating throughout the day.
 - Try to eat a balanced breakfast every day.
 - Try to eat small meals and snacks rather than large meals.
- Eat foods that provide sustainable energy; avoid foods that do not.
 - Try to include a source of protein at every meal to sustain energy released from food.
 - Try to limit sweets and sugary foods.
 - Avoid alcohol, caffeine, and chocolate in the evening.
- Stay hydrated by drinking liquids throughout the day.
- Stock your kitchen with easy-to-prepare foods and meals.
 - Ask your family and friends to help you shop for food and prepare meals.
 - Prepare food when you feel your best, and save it for later.
 - Prepare large amounts of your favorite meals then freeze meal-sized portions for later.
- Try keeping a food and fatigue journal to find patterns that trigger fatigue.
- Discuss fatigue with your healthcare team.

- Ask your doctor to check for nutrient deficiencies, such as anemia, protein, iron, B vitamins, and vitamin D.
- Talk to your healthcare team about other side effects such as pain or vomiting.

Gastrointestinal Issues

Gastrointestinal issues such as nausea, diarrhea, and/or constipation are common after cancer treatment. Gastrointestinal issues can cause discomfort, dehydration, poor nutrition, and weight loss. The following are tips on dealing with the most common gastrointestinal issues.

Nausea

- Take anti-nausea medications as prescribed by your healthcare provider.
 - It is important to take anti-nausea medications as prescribed.
 - Do not wait until the onset of nausea to take medication.
 - It is best to attempt to keep nausea managed with medication to allow for consistent eating and optimal nutrition.
 - Call your healthcare provider if you are taking the medication as prescribed and it is not providing any relief. A different medication may be needed.
- Track nausea to determine causes and trends.
 - Some nausea may be directly related to chemotherapy.
 - It is beneficial to know how soon after chemotherapy the nausea begins; sometimes it is immediate and other times the onset is delayed.
 - Tracking may help to identify other triggers or causes of nausea.
- Keep food odors to a minimum.
 - Odors can lead to nausea so it is best to choose foods with little or no odor such as oatmeal, cereals, canned fruit, shakes, and smoothies.
 - When preparing food at home, opt for foods with short cooking times and minimal odor such as pancakes, scrambled eggs, reheated soup, or other prepared foods that just require reheating.
 - Cool and room temperature foods usually have fewer odors than hot food.
 - Avoid cooking foods that have long cooking times such as casseroles, meats, and slow cooked meals.
 - Ask friends or family members to cook these items in an alternative location like a neighbor's kitchen.
- Eat several small meals or snacks during the day.
 - Eating small meals or snacks 5-6 times per day instead of 2 or 3 larger meals may help with nausea management. This keeps the stomach from getting too empty and prevents excess stomach acid.
 - Chew all foods very well. The digestion process begins in the mouth.
 - Keep bland, odorless snacks on hand for easy meals and snacking. Some examples are crackers, cheese, canned fruit, yogurt, toast, rice, and pasta.

- Not all foods are appealing to everyone. The key is to find the foods that are tolerable and stock up on those.
- Create a relaxing environment for eating and snacking.
 - Lighting, temperature, and other external cues may make nausea worse.
 - Dim lighting and cooler temperatures tend to be better for nausea management.
 - The use of a fan or ceiling fan may also make a difference.
 - It is important to be removed from situations that contribute to anxiety when attempting to enjoy a meal or a snack. (i.e. loud voices, arguing, loud music, or non-relaxing television programs).
 - Soft, relaxing music, a relaxing television program or another activity that is relaxing in a cool, dim room may be the best environment for meals and snacks.
 - Rest after meals, but do not lie flat as this may trigger nausea.
- Experiment with different foods.
 - Everyone is an individual and not all foods work for everyone when nausea is an issue. Try to be patient and experiment with different foods.
 - Start with bland foods with minimal odor and introduce them one at a time.
- Avoid foods and behaviors that tend to trigger nausea.
 - Some foods are triggers for nausea for unexplained reasons. Some of these reasons may be psychological. It is best to avoid these foods for optimal nutrition. The time that it takes to recover from an episode is time that the body is missing out on good nutrition.
 - Foods that are harder to digest and stay in the stomach longer can be triggers for nausea. These foods are usually higher fat foods such as fried foods and foods prepared with a lot of butter or oil.
 - Spicy foods are usually not tolerated well.
 - Some behaviors such as eating in a restaurant may trigger nausea. If this is the case, order food to carry out and eat it in a more relaxing environment.
 - Caffeine and smoking contribute to nausea.
 - Limit or avoid smoking, and drink only decaffeinated beverages.
- Try foods and drinks containing ginger.
 - Ginger is a spice that has shown some promise for relief from nausea.
 - Ginger snaps, ginger ale, ginger gum, or ginger tea may be options that can help manage nausea.
 - Ginger is also common in some Asian recipes.
 - Ginger supplements are available; however, they have not been studied extensively to determine an effective dose.
- Avoid drinking while eating.
 - Sometimes excess liquid in the stomach contributes to nausea.
 - It is best to drink any beverages at times other than meal times.

- The best beverages to choose are water, 100% fruit juices without added sugar, and caffeine-free soda that no longer has carbonation.
- Ginger ale specifically may help with nausea.
- Wear loose-fitting, comfortable clothing.
 - Clothing that is tight especially around the midsection can trigger nausea.
 - Soft, comfortable fabrics tend to be more relaxing as well.
- Stay hydrated if vomiting occurs.
 - Continue to drink clear liquids including water and other electrolyte-containing beverages like sports drinks.
 - Attempt to eat bland foods such as crackers or toast.
 - If vomiting is continuous and cannot be controlled, contact your healthcare provider immediately.

Diarrhea

- Contact your healthcare team for advice managing diarrhea.
 - If you have sudden diarrhea, have diarrhea for more than 24 hours or are experiencing pain, cramping, or blood in your stools, call your healthcare provider immediately.
 - Take medications or supplements only if they are recommended by your healthcare team.
 - Always ask your healthcare team before taking anti-diarrhea medications.
 - Always talk to your healthcare team or a dietitian before taking any supplements.
- Stay hydrated to replace fluid losses.
 - Be sure to drink plenty of clear liquids (water, ginger ale, sports drinks, or electrolyte replacement drinks) for 12 to 24 hours after a sudden bout of diarrhea.
 - Make a homemade electrolyte replacement drink by mixing the following ingredients: ¼ teaspoons salt, 8 teaspoons sugar, 3 tablespoons orange juice concentrate, and 4 cups water.
 - Let carbonated drinks lose their fizz before you drink them.
 - Drinking clear liquids helps the bowel rest and replaces lost fluids.
 - Healthy people need a minimum of 8 cups of liquid per day. You may require more to replace fluids lost with diarrhea.
- Eat 5 or 6 small meals per day instead of 3 larger meals.
 - Eating smaller meals may put less stress on your bowels and will make it easier for your body to digest food.
- Choose foods and drinks carefully.
 - Very cold foods and very hot foods can make diarrhea worse.
 - If your diarrhea gets worse after eating a certain food, stop eating that food until you recover.
 - Avoid foods and drinks that can make your diarrhea worse. High fiber foods, raw fruits and vegetables, full-fat dairy products, foods and drinks that contain caffeine, and spicy or high-fat foods can make diarrhea worse.

- Choose foods that help manage diarrhea, like white rice, puffed rice cereal or other low-fiber grains, soft fruits like bananas and applesauce, cooked soft vegetables, and low-fat meats and dairy products.

Constipation

- Drink plenty of liquids.
 - Fluid helps your body process fiber without discomfort. A good starting goal is eight 8-ounce glasses of fluid per day.
- Gradually increase your fiber intake.
 - Your daily goal should be between 25-35 grams daily.
 - Fiber is mostly found in plant foods, such as fruits and vegetables, beans, legumes, whole grain cereals, breads, and oatmeal.
- Eat 3-5 servings of fruits and vegetables daily.
 - Choose whole fruit instead of juice.
 - Eat the skins and seeds for extra fiber.
 - Try to have a fruit or vegetable with each meal or snack.
- Choose foods that promote regularity.
 - Eat cereals, breads, and pastas that are made with 100% whole grain.
 - Have brown or wild rice in place of white rice or potatoes.
 - Choose hot cereals like oatmeal or cold cereals with at least 5 grams of fiber.
 - Choose whole wheat breads, whole corn or wheat tortillas, and whole grain crackers instead of refined products.
 - Eat more beans, lentils, and peas. Add them to soups and casseroles, or have as a main entrée.
 - Beans are also a great source of protein, so you can use them as a substitute for meat at mealtimes.
 - Beans can be gas forming, so add them gradually. If you experience bloating or discomfort, you may want to limit them in your diet.
- Try plum or prune juice.
 - Start with a small amount, such as a ½ cup.
 - Eating dried prunes may also help relieve constipation.
- Try to include exercise or physical activity in your daily routine.
 - Physical activity is a natural way to help constipation.
 - Always discuss any exercise or physical activity with your healthcare team before making changes.
- Talk to your healthcare team about medication or supplements to help with constipation.
 - There are over-the-counter medications that may help with constipation but you should always check with your doctor before taking anything.

Insomnia and Difficulty Sleeping

Many cancer patients report that they occasionally have trouble sleeping or that they can't sleep at all (insomnia). Lack of sleep can lead to other issues such as fatigue, loss of concentration, headaches, and irritability.

To minimize the impact of insomnia, focus on these three possible solutions: managing other side effects of cancer or treatment, creating a good sleep routine, and talking to your healthcare team.

Manage other side effects.

Some side effects of cancer treatment can lead to difficulty sleeping. If you can minimize those side effects, then your sleep may improve.

Nausea

Nausea may make it difficult for you to go to sleep, and vomiting may wake you up at night.

- Sleeping with your head slightly elevated may help you get more comfortable.
- If your doctor has prescribed medication for nausea, make sure you take it as recommended, especially before bedtime.

Pain

Any type of pain can keep you up at night and make it difficult to be comfortable.

- Make sure you take pain medication as recommended, especially before bedtime.
- For more information on managing pain, read the "Pain Management" section of this handbook.

Weight Gain

If you gained weight as a result of cancer treatment, you may have trouble falling asleep and staying asleep. The extra weight can make it difficult to get comfortable. It can also make sleeping more difficult because your body has to work a little harder to function normally, such as regulating breathing.

- Try using a body pillow to give you more sleeping positions.
- Read the weight gain section of this handbook for more information on how to maintain a healthy weight.

Hormonal Changes

Hormonal changes, such as menopause for women, can disrupt sleep, especially with side effects such as hot flashes and night sweats. Talk to your healthcare team about the best ways to manage hormonal changes. Your doctor may be able to prescribe medications to help manage hormonal changes.

- Cool temperatures can help promote sleep. Make sure your bedroom thermostat is set low and that your pillowcase feels cool to your skin.
- If night sweats are a problem, buy wicking sleepwear to keep you dry at night.

Stress and Anxiety

Stress and anxiety can keep you up at night. It may feel difficult to “turn off your brain.” Finding ways to cope with your stress and anxiety is very important.

- Enjoy a relaxing activity every night before bed to take your mind off cancer. Try working on a crossword puzzle, reading a book, or listening to music.
- Try simple stretches, yoga, or meditation to clear your mind.

At any point in your cancer journey, you may wish to seek emotional support. Support groups, peer matching programs, or individual counseling may help relieve stress and anxiety.

Create a good sleep routine.

Try to create a comfortable and relaxing sleep routine. For example, every night before bed take a hot bath or read a few chapters of a good book. If you do this every night, it will signal to your body that it is time for sleep. The most important thing is that this routine works for you. Here are some tips to get you started:

Tips for creating relaxing sleep environment:

- Make sure your mattress, bedding, and pillows are comfortable for you.
- Pleasant smells, like lavender, may help you sleep. Try an aromatherapy mist on your pillow. Use caution if you have been nauseated because this may trigger your nausea.
- Buy a fan or white noise machine to drown out other distracting noises.
- Turn out all the lights, and use blinds or curtains to cover the windows.
- Do not leave the TV or computer on while you are trying to fall asleep. In fact, it is recommended that you not watch TV or use the computer while in bed.
- Silence all call, email, and text alerts on your phone.

Tips for sleeping through the night:

- Try to go to bed and wake up at the same time each day.
- Choose a small snack, not a large meal, before bed.
 - Digestion may wake you up, but a small snack will keep you from getting hungry during the night.
- Use the restroom right before going to bed.
- Exercise during the day, but do not exercise right before bed.
 - The buildup of adrenaline and endorphins from exercise makes it difficult to wind down.
- Limit daytime naps to no more than 30 minutes.
- Avoid caffeine, alcohol, and tobacco products.

Talk to your healthcare team.

Always talk to your healthcare team if you are having insomnia or difficulty sleeping. Your doctor may recommend prescription medications or over-the-counter sleep aids to help you fall asleep and stay asleep. Do not take any medications without consulting your healthcare team

first. Some sleep aids can be habit-forming so only take these medications as directed by your doctor.

Lymphedema

Lymph nodes are part of your body's immune system. The immune system helps your body fight infection and disease by circulating lymph fluid throughout the body. Lymph nodes carry lymph fluid from node to node through this web-like system.

Cancer may affect the lymph nodes, making it necessary to remove those nodes. When lymph nodes are removed, it changes the flow of the lymph fluid.

Lymph fluid may build up in parts of the body where lymph nodes have been removed or damaged. This causes lymphedema, a swelling that can be very painful. It is important to learn if you are likely to suffer from lymphedema, as you can take steps to avoid or lessen its impact. Patients can experience lymphedema years after treatment.

Who is at risk for lymphedema?

- Breast cancer patients whose surgery required removal of lymph nodes under the arm
- Other cancer patients whose treatment also required the removal of lymph nodes under the arm
- Cancer patients whose surgery required removal of lymph nodes in the neck (head and neck cancers, thyroid cancer)
- Cancer patients who have had lymph nodes removed from the groin area (testicular cancer)
- Cancer patients who had radiation treatment that damaged lymph nodes

What are the symptoms of lymphedema?

- Swelling (pressing the skin with your finger may leave a dent or impression)
- Pain
- Numbness
- Loss of ability to move the affected area
- Hardened skin
- Ulcerations/tears in swollen skin

How can I avoid lymphedema or avoid making my lymphedema worse?

- If you had lymph nodes removed from under your arm, do not have your blood pressure taken from that arm, especially if you have had the symptoms of lymphedema.
- Similarly, do not have blood drawn or receive shots or IVs in an area where lymph nodes have been removed.
- Avoid sunburns by staying out of the sun and always wearing at least SPF 30 sunscreen.
- Use insect repellent when outside to help avoid bites that could lead to infection.
- Avoid trauma or injury to the area where lymph nodes have been removed.
- Avoid heavy lifting with the affected arm.
- Do not get tattoos on the affected arm.
- Do not wear tight clothing, bands, shoes, or jewelry on the affected area.
- Wear a compression sleeve or stocking, if ordered by your doctor.
 - The snug way a compression sleeve or stocking fits on your arm or leg helps lymph fluid move through the system instead of getting blocked.
 - Compression sleeves for lymphedema need to fit correctly. An ill-fitting compression sleeve may make lymphedema worse.
 - Your healthcare team can help you find the correct compression sleeve for you.
 - Compression sleeves and stockings are often not covered by health insurance, including Medicare and Medicaid plans.
 - Ask your case manager or representative if lymphedema sleeves and treatments are covered by your plan.
 - Ask your healthcare team about free or reduced-cost resources in your area or at your treatment center.
 - Seek financial assistance.
 - CancerCare: (800) 813-HOPE (4673)
 - Patient Advocate Foundation: (800) 532-5274
- Keep your skin moisturized and healthy to avoid cracks that may lead to infection.
- Maintain a healthy body weight.
 - Eat a variety of fruits and vegetables.
 - Choose whole grains.
 - Choose lean proteins.
 - Limit sugar and sweets.
 - Drink eight glasses of water a day.
- Exercise.
 - Ask your healthcare team which exercises are right for you. Some exercises may make lymphedema worse.
 - Talk to your healthcare team before beginning any new exercise program.

How can I manage lymphedema?

- Tell your healthcare team as soon as you notice the symptoms of lymphedema.
- If your lymphedema is moderate to severe, your doctor may refer you to a lymphedema therapist or a physical therapist for complex decongestive therapy (CDT).
 - Complex decongestive therapy involves a few different strategies, as follows:
 - Massage
 - The massage is called manual lymphatic drainage (MLD). This massage style helps move lymph fluid through the system to decrease pain and swelling.
 - Skin care
 - Special exercises
 - Compression bandages
 - Your lymphedema therapist may also recommend a pneumatic compression sleeve.
 - These sleeves have an attached pump that inflates and deflates the sleeve around the affected arm or leg.
 - The pump helps move lymph fluid through the system.
- Follow the same guidelines for avoiding lymphedema listed above.
- A risk of lymphedema is that you are open to have infections in the affected area.
 - Tell your healthcare team immediately if you notice any of the signs of infection:
 - Fever
 - Redness or red streaks
 - Warmth or heat at the swelling area
 - Cloudy pus or drainage

Menopause Symptoms

After chemotherapy or gynecological surgery, some women stop having periods or their periods become irregular. For some women, after treatment, their periods will return to normal, but for other women, their periods will not return. These hormonal changes can cause the symptoms of menopause such as hot flashes, vaginal or bladder issues, fatigue, memory loss, mood swings, and weight gain.

Hot flashes: Hot flashes are a sudden feeling of warmth and sweating. They may be worse at night. Turn your thermostat down at night or sleep with a fan on. Wearing loose, cotton clothing may also keep you cooler.

Vaginal or bladder issues: You may experience vaginal dryness and a lack of interest in having sex. See the “Sexual Side Effects and Functioning” section of the handbook for tips on managing these issues. You may also have trouble controlling your bladder. Try Kegel exercises to strengthen genital muscles. Wearing a pad or underwear liner can also be helpful.

Fatigue: Fatigue and difficulty sleeping are common during menopause. See the “Fatigue” and “Insomnia and Difficulty Sleeping” sections of the handbook for tips on managing these side effects.

Memory loss: Changes in mood and memory are often side effects of menopause. To manage changes in memory, try to plan ahead and write to-do lists and notes for yourself. You can even set reminders on your phone. Exercise your brain by doing puzzles, crosswords or Sudoku. Eat well, exercise, and get plenty of rest.

Mood swings: For mood swings, take a deep breath and try to relax. Find an activity that calms you such as yoga, meditation, or walking in the park. Try exercising. Exercise is not only good for your body; it can elevate your mood as well by releasing endorphins. If your mood swings or depression is interfering with your daily activities, speak with your healthcare team. You may need assistance from a healthcare professional.

Weight gain: After menopause, women tend to hold more fat around their waists. To help with extra weight gain, eat a healthy, balanced diet and exercise daily. To learn more about managing weight gain, see the “Weigh Gain” section of the handbook.

Neuropathy

Some chemotherapy drugs or radiation treatments can damage the nerves far away from the brain and spinal cord. This is called *chemotherapy-induced peripheral neuropathy* (CIPN). These nerves carry the sensation of feeling to the brain, and control the movement of your arms and legs. They also control the bladder and bowel. Neuropathy can develop at any stage of your cancer journey, including after your treatments have ended.

Who is more likely to develop neuropathy?

Cancer treatments can cause neuropathy. The cancer types with a higher risk of neuropathy include: lung, breast, ovarian, myeloma, lymphoma and Hodgkin's lymphoma, and testicular. Here are a few more factors that can increase the chances of developing neuropathy:

- Being an older patient
- A family history of neuropathy
- Lack of nourishment
- Excessive use of alcohol
- Having a preexisting medical condition like diabetes or thyroid problems

Neuropathy most often affects both sides of the body in the same way. It can begin any time after treatment starts, and it often gets worse as treatments go on. Symptoms tend to start far away from the head but move closer over time. In most cases, people will first notice symptoms in the tips of the finger or toes and can progress over time.

Neuropathy can affect your ability to do everyday things like walk, write, button your shirt, or pick up coins. It can also cause more serious problems like changes in your heart rate and blood pressure, trouble breathing, or even organ failure. The most common symptoms are:

- Stabbing pain or burning
- Tingling or numbness
- Trouble picking up things or holding things
- Muscle weakness or loss of balance

More severe forms of neuropathy can cause:

- Trouble swallowing
- Constipation or trouble urinating
- Blood pressure changes

Sometimes the symptoms of neuropathy may go away soon after treatment is done. In other cases, they can take years to resolve. In the worst cases, neuropathy symptoms may never go away.

Talk to your doctor or nurse right away about any signs of neuropathy that you may have. They'll watch you closely to see if the problems get worse, and may need to change your follow-up care plan. There are a number of treatment options and ways your doctor can lower the risk of neuropathy.

Pain

Cancer and Pain

Pain related to cancer comes in many different forms. Pain can be caused by the cancer itself, or it can be a side effect of treatment.

For the best pain management, you and your healthcare team will first need to find out the cause of your pain. Be prepared to answer these questions:

- How severe is your pain?
- Is there anything that makes it better?
- Is there anything that makes it worse?
- What does it feel like—an ache or a sharp pain, dull, throbbing, or tingling?
- Is the pain in only one part of your body?
- How does the pain interfere with your daily life?

Keeping a pain journal can be helpful. Use the Treatment and Side Effects Log included in this handbook.

Is the pain a side effect of treatment?

Chemotherapy, radiation, and surgery are the three most common cancer treatments, and pain is a potential side effect for all three. However, the type of pain caused by each is different.

Chemotherapy can cause the following types of pain: muscle and joint aches, mouth sores, headaches, and neuropathy. Neuropathy is an unpleasant tingling or numbness, usually in the hands or feet. Damage to nerve endings causes this feeling.

Radiation causes the skin at the treatment site to become dry, red, and painful like a mild to moderate sunburn. Sometimes these burns may cause blisters. Depending on the location of radiation, there may be other side effects. For example, radiation to the brain may cause headaches.

Surgery causes pain at the incision site. Depending on the extent and location of the surgery, this pain could be mild to severe. Surgery can damage muscles and tissues leading to range of motion problems. Surgery can also damage nerves and cause neuropathy.

Is the pain a side effect of the cancer itself?

Depending on size and location of the tumor, pain could be from the cancer itself. If the tumor is pressing on nerves, joints, or bones, it can cause pain. This type of pain is more common with advanced or metastatic cancer, especially when the cancer spreads to the bones. Tumors in the bones can cause fractures as the tumors continue to grow.

Osteoporosis and Joint Pain

Chemotherapy, steroids, and hormonal therapy can cause your bones to weaken and your joints to feel stiff and painful. This weakening or thinning of the bones is called osteoporosis. You can lower your risk of osteoporosis by doing the following:

- Eating foods with calcium and vitamin D such as dairy products
- Staying active and exercising regularly
- Avoiding tobacco products (See the “Smoking Cessation” section of the handbook.)
- Taking medications as prescribed by your doctor to prevent osteoporosis.

Pain Management Plans

Your healthcare team can help create the best pain management plan for you. If the first plan you try does not work, tell your healthcare team. You may need to try a different plan. Open and honest communication with your healthcare team is very important. Pain is a difficult side effect to treat. It may take a few tries to find the best plan for you. Do not be afraid to seek a second opinion if needed.

Your pain management plan may include:

Pain Medications

Your doctor may prescribe pain medications or suggest over-the-counter pain medications. Ask your doctor before taking any over-the-counter medications. Some pain medications can cause nausea or constipation. Your doctor may be able to suggest additional medications to help with these side effects. You may have to try a few different types of medications or dosages to find what works for you.

Physical Therapy

Physical therapy uses exercises to help improve strength and motion. If your pain is related to loss of range of motion or difficulty doing physical activities such as walking, physical therapy may help ease pain.

Exercise

Regular exercise, even something as simple as a daily walk, may also help with pain. Exercising is good for the body. It can also make you feel better mentally too. Exercising releases endorphins, natural chemicals that make you feel happier. Exercising also combats fatigue which is a common side effect along with pain. Always ask your doctor before beginning an exercise plan.

Complementary and Alternative Medicine

Some cancer patients find success at relieving pain with complementary and alternative medicine (CAM) such as acupuncture, guided imagery, massage, supplements and vitamins, or yoga. The phrase “complementary and alternative medicine” means treatments outside the standard scope of what you would find at a hospital or treatment center. Complementary medicine is used along with standard treatment. Alternative medicine is used instead of standard treatment.

Always discuss the pros and cons of each treatment you consider with your healthcare team. If you are considering a complementary treatment, inform your medical team BEFORE you are treated to make sure it will not negatively interact with your standard treatment. If you are considering quitting standard treatment for an alternative treatment, remember: standard treatments go through a long and careful research process to ensure that they are safe and effective, but less is known about most types of CAM.

For more information on CAM, visit the National Center for Complementary and Alternative Medicine website at nccih.nih.gov.

Palliative Care

Palliative care provides relief from pain and other symptoms, but it does not provide a cure. For cancer patients, common palliative therapies include surgery, radiation, or chemotherapy as a method of shrinking tumors that are causing pain. Palliative care is most commonly used for advanced or metastatic cancers.

Emotional Support

Taking care of your emotional well-being can also help manage pain. There are a number of ways to find emotional support—peer partnering programs, support groups, and one-on-one counseling.

Your doctor may even prescribe antidepressants, which have been shown to help with nerve pain as well as emotional well-being.

Managing Other Side Effects

Other side effects of treatment, such as fatigue, nausea, or loss of appetite, may be making your pain worse. You may be able to manage many of these side effects with simple nutrition and habit changes.

Sexual Side Effects and Functioning

Female Sexual Side Effects

Many female cancer patients experience sexual dysfunction or changes in their sex lives after a cancer diagnosis. These changes can be physical or mental. Many women are not comfortable discussing these issues with their healthcare team or with their partners, but being able to speak openly is important.

Each type of cancer treatment—chemotherapy, radiation, surgery, and hormonal therapy—can cause possible sexual side effects. Side effects may vary depending on the type of cancer, the specific mode of treatment, and the individual's response to treatment. Talk to your healthcare team about what you should expect from treatment.

Managing Side Effects

Below are some of the most common sexual side effects and tips for managing each.

Lack of Desire

During and after cancer treatment, many women report a lack of sexual desire. Lack of desire may come from hormonal changes such as early menopause or other side effects, making sex unenjoyable.

- Rethink what sex and intimacy mean.
 - Do not expect sex after cancer to be exactly the same as sex before cancer. Your body has been through a lot of changes.
 - Be patient. It may take some time to discover what is comfortable and pleasurable for you.
- Ask your doctor about estrogen therapies to increase estrogen and if they are safe for you to use.
 - Low levels of estrogen can cause female sexual dysfunction.
 - Estrogen therapies can help with lack of desire and dryness.
 - Estrogen therapies come in pills, creams, patches, and vaginal rings.
 - If your cancer is hormone driven, estrogen therapy may not be safe for you.
- If you are taking anti-depressants or pain medication, talk to your doctor about adjusting your dosage.
 - Both these medications can cause lack of desire.
- Manage other side effects such as dryness, pain, nausea, or fatigue that may be causing your lack of desire.

Dryness

Early menopause, triggered by chemotherapy, adjuvant therapies, or surgery, can cause vaginal dryness. Radiation to the pelvic region can also cause dryness.

- Use a water-based lubricant during sex.
 - Stay away from scented and warming lubricants. These can irritate the vagina, actually making dryness worse.
 - Do not use petroleum jelly based lubricants.
- Try vaginal moisturizers to improve overall dryness.
 - Vaginal moisturizers are different from lubricants. You do not use them only during sex. If used regularly, they improve overall dryness and vaginal health.
- As mentioned above, ask your doctor about estrogen therapies and if they are safe for you to use.

Pain

Pain during intercourse may occur for a few reasons such as dryness or scar tissue. Radiation to the pelvic region may cause minor burns as well as scarring that causes the vaginal canal to shrink. Gynecological surgery can damage or result in the removal of sex organs.

- After surgery, ask your doctor if and when it is safe to have sex.
- If the shape of the vagina has changed from treatment, you may need to adjust the way you have sex by trying new positions or new activities.
- After gynecological surgeries that affect the vagina, reconstructive surgery may be an option.
- A vaginal dilator can be used to stretch the vaginal canal. Vaginal dilators are smooth plastic cylinders of different widths. By beginning with the smaller ones and inserting them into the vaginal canal regularly, the vagina begins to stretch, making intercourse less painful. Vaginal dilators also make medical pelvic exams more comfortable.
- Pain may come from dryness. If you are also experiencing dryness, try the tips above.

General pain in other parts of the body can also make sex uncomfortable and decrease your desire to be intimate. To learn more about pain management unrelated to sex, read the “Pain” section of this handbook.

Difficulty Reaching Climax or Orgasm

Surgery and other treatments that directly affect the pelvic region can result in loss of sensation if nerves are damaged. This can make achieving an orgasm difficult for some women. Actions that worked before treatment may no longer feel the same. Other side effects mentioned in this handbook such as pain, lack of desire, and emotional issues can also make achieving orgasm difficult.

- Work on managing all side effects that may be affecting your sex life.

- For most women, vaginal penetration does not provide enough stimulation for orgasm. Extended clitoral stimulation may be needed.
- Use your mind. Make sure you are comfortable and in the right mindset for sexual activity. Try imaging sexual fantasies to get in the mood.
- Try using a vibrator to increase stimulation. Vibrators can be purchased at a drug store or discreetly online.

Managing Non-Sexual Side Effects

Other treatment side effects, such as nausea and fatigue, may interfere with your sex life. Manage these side effects by using the tips in this handbook.

Self-Esteem and Body Image

How you feel about yourself can affect your sex life. Cancer and cancer treatment can cause significant changes to your body. You may have hair loss, weight loss, weight gain, or scars. With these changes, you may not feel the same way about your body. This is all normal. Do not be critical of yourself. Your body battled cancer.

Below are tips for managing issues related to self-esteem and body image.

Hair Loss

- Hair usually grows back after treatment ends.
- In the meantime, try wigs, hats, and scarves.
- When your hair does begin to grow back, use a gentle shampoo such as baby shampoo.

Weight Changes

- Talk to your healthcare team about reaching and maintaining a healthy weight.
- Ask your healthcare team if it is safe for you to start an exercise program.
 - The endorphins released during exercise can also make you feel better emotionally.

Surgical Scars

- Most surgeries leave some scars. Try using over-the-counter lotions and gels to help minimize incision scars. Moisturizers made with cocoa butter also minimize scars.

Emotional Support

You have to care for your mental health as well as your physical health. If you are struggling with anxiety or sadness, you probably don't feel like having sex. Some options for emotional

support include: peer partnering programs, support groups, and one-on-one counseling. Read the “Emotional Support Programs” section of this handbook for more information.

Fertility

Cancer treatments can lead to infertility. Gynecological surgery can cause infertility. Chemotherapy and adjuvant therapies can trigger early menopause in women. Even though this process sometimes reverses in young women, it can still make conceiving difficult. Radiation to the pelvic area can damage reproductive organs.

Women do have options to preserve their fertility. However, it is important to talk to your healthcare team about fertility and your options *before* you begin treatment. Many fertility-preserving options must be done before the damage caused by treatment occurs.

Before beginning treatment, some women freeze and bank eggs and embryos. Fertility-preservation can be a long process so you will need to factor this into your timeframe for treatment.

Some steps can be taken to protect reproductive organs during treatment. For example, during radiation treatment, depending on the area receiving radiation, you may be able to use a shield.

If you continue to have sex during treatment, be sure to use proper protection. Pregnancy during chemotherapy or radiation is not safe for the mother or the child. Even if your periods stop during treatment, you may still be able to conceive so always use a form of birth control. Some cancers may affect your ability to use hormonal birth control methods, such as oral medication and devices such as IUDs and hormone rings. Make sure you ask your doctor before resuming any birth control you used before your diagnosis. Since cancer treatment can compromise your immune system, be sure to always use condoms to protect against sexually transmitted diseases (STDs).

Talk to your healthcare team as soon as possible about your fertility status and options.

Talking to Your Partner About Sexual Dysfunction

Being able to talk openly with your partner about sex is very important. What worked for you both before cancer may not work now. You may need to try different things to find what works for you both. If it has been a while since you’ve been intimate, start slowly with simple kissing and touching. Here are some basic guidelines for talking to your partner:

- Be honest.
- Always tell your partner if something hurts or is uncomfortable.
- If something feels good, let your partner know.
- Be patient with yourself and your partner.

- Set the scene by going on a romantic date or watching a movie together at home.

Talking to Your Healthcare Team About Sexual Dysfunction

Your healthcare team is made up of health professionals. You should feel comfortable telling them anything. There is nothing embarrassing about sexual dysfunction, as it can happen following cancer and its treatment. After fighting cancer, you deserve to have a healthy sex life.

You may wish to talk to healthcare professionals who specialize in areas related to sexual dysfunction including:

- Gynecologist
- Endocrinologist
- Sex therapist
- Psychologist or counselor

Talking about sexual dysfunction can be difficult. Here are some sample questions to begin your conversation with your doctor:

- How will treatment affect my sex life?
- What can I do to manage sexual side effects?
- I have pain and dryness during sex. What can I do to manage this?
- I no longer feel any desire to have sex. What can I do to feel like myself again?
- Could you recommend a specialist?
- Will treatment affect my fertility?

Male Sexual Side Effects

Many male cancer patients experience sexual dysfunction or changes in their sex lives after a cancer diagnosis. These changes can be physical or mental. Many men are not comfortable discussing these issues with their healthcare team or with their partners, but being able to speak openly is important.

Common Side Effects of Treatment

Each type of cancer treatment—chemotherapy, radiation, surgery, and hormonal therapy—can cause possible sexual side effects. Side effects may vary depending on the type of cancer, the specific mode of treatment, and the individual's response to treatment. Talk to your healthcare team about what you should expect from treatment.

Below are some of the most common side effects of each treatment type that causes sexual dysfunction.

Chemotherapy

Chemotherapy does not usually directly affect sexual function, but the side effects of chemotherapy, such as nausea and fatigue, may lead to loss of sexual desire. Chemotherapy can also cause infertility. Men who plan to try to father children should ask a doctor about fertility preservation before beginning treatment.

Radiation

Radiation to the pelvic region may cause the following side effects:

- Damage to blood vessels or nerve endings leading to erectile dysfunction
- Redness and pain at the treatment site
- Fatigue which may lead to loss of desire
- Infertility

Managing Side Effects

Below are tips for managing the most common side effects related to sexual dysfunction in men.

Erectile Dysfunction

Erectile dysfunction can be either mental or physical. Your doctor can do a test to determine the cause. If the cause is mental, see the suggestions below for managing emotional issues. If the cause is physical, you have several options.

- Prescription medications can treat erectile dysfunction by increasing blood flow to the penis. (If erectile dysfunction is caused by nerve damage, medications such as these will not help.) Common medications include:
 - Sildenafil (Viagra)
 - Tadalafil (Cialis)
 - Vardenafil (Levitra, Staxyn)
- Penile injections are shots delivered before sex into the penis to help cause and sustain an erection. Your doctor may wish to do a practice injection at a healthcare office to make sure they work for you.
- A vacuum constriction device (or pump) is a plastic tube placed over the penis. Air is then pumped out of the device, creating suction. This suction causes more blood to flow to the penis.
- Penile implants are prostheses (artificial devices) surgically placed inside the penis to help create an erection. There are three main types of penile implants:
 - A semirigid penile implant is a flexible rod placed inside the penis that can be bent up or down.
 - A two-piece penile implant is made up of an inflatable cylinder inside the penis and a pump inside the scrotum.
 - A three-piece penile implant is made up of an inflatable cylinder inside the penis, a pump inside the scrotum, and a fluid supply in the abdomen.
- Being overweight may also cause erectile dysfunction. If you have gained weight during treatment, read the “Nutrition Tips for Managing Weight Gain: section of this handbook.

Talk to your healthcare team about which of these options may be best.

Lack of Desire

During and after cancer treatment, many men report a lack of sexual desire. Lack of desire may come from hormonal changes or from other side effects that make sex unenjoyable.

- Rethink what sex and intimacy mean.
 - Do not expect sex after cancer to be exactly the same as sex before cancer. Your body has been through a lot of changes.
 - You most likely will still be able to reach orgasm. Depending on your treatment type, orgasms may no longer result in ejaculation, or you may have difficulty reaching orgasm.
 - Be patient. It may take some time to discover what is comfortable and pleasurable for you.
- If you are taking anti-depressants or pain medication, talk to your doctor about adjusting your dosage.
 - Both of these medications can cause lack of desire.
- If low testosterone is causing your lack of desire, you may be able to take testosterone supplements. Talk to your healthcare team about your options.
- Other treatment side effects such as nausea, fatigue, and pain may interfere with your sex life.
 - Use the other side effect management sections of this handbook to help manage other side effects.

Self-Esteem and Body Image

How you feel about yourself can affect your sex life. Cancer and cancer treatment can cause significant changes to your body. You may have hair loss, weight loss, weight gain, or scars. With these changes, you may not feel the same way about your body. This is all normal. Do not be critical of yourself. Your body battled cancer.

Below are tips for managing issues related to self-esteem and body image.

Hair Loss

- Hair usually grows back after treatment ends.
- In the meantime, try a hat, bandana, or cap.
- When your hair does begin to grow back, use a gentle or baby shampoo.

Weight Changes

- Talk to your healthcare team about reaching and maintaining a healthy weight.
- Ask your healthcare team if it is safe for you to start an exercise program.
 - The endorphins released during exercise can also make you feel better emotionally.

Surgical Scars

- Most surgeries leave some scars. Try using over-the-counter lotions and gels to help minimize incision scars. Moisturizers made with cocoa butter also minimize scars.

Emotional Support

You have to care for your mental health as well as your physical health. If you are struggling with anxiety or sadness, you probably don't feel like having sex. Some options for emotional support include: peer partnering programs, support groups, and one-on-one counseling. Other patients are often great resources for men experiencing sexual side effects of cancer. It can be difficult to talk about these issues, but having someone who has experienced the same journey can be beneficial.

Fertility

Cancer treatments can lead to infertility.

Men do have options to preserve their fertility. However, it is important to talk to your healthcare team about fertility and your options *before* you begin treatment. Many fertility-preserving options must be done before treatment begins. Before beginning treatment, some men can freeze and bank sperm. Talk to your healthcare team as soon as possible about all your options and your fertility status.

If you continue to have sex during treatment, be sure to use proper protection to protect against unplanned pregnancies and sexually transmitted diseases. Since cancer treatment can compromise your immune system, be sure to always use condoms to protect against STDs.

Talking to Your Partner About Sexual Dysfunction

Being able to talk openly with your partner about sex is very important. What worked for you both before cancer may not work now. You may need to start slowly and try different things to find what works for you both. If it has been a while since you've been intimate, start slowly with simple kissing and touching. Here are some basic guidelines for talking to your partner:

- Be honest.
- Always tell your partner if something hurts or is uncomfortable.
- If something feels good, let your partner know.
- Be patient with yourself and your partner.
- Set the scene by going on a romantic date or watching a movie together at home.

Talking to Your Healthcare Team About Sexual Dysfunction

Your healthcare team is made up of health professionals. You should feel comfortable telling them anything. There is nothing embarrassing about sexual dysfunction, as it can happen following cancer and its treatment. After fighting cancer, you deserve to have a healthy sex life.

You may wish to talk to healthcare professionals who specialize in areas related to sexual dysfunction including:

- Urologist
- Endocrinologist
- Sex therapist
- Psychologist or counselor

Talking about sexual dysfunction can be difficult. Here are some sample questions to begin your conversation with your doctor:

- How will treatment affect my sex life?
- What can I do to manage sexual side effects?
- Will I have difficulty having an erection? What can I do to manage this?
- I no longer feel any desire to have sex. What can I do to feel like myself again?
- Could you recommend a specialist?
- Will treatment affect my fertility?

Trouble Swallowing

Some cancer treatments can make swallowing difficult and painful. This may make it hard to eat well and maintain a healthy weight. Follow these tips to make swallowing easier.

- Chemotherapy or radiation to the head and neck can harm the cells that line the throat and cause discomfort.
 - Higher doses of radiation can cause more discomfort.
 - Chemotherapy and radiation treatment at the same time may make side effects worse.
 - Drinking alcohol or using tobacco can make side effects worse.
- Use mealtime tactics to make swallowing easier.
 - Eat 5 or 6 small meals each day instead of 3 large meals. It may be easier to eat a smaller amount of food at one time.
 - Cook foods until they are soft and tender.
 - Moisten and soften foods with gravy, sauces, broth, or yogurt.
 - Consume liquids with meals.
 - Sip drinks through a straw; this may make them easier to swallow.
- Avoid foods that are hard to swallow or irritating.
 - Avoid coarse foods that do not soften in the mouth.
 - Avoid sharp and crunchy foods like potato and tortilla chips.
 - Avoid spicy foods.
 - Avoid acidic foods like lemons, lime, oranges, and tomatoes.
 - Be careful eating hot foods to reduce the risk of burning your mouth. Cold foods may be soothing.
 - Avoid alcohol.
- Choose foods that are easy to swallow.
 - Try breakfast foods like instant oatmeal, grits, pancakes, waffles, and cold cereal that have been softened in milk.
 - For a main dish, try chicken, tuna or egg salad, soups and stews, soft cooked fish, tofu, and meatloaf.
 - Pick side dishes like cottage or ricotta cheese, macaroni and cheese, mashed white or sweet potatoes, and rice or risotto.

- Try desserts like custard, tapioca pudding, ice cream, milkshakes, and sherbet.
- Choose snacks like creamy nut butters, applesauce, gelatin, smoothies, and yogurt.

Weight Gain

Weight gain is common among cancer patients. This can be for a variety of reasons. The following tips help maintain a healthy weight after cancer treatment.

- Know the factors that can cause weight gain.
 - Medication, hormone therapy, or chemotherapy can lead to weight gain.
 - Fatigue and other side effects can cause decreased physical activity.
 - Stress, fear, or depression can lead to changes in eating habits.
 - Fluid retention causes swelling.
- Eat a variety of fruits, vegetables, whole grains, and beans.
 - All of these foods are high in fiber and low in calories.
 - Fiber helps you feel fuller longer.
- Choose whole grain foods.
 - Whole grains also contain fiber and are a lasting energy source.
 - Whole grain foods include whole grain breads, cereals, pasta, crackers, and brown rice.
- Choose lean proteins.
 - Protein foods also help you feel fuller longer.
 - Lean proteins include eggs, fish, skinless chicken, turkey, lean beef, lean pork, beans, and soy products.
- Choose low-fat or fat-free dairy products.
 - Low-fat and fat-free dairy products contain the same amount of protein as regular dairy products.
 - Low-fat and fat-free dairy products include 1% or skim milk, low-fat yogurt and reduced-fat cheese and cottage cheese.
- Limit foods high in fat and calories.
 - High-fat foods like butter, creamy dressing and sauces, sour cream, mayonnaise, fried foods, and dessert contain more calories and can contribute to weight gain.
 - Limit frequency and portions of high-fat foods and choose reduced-fat items when possible.
 - Avoid high-fat cooking methods, such as pan or deep frying. Broiling, steaming, grilling, and roasting are recommended.
- Avoid high-calorie beverages.
 - Avoid drinking large amounts of sugar-sweetened beverages such as sodas, sports drinks, sweetened teas, lemonade, and sweetened fruit juice.

- Choose low-calorie, low-sugar beverage options such as water and unsweetened tea.
- Limit or reduce alcohol consumption. If alcohol is consumed at all, it is best to limit to no more than one drink per day for women and two drinks for men.
- Avoid eating when you are not physically hungry.
 - Listen to your body. Don't confuse boredom or stress with hunger.
 - Try making a list of alternate activities you can do when you have the urge to eat when not hungry.
- Watch your portion sizes.
 - Try measuring out your portions so you know exactly how much you are eating.
 - Check the nutrition label to determine serving sizes.
 - Choose to eat all meals and snacks off of a plate rather than out of the package so you can keep track of how much you are eating.
- Limit eating out.
 - Restaurants often serve large portions of higher calorie and higher fat foods.
 - Limit eating out so you are not tempted with large portions of these foods as often.
- Write down your intake.
 - Studies show that those who record all of their food and drink intake eat fewer calories than those who do not.
 - Keeping a food journal could help keep you mindful about appropriate portion sizes and urges to eat when not hungry.
- Try exercise.
 - Aim for 30 minutes of exercise every day if able.
 - Always discuss any changes in exercise with your physician.
- Always discuss weight gain with your physician.
 - A physician can help determine the cause of weight gain and can give recommendations for how to appropriately manage weight gain.
 - Do not go on a diet to lose weight without discussing with your physician first.

Weight Loss

During cancer treatment, the body needs more calories and protein, especially when side effects can make it difficult to eat. Follow these tips to increase intake.

- Eat small, frequent meals (5-6 a day) instead of 3 large meals.
 - Eat every 2 to 3 hours even if you do not feel hungry.
 - Set a timer to remind you it is time to eat. Eat the most when you feel hungriest.
 - Eat protein foods like chicken, fish, meat, eggs, nuts, and beans first.
- Use smoothies and shakes to get in calories and protein.
 - Liquids can be easier to consume than solid foods.

- Smoothies or shakes can serve as a small meal replacement.
- Add ingredients such as whole milk, powdered milk, protein powder, peanut butter, ice cream, or yogurt to smoothies or shakes to add calories and protein.
- Premade liquid nutrition supplements are available at grocery and drug stores. Ask a registered dietitian which type is best for you.
- Ingredients such as whole milk, peanut butter, ice cream, yogurt, or fruit can be added to liquid nutrition supplements.
- Add more fats to foods to increase the calories.
 - Fat has more calories per gram than carbohydrates or protein.
 - Use butter, oils, mayonnaise, sour cream, and salad dressings liberally.
 - When cooking, use oil or butter instead of a nonstick spray.
 - Add mayonnaise to sandwiches and tuna or chicken salad.
 - Add peanut butter or cream cheese to toast or crackers.
- Drink most liquids between meals instead of with meals.
 - Liquids such as water, juice, or soda while you eat can make you feel full faster.
 - Drink only small amounts with meals.
 - Drink higher calorie liquids like juice and milk between meals.
- Snack regularly throughout the day.
 - Keep quick and easy snacks with you.
 - Try granola bars, trail mix, peanut butter crackers, nuts, and dried fruit.
 - Keep your favorite snacks around so you will eat more.
 - Eat a bedtime snack. It will not affect your appetite at your next meal.

Practical Concerns

When you are finished with cancer treatment, you may still have practical issues to manage such as paying medical bills, maintaining health insurance, applying for social security benefits, or returning to work. You may also need to work on your personal relationships with your family. Use the following sections to navigate the practical concerns of survivorship.

Financial Consequences of Cancer

Cancer care can present serious financial challenges for cancer patients. After treatment ends, some survivors are left with medical bills, debt; and as a result, may delay or forgo treatment or maintenance therapy to save money. Financial issues can even be a concern for patients with private health insurance. Many cancer patients are unable to work during treatment or are not able to work as much and therefore, see a drop in income.

There are five main gaps in the health care system that can leave cancer survivors and their families in a financial mess following their diagnosis:

- The various types of cost-sharing and limits on benefits found in some insurance plans may quickly lead to high out-of-pocket costs once cancer treatment begins.
- Those with employer-sponsored coverage may not be protected from high health care costs if they become too sick to work. Most people get their health coverage through their employers. The law currently states that if you lose your job because you're unable to work, you must decide within 60 days whether to temporarily keep your coverage through COBRA by paying the full premium costs.
- Some cancer patients and survivors have a hard time finding adequate and affordable coverage on their own. Those who have been in remission for years and have a good long-term prognosis may still have trouble finding coverage or pay higher premiums.
- High-risk insurance pools are designed to help cancer patients who are difficult to insure, but there are drawbacks. They aren't available to all cancer patients, premiums can be very expensive, and they aren't available in all states.
- Waiting periods, strict eligibility restrictions, or delayed application for public programs can leave people who are too ill to work without an affordable insurance option. Cancer patients too sick to work may qualify for Social Security Disability Insurance (SSDI) income, and after two years of receiving this income, may qualify for Medicare coverage. During the waiting period though, patients typically have reduced incomes and may not be able to afford private insurance coverage. To learn more, read the "Social Security Disability Benefits" section of the handbook.

Financial Tips for Cancer Survivors

Whatever your financial situation, a cancer diagnosis can throw off your budget. The following tips can help you better navigate your finances after cancer.

1. Understand your current and upcoming financial situation.

Start by working out a budget to help you understand your regular income and expenses. This will help make sure you aren't caught off guard by the impact of any extra expenses. Learn about the costs of your follow-up care and/or maintenance therapy. The billing department of your doctor's office or treatment facility may be able to give you an estimate of future costs.

2. Ask your doctor if there are more affordable options for follow-up care.

Many don't feel comfortable bringing up money while talking with their healthcare team. But cost is something you should address as soon as possible. You may need to speak with your insurance provider and/or the hospital's billing department. Use these questions to start a conversation with your healthcare team:

- I'm concerned about how much follow-up care is going to cost me. Can we talk about it?
- Are there less expensive options? Would these options be as effective?
- Will my health insurance pay for follow-up care? How much will I have to pay out of pocket?
- Where can I find financial assistance or reduced-cost medical care?

3. If you don't already have a system for handling your finances, develop one.

Decide how you will keep track of your finances. Will you keep handwritten records? Will you use a computer program or app? Set aside a day and a time every month to pay your bills (or weekly if needed). Ask a financial planner for help. Your bank may also have a customer service agent who can help.

4. Keep accurate records of all medical bills, insurance claims, payments, and receipts, as well as any mail regarding those items.

Get a notebook or special folder to keep everything in one place.

5. When looking for financial assistance, always start with your doctor's office.

Practices often have financial assistance and options for uninsured and underinsured patients. Your doctor's office may also have a social worker or patient representative who can help you identify resources. Be sure to request any applications or possible services offered.

6. When contacting the billing department or your insurance provider, ask to speak with the same representative each time.

7. When asking for assistance, see if the billing department is willing to set up a payment plan for you.

You may get a discount if you are able to pay your bill in full at the time of service.

8. Working with your insurance company and understanding your coverage will help you know all your options.

Many insurance companies offer case managers for diagnoses like cancer.

9. Look to nonprofit organizations for help.

Many national organizations have local branches that may be able to help with specific costs. The assistance might not be much, but every little bit can help. Examples of organizations include: local churches, American Cancer Society, CancerCare, and the United Way. See the “Additional Resources” section at the end of the handbook for more organizations.

10. If you know you’re going to be late making a payment, call your creditors as soon as you can and let them know of your situation.

Some companies like your credit card or mortgage company might temporarily change your payment requirements or interest rate.

Insurance Options

Even once active cancer treatment ends, it’s very important as a cancer survivor to keep health insurance at all times. Follow-up care and checkups, especially imaging, can be very expensive if you don’t have insurance. You may be eligible for health insurance through your employer or your spouse’s employer. You can also purchase private health insurance on your own, but this can vary in experience. Here are some other options for health insurance and reduced-cost medical care:

Medicaid

- Medicaid is an insurance program for those who are low income and meet the eligibility requirements. Medicare is funded by state and federal governments.
- Eligibility depends on what state you live in because each state individually runs its own program.
- Visit your local government website or Department of Human Services for more information.
- Medicaid programs have strict rules about who can qualify. If someone in your household is able to work, you may not be able to receive Medicaid.
- Medicaid programs often include:
 - Children
 - Pregnant women
 - Social Security insurance recipients

- People diagnosed with some cancer types
- Even if you are in one of the above categories, you will still need to qualify based on your income.
- Under the Affordable Care Act, many states expanded their Medicaid programs to include almost all adults with an income below 138% of the federal poverty limit. For example, if two people live in your household and have a combined income of less than \$21,707 a year, you may qualify.
- For the most up-to-date information on these expansions, visit healthcare.gov and the Kaiser Family Foundation.

COBRA

- The Consolidated Omnibus Budget Reconciliation Act (COBRA) was created to allow some people to temporarily keep insurance coverage if there are changes in their employment. The program allows you to keep your former job's insurance by paying the full price of the insurance to your employer (not the reduced rate you paid as an employee). Examples of employment changes include the following:
 - Being fired or laid off from your job
 - Voluntarily leaving your job
 - Having your hours reduced, making you ineligible for insurance
 - Having had health insurance through a spouse's job and he or she died, or you are now divorced or separated
- COBRA is a very expensive option and may seem unaffordable, but COBRA can buy you some time. If you have cancer, your medical bills from being uninsured could be more than the COBRA premium.

Affordable Care Act

The Affordable Care Act (ACA) was signed into law in 2010 and is often referred to as Obama Care or PPACA. The ACA changed a lot of the laws of the U.S. healthcare system. The goal of the ACA was to increase the quality and affordability of healthcare in the U.S. As part of the ACA, people can sign up for health insurance through their state or the government-run healthcare marketplace if they do not have insurance through their employers or another source.

- Visit healthcare.gov to apply and to learn more about your options.
- If the enrollment deadline for the year has passed, the only way to apply for coverage through the ACA marketplace is to see if you qualify for a special enrollment period, such as having lost employer-provided coverage.
- Now that insurance companies can no longer disqualify individuals based on pre-existing conditions, the marketplace has multiple options that are great for those with a cancer diagnosis.
- If you are under 26 years old and single, you can still be on your parent's health insurance plan.
- Your options through the marketplace depend on where you live. It is best to check the marketplace directly to see your individual options. Visit healthcare.gov for more information.

Local Health Department and Local Free Clinics:

- Look to local free clinics to get your medical treatment.
- You can also do a search of free clinics in your area at The National Association of Free & Charitable Clinics (www.nafcclinics.org).
- In addition to free clinics, there are approximately 170 healthcare facilities that still provide free or reduced cost services under the Hill Burton free and reduced cost healthcare law.
- You must apply at the admitting office of the participating hospital to determine if you meet eligibility requirements.
- For more information, visit U.S. Department of Health and Human Services (www.hrsa.gov).

Navigating Your Health Insurance

Even with insurance, the cost of cancer care is high. Your insurance may not cover the cost of everything. You'll also have out-of-pocket costs such as co-pays and deductibles that may build up. To stay on top of these, make sure you know what to expect ahead of time. Here are some tips for navigating your health insurance and the cost of cancer care:

Be familiar with your health insurance policy. Learning about your health insurance can be a very daunting task. The best place to find out about your policy is through your health insurance company.

- If possible, see if your provider will assign to you a case manager. If not, ask to speak with the same representative each time you call. This will make communication easier for both you and the representative.
- If your insurance is through your employer, you can also contact your human resources representative with any questions.

Know what you are expected to pay before appointments, scans, tests, or beginning maintenance therapy.

- A portion of the costs will be out-of-pocket regardless of your insurance plan.
- See if there is an option to get this cost automatically taken out of your bank account or pay by check or with a credit card.
- Most health insurance plans have a deductible. A deductible is the amount that you will have to pay ("meet") before the insurance plan will start paying. Even with the deductible met, you may have to make co-payments.
- Always know in advance what your co-payment will be for each appointment.

To make sure your health insurance company pays or reimburses your covered medical expenses you'll need to:

- Know the terms of your policy
- Be aware of preferred or in-network doctors, hospitals, or clinics
- Keep careful records

If any out-of-network doctors or providers will deliver any of your follow-up care, ask about those costs, too. If they are high, ask for a referral within your network, covered by your insurance.

If you have Medicare, Medicaid, or other public insurance, your healthcare team can help you get more information on costs and coverage.

Doctors' offices and clinics usually have someone who handles health insurance concerns and problems. Ask your doctor if that person can help you file the proper paperwork with the insurance company.

Submit everything to your insurance company. Submit all of your medical expenses, whether you think your insurance company will cover it or not. The only way to get an expense covered is to submit it. It is better to ask and be turned down than spend unnecessary money out-of-pocket.

Social Security Disability Benefits

If you have a cancer diagnosis, and you are no longer able to work, you may qualify for Social Security Disability benefits.

The Social Security Administration (SSA) offers financial assistance in the form of Social Security Disability benefits. **A cancer diagnosis does not automatically make you eligible for SSA benefits.** You have to apply. Here is what you need to know about Social Security Disability benefits and cancer:

- Social Security Administration (SSA) and Social Security Disability benefits
 - To qualify, you must meet the SSA's definition of disability.
 - A cancer diagnosis does not automatically meet the SSA's definition of disability.
 - The SSA processes cancer disability claims on a case by case basis.
 - You must prove you cannot work for at least one year because of your diagnosis.
 - You need proof from your doctor that you cannot work.
 - People who have stem cell or bone marrow transplants automatically meet the definition.
 - In cases of advanced stage cancer, you may qualify for "Compassionate Allowance."
 - This allows applicants to qualify for benefits in as little as ten days.
 - Visit <http://www.disability-benefits-help.org/compassionate-allowances> for more info.
 - Apply as soon as possible. The SAA denies most disability claims at first. You can and should appeal the decision.
 - You can fill out the forms online at <http://www.ssa.gov/> or at your local Social Security Office.

The SSA offers two types of disability programs.

1. Social Security Disability Insurance (SSDI)
 - You must have worked jobs in which you paid Social Security taxes.
 - You must meet the SSA's definition of disability.
 - People approved for SSDI are eligible for Medicare after a two year waiting period.
 - SSDI is not health insurance.
2. Supplemental Security Income (SSI)
 - SSI is a needs-based program. You must prove your income and assets are below the limit.
 - You do not need work credits to qualify.
 - You must meet the SSA's definition of disability.
 - SSI is also available for individuals over 65 without a disability who meet the financial need requirement.
 - People approved for SSI automatically qualify for Medicaid.
 - In some cases, you may qualify for both SSDI and SSI.
 - SSI is not health insurance.

To check your eligibility for all SSA programs, use the Benefit Eligibility Screening Tool (BEST) at <http://www.benefits.gov/ssa>. Based on your answers, this tool lists benefits you may be eligible to receive. This tool does not guarantee approval.

For more information you can also call the Social Security Administration at (800) 772-1213.

Returning To Work

If you stopped working because of cancer treatment, returning to work can help you create your “new normal.” Ask your healthcare team if you are cleared to work. You may need to provide paperwork to your employer as well.

Returning To A Past Job

As you make your plans to go back to work, you may want to talk with your employer about possible options. Employers can offer help in the form of flex-time, job sharing, or possibly even allowing you to work from home (telecommuting). Options like these may help ease your mind and body back into the demands of your job.

For some, the transition back to working full-time is easy, but for others it takes longer. You may find at first that you get tired easily or have trouble focusing. Remember to be patient and take care of yourself as you get back to your “normal” life.

Talking to Your Coworkers

How open you are with your co-workers about your health after cancer treatment is completely up to you. It's a personal decision. Only you can decide who you know best and who will most

likely understand your situation. Confide only in those few people. Your friends at work might be able to help you with the best plan for telling others, and give you ideas on how to transition back to work. Don't allow yourself to feel pressured to explain things or go into any details. It's your place to decide what works best for you and your situation.

Your co-workers will probably have many different reactions to you when you go back to work. Those who know best what you've been through may respond with understanding and offer to help. Others may honestly feel uncomfortable around you. Some may be reminded of a loved one's time with cancer, and many see cancer a reminder of their own mortality. They may act a little awkward out of fear or worry, thinking of cancer as some kind of lurking, mysterious danger. Some co-workers may not like that they had to take on extra duties while you were gone. Others may ask questions about your health or why you've been gone that make you feel uncomfortable. Some might even try to stay away from you altogether.

It helps to plan ahead how you'll handle the reactions of other people, and how much you want to share. Everyone's cancer journey is different.

Finding a New Job

You have the right to remain silent. People who have had cancer do not have to talk about health conditions when applying for a new job. On the other hand, if you have a disability, the potential employer could make a reasonable change (often referred to as reasonable accommodation) to make it possible to do the job. In this case, you may need to discuss the reason the change would be helpful.

Employers cannot ask about a medical condition. However, they can ask if you're able to perform all of the required duties of the job.

Employers can ask new employees to take a medical exam if a job offer is based on passing the exam. If this is required of one person, it must also be required of everyone else applying for that position. The employer cannot take back the job offer if the exam is passed.

Resume Gaps

For those who weren't able to return to work and needed more time to recover, a problem arises. What about the "gap" in their resume? Explaining the gap in work history is a common concern of cancer survivors looking for work. But there is good news for those facing this challenge. Due to the ongoing trouble in the economy, more and more people have big gaps in their resumes.

Experts say you shouldn't address the gap in your cover letter. Focus instead on why you're a fit for that position right now. It's important to remember that your diagnosis is confidential and you do NOT have to disclose your cancer in an application or in an interview.

How to Handle the Gap

- List your skills first. List all of your career skills at the top of your resume and beneath each heading with three to six bullet points that summarize your skills. Then at the bottom of your resume, briefly list the companies you've worked for, your job titles, and the years you've worked.
- Forget the calendar. If you've been out of the work for several years, leave the calendar year out and instead include the number of years you worked. For example, "Two years of managerial work in sales."
- Highlight non-career achievements. Include your volunteer and community work. Show how they translate into relevant job skills like the ability to multitask, plan events, and organize.
- Try freelance and part-time work. Treat your freelance work or part-time work as a career builder. Lay out all achievements and skills as a consultant position.

The ideal practice for all resumes is to cover only 10 to 15 years in detail in a resume. All other skills and experience you want to highlight should be under the heading "Additional Work Experience" or "Additional Skills."

For more tips about returning to work after cancer, visit Cancer and Careers at www.cancerandcareers.org. If you are looking for a new job, Cancer and Careers provides free resume review services for cancer survivors.

Parenting

One of the most difficult challenges for parents who are fighting cancer is often the challenge of maintaining a healthy home life. Being a parent while living with cancer is often physically and emotionally exhausting. You may wonder how you can continue to care for your family and still take care of yourself while dealing with a cancer diagnosis. One key is to focus on quality time with your family and enjoy time with them in a relaxed way.

Talking to Your Kids

Children are very perceptive, no matter their age. While you may wish to protect your children by not telling them about your diagnosis, even young children may be able to tell that something is wrong. Not knowing what is wrong may cause them more stress and anxiety. Here are some tips to talk to your children and teens about your cancer diagnosis:

- Wait until your emotions are under control and decide what to say ahead of time.
- Tell the truth and answer questions honestly. Depending on your children's ages, it may not be appropriate to give them all the details, but do be truthful.
- Let them know what to expect. For example, let them know that after surgery you will need a lot of rest and may need to stay in the hospital. If your chemotherapy may cause

you to lose your hair, let them know. Keep your children in the loop as much as possible.

- Explain to your children, especially younger children, that they cannot “catch” cancer.
- Let your children know that it is okay to cry or be upset. This may be especially important for your teens to hear.
- Tell teachers, babysitters, and others with responsibilities with and around your kids about your diagnosis in case they see behavior changes you may need to know about.
- Maintain normal schedules as much as possible.
- Let your kids help. Allow them to help with chores, and let them know that their help is important. Teens may want to take an active caregiver role. Let them do so, at appropriate levels.
- Look for support groups in your area. Many places offer support groups for children and teens whose parents have a cancer diagnosis.
- Know when to seek professional help. If your child begins to demonstrate unusual behavior such as angry outbursts, nightmares, or poor grades in school, ask your healthcare team for a recommendation for a counselor.

Get Support from Family and Friends

Most parents struggle to fit everything into their family’s schedule, even without the demands of cancer and cancer treatment. It’s important to accept that you don’t have the time or energy for everything. Be realistic about what you can and cannot do.

If you have a spouse or partner, talk about how parenting responsibilities may need to shift during this time and let them know how much you appreciate his or her support. Recognize that these added responsibilities can become overwhelming and may lead to feelings of frustration. It helps to talk openly about each other’s limitations and brainstorm possible solutions.

Other family members, friends, and neighbors may also want to support you but may not know how. The kids can help and will probably want to help even more than before. When a parent has cancer, children often feel powerless to change the circumstances. Asking your children to do chores around the house can help them feel like they are making a difference. On the other hand, having unrealistic expectations for help around the house can add to the stress your child or teen is already feeling about your cancer diagnosis.

Make a list of specific tasks you know you’ll need help with. These tasks may include picking up your children from activities, walking the dog, grocery shopping, or making meals. When someone offers to help, choose a task from your list that suits the person. For example, allow a classmate’s mother to drive your child to school each day.

Some people find it helpful to designate a friend or family member as the point person to coordinate requests. This will save you time and energy that you can devote to your family. Some online communities even allow you to coordinate volunteer efforts through a shared calendar.

Seek Support from Your Community

Your local community may offer resources to help you balance living with cancer and your family life.

- School guidance counselors can offer your children extra support, and after-school programs can provide them a safe place to be when you have a doctor's appointment or need time for yourself.
- If you belong to a place of worship, ask about their support programs. Many religious institutions offer financial, physical, or emotional assistance that can help you focus on parenting. Some even provide support to non-members.
- Charitable organizations in your community may be able to provide everything from childcare and transportation, to meals and financial assistance. Your healthcare team can provide referrals.

Take Care of Yourself

With all the demands on your time, it can be easy to overlook your own needs. Taking care of yourself should be a priority or it may become difficult for you to take care of your family the way you would like. If you find yourself struggling with things like fatigue, pain, or depression, talk with your doctor or nurse about ways to manage them. See the "Side Effect Management Section" of the handbook.

In addition, try to find time to do something you enjoy, like meeting with friends or watching a movie. Don't feel guilty about taking time for yourself when the laundry isn't finished or when someone wants a ride to a friend's house. Time spent resting and doing activities that you enjoy helps to provide you with more energy, giving you the strength to invest in your family.

Marriage and Relationships

Marriages and other long-term partnerships are most affected by cancer. When diagnosed with cancer, both of you may feel sadness, anxiety, or anger. These feelings usually don't just disappear when treatment ends. Facing the challenges of cancer together can strengthen your relationship and commitment. For those who had troubles in their relationship before cancer, the stress may create new problems and make existing problems worse.

Here are some changes that may happen in relationships after a cancer diagnosis.

Roles: Cancer often changes roles, which can be challenging. A person who has always been in charge or served as the caregiver may have trouble accepting a more dependent role, while

a person who has not served as a caregiver may struggle to take charge and provide care. After cancer treatment is finished, it may also be difficult to transition back into peer roles, instead of caregiver/patient roles.

Responsibilities: In most relationships, each partner is responsible for specific chores. One partner may do yard work and cook, while the other cleans and pays bills. If cancer leaves you feeling exhausted or unable to perform your usual jobs, those responsibilities may fall on your partner's shoulders. If you are unable to work, your partner may need to work extra hours. This can be overwhelming. You may feel guilty for burdening your partner and feel saddened and frustrated by your limitations. Talk openly about limitations and brainstorm possible solutions. This will help you both feel more comfortable with changes in responsibilities. Though it may be difficult for both of you, it's important to accept outside help from friends, family members, or professionals as needed.

Needs: Physical and emotional needs change as couples cope with cancer, so it's important for both of you to communicate your needs. Asking for help with basic activities of daily life, like getting dressed or washing your hair, may be not be easy to do, but your partner may not know you need help or may not want to offend you by offering it. Clearly share your needs to make sure you understand each other.

Communication: Cancer can change the way you connect with your spouse. It's not uncommon for a partner to become overly protective in their caregiving role. They may feel a need for a sense of control. If this makes you uncomfortable, you need to express that. Though it may seem normal, or even generous, to spare your partner some details of your diagnosis, keeping secrets usually always results in feelings of isolation for both people. It's important to talk with your partner about your feelings and work together as much as possible to make decisions about treatment, caregiving, and other issues.

Sexuality and intimacy: Cancer and its treatment can take its toll on sexuality. Depression, fatigue, nausea, erectile dysfunction, vaginal dryness, and other physical or emotional problems may lower sex drive or make intercourse difficult or even painful. Both of you may feel anxious about this, but you may be reluctant to talk about it. Every couple has a different level of comfort in discussing sexuality and intimacy. If sharing your concerns and challenges is especially uncomfortable for you, consider getting help from a counselor, your doctor, or a social worker. If your doctor doesn't bring up the topic of sexual side effects, feel free to ask questions. Your doctor or another member of the health care team can provide suggestions for managing sexual side effects and suggest ways to maintain intimacy. See the "Sexual Side Effects and Functioning" section of the handbook for more information.

Future plans: Cancer may change the hopes and dreams couples share. Your plans for retirement, traveling, or parenthood may change. This leads to feelings of sadness or even anger. It helps to rethink priorities and work together to establish new, short-term goals. This

can actually help you feel more connected to each other. Things that seemed important before the cancer diagnosis may give way to new priorities, like enjoying more time together. Putting some goals on hold, rather than throwing them out completely, may help your vision for the future.

Tips for Singles

If you are single, you may not know how and when to share a cancer diagnosis with a romantic partner. Only you can know the best time to share this news. Remember this decision is yours to make. Try to give this person a chance to deal with the news in his or her own time and way. Don't assume they will back away from your relationship because of the cancer. Whatever the reaction, you're not at fault for sharing the news at a "bad time." You may find it helps to practice what you'll say with a friend before talking with your new partner.

Worksheets

The following worksheets can help you organize your life and keep track of all your information during your cancer journey. If you visit My PearlPoint at my.pearlpoint.org and sign up for a personalized dashboard, you can print as many worksheets as you need.

- My Follow-Up Care Plan
- My Medical History
- Immunizations Record
- My Healthcare Team Contact List
- Calendars
- Appointment Planner

My Follow-Up Care Plan

Ask your survivorship navigator or another member of your healthcare team fill out this worksheet so you understand your follow-up care plan.

Follow-Up Care Primary Contact*	
Name	
Phone Number	
Office Address	
Email	

* This may be your oncologist, survivorship navigator, or your primary care physician.

Recommended Screening Schedule

Scan/ Test	How Often	Why

Maintenance Therapy

Additional Follow Up-Care

(Physical Therapy, Pain Management, etc.)

My Medical History

Your survivorship team will need to know your medical history so they can determine the care that is best for you. They may have specific forms for you, but this form will help you collect basic information you will need before your appointments.

Basic Information

Name:

Birthdate:

Phone Number(s):

Address:

Social Security Number:

Employer:

Spouse's Name:

Spouse's Phone Number:

Emergency Contact:

Emergency Contact's Phone Number(s):

Primary Care Physician

Primary Care Physician:

Practice:

Phone Number:

Address:

My Medical History (continued)

Past Medical History

In the past, have you been diagnosed with any of the following?

Circle all that apply.

Anemia Arthritis Asthma Blood Clots Cancer Colitis Concussions Depression
Diabetes Heart Disease Hepatitis High Blood Pressure High Cholesterol HIV/AIDS
Impaired Mobility Irritable Bowel Syndrome Kidney Disease Liver Disease
Lung Disease Migraines Other STDs Urinary Tract Infections Other_____

List any past surgeries, imaging, hospitalizations, or other major procedures you've had.

Procedure	Description	Date

My Medical History (continued)

Family Medical History

Has anyone in your family experienced any of the following? If so, who?

	Relation
Asthma	
Blood Clots	
Cancer (List Cancer Type)	
Depression	
Diabetes	
Heart Disease	
High Blood Pressure	
High Cholesterol	
Blood Clots	
Low Blood Pressure	
Kidney Disease	
Lung Disease	
Irritable Bowel Syndrome	
Liver Disease	
Colitis	
AIDS/HIV	
Other	
Other	

Do you know any other pertinent family medical history?

My Medical History (continued)

Current Issues

Are you experiencing any of the following? Circle all that apply.

Bloating Constipation Diarrhea Dry Mouth Fatigue Gas High Blood Sugar Nausea
Pain Unable to Sleep Vomiting Weight Gain Weight Loss Other_____

Please describe any problems you are having.

Are you able to go about daily activities normally? Yes or No

Do you feel like your normal self? Yes or No

What questions do you have for the doctor?

My Medical History (continued)

Insurance Information

Be sure to take all insurance and prescription cards with you to your appointment.

Insurance Provider:

Policy/ Group #:

Policy Holder's Name:

Patient's Relation to Insured:

Secondary Insurance Provider:

Account Number:

Policy Holder's Name:

Patient's Relation to Insured:

My Immunization Record

For cancer patients, immunizations are especially important because cancer treatments weaken the body's immune system. Immunizations help your body build a resistance to specific diseases. Most immunizations work by introducing a small, safe amount of the disease to your immune system. This way if you are ever exposed to the disease, your body's immune system already knows how to fight it. Ask your healthcare team which immunizations you need. Use this chart to keep track of your immunization record.

Vaccine	Date Given	Next Date Due	Comments/Reactions
Tetanus			
Diphtheria			
Pneumococcal Influenza			
MMR			
Hepatitis B			
Hepatitis A			
Influenza (Flu)			
Other			
Other			

My Healthcare Team Contact List

Your healthcare team may include many different doctors, nurses, and specialists. Keep all your important contact information in one easy-to-find place.

	Name	Contact Info
Caregiver		Phone: Phone: Fax: Email: Address:
Primary Care Doctor		Phone: Phone: Fax: Email: Address:
Survivorship Navigator		Phone: Phone: Fax: Email: Address:
Medical Oncologist		Phone: Phone: Fax: Email: Address:
Radiation Oncologist		Phone: Phone: Fax: Email: Address:

My Healthcare Team Contact List (continued)

	Name	Contact Info
Surgeon		Phone: Phone: Fax: Email: Address:
Hospital		Phone: Phone: Fax: Email: Address:
Pharmacy		Phone: Phone: Fax: Email: Address:

My Healthcare Team Contact List (continued)

Name	Contact Info
Home Health	Phone: Phone: Fax: Email: Address:
Physical Therapist	Phone: Phone: Fax: Email: Address:
Survivorship Team Member	Phone: Phone: Fax: Email: Address:
Survivorship Team Member	Phone: Phone: Fax: Email: Address:

Calendars

Month: _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Notes:

Calendars (continued)

Week: _____

Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday/Sunday	

Notes:

Appointment Planner

Use this tool to plan for your next appointment.

Appointment Date/Time: _____

Appointment Location: _____ Provider: _____

Reason for visit: Office Visit Imaging Lab Work Surgery Treatment Other: _____

Transportation: _____

Lodging: _____

Current Issues

I am experiencing the following problems (circle all that apply):

Anxiety Bloating Bladder/Bowel Problems Constipation Depression Diarrhea
Difficulty Concentrating Difficulty with Sexual Functioning Dry Mouth Emotional Problems Fatigue
Gas High Blood Pressure Nausea Pain Unable to Sleep Vomiting Weight Gain Weight Loss
Other: _____

Description of Problems:

Additional Supplements, Medications, Herbs, or Vitamins you are taking:

Are you able to go about your activities normally? Yes or No

Any changes in your Family Medical History:

Additional Resources

My PearlPoint

At *My PearlPoint*, a website for adults impacted by cancer, you can find more educational, nutritional, and practical information to help you through your cancer journey. You can also find recipes, videos, survivor stories, and more. Create a personalized dashboard to save all the resources you find in one convenient location.

mypearlpoinpoint.org

(877) 467-1936 X 101

guidance@pearlpoinpoint.org

American Cancer Society

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

www.cancer.org

(800) 227-2345

National Cancer Institute

A collection of information run by the National Institutes of Health. For cancer survivors, NCI provides *Facing Forward: Life After Cancer Treatment*.

www.cancer.gov/publications/patient-education/facing-forward

(800) 4-CANCER

American Society of Clinical Oncology

Cancer.Net provides timely, comprehensive, oncologist-approved information from the American Society of Clinical Oncology (ASCO), with support from the Conquer Cancer Foundation.

www.cancer.net/survivorship

(888) 651-3038

The Livestrong Foundation

Provides support to guide people through the cancer experience, bring them together to fight cancer—and work for a world in which the fight is no longer necessary. The Livestrong Foundation provides many useful educational tools for survivorship.

www.livestrong.org
(877) 379-0463

STAR Program

The Survivorship Training and Rehab (STAR) Program provides hospitals, cancer centers, group practices with the training, protocols and other tools needed to deliver evidence-based “best practices” cancer rehab services.

www.oncologyrehabpartners.com

Aging with Dignity’s *Five Wishes*

Five Wishes is a living will worksheet that lets your family and doctors know:

- Who you want to make health care decisions for you when you can't make them.
- The kind of medical treatment you want or don't want.
- How comfortable you want to be.
- How you want people to treat you.
- What you want your loved ones to know.

<http://www.agingwithdignity.org/five-wishes.php>

CancerForward

Works to connect, educate, and share information among cancer survivors, empowering them to move forward with their lives.

www.cancerforward.com

CancerCare

CancerCare provides telephone and online counseling, support groups, education, and financial and co-pay assistance.

www.cancercare.org

(800) 813-HOPE (4673) — Call to speak to a social worker.

The Cancer Insurance Checklist

The Cancer Insurance Checklist is designed to help you when shopping for insurance on your state’s Health Insurance Marketplace if you have cancer or a history of cancer.

www.cancerinsurancechecklist.org

Cancer and Careers

Cancer and Careers empowers and educates people with cancer to thrive in their workplace by providing education and career coaching

www.cancerandcareers.org

Cancer Support Community

The Cancer Support Community is an international non-profit dedicated to providing support, education and hope to people affected by cancer. Cancer Support Community includes Gilda's Club and the Wellness Community. All offer support groups and programs to help survivors cope after a diagnosis.

www.cancersupportcommunity.org

(888) 793-9355

Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) is a government agency that provides information about cancer and other diseases. You can find up-to-date screening and immunization recommendations through the CDC.

www.cdc.gov

(800) 232-4636

United Way

Local United Way chapters offer a variety of programs to support their communities. For resource navigation within your community call 211 to reach the United Way helpline.

www.unitedway.org

211