Non-Hodgkin Handbook

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

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# Table of Contents

## Learn About Your Diagnosis
- Understanding Non-Hodgkin Lymphoma .................................................................................. 5
- What is Non-Hodgkin Lymphoma? ............................................................................................... 5
- The Diagnosis .................................................................................................................................. 7
- The Stages ......................................................................................................................................... 9

## Explore Your Treatment Options
- Specific Questions To Ask Your Doctor .......................................................................................... 13
- Chemotherapy .................................................................................................................................... 13
- Biological Therapy ............................................................................................................................ 17
- Radiation Therapy .............................................................................................................................. 17
- Stem Cell Transplant ......................................................................................................................... 19

## Clinical Trials
- All About Cancer Research ............................................................................................................... 22
- Why Should I Consider a Clinical Trial? ............................................................................................ 24
- Next Steps: How To Talk to Your Doctor About the Latest Cancer Research ................................. 26

## Side Effect Management
- Change in Taste and Smell .................................................................................................................. 28
- “Chemo Brain” (Cognitive Issues) ....................................................................................................... 29
- Constipation ........................................................................................................................................ 32
- Diarrhea ............................................................................................................................................ 33
- Difficulty Swallowing ......................................................................................................................... 33
- Dry, Itchy Skin .................................................................................................................................... 34
- Dry Mouth ......................................................................................................................................... 36
Fatigue .................................................................................................................. 38
Feeling Full Quickly ............................................................................................. 38
Gas and Bloating ................................................................................................. 39
Hypothyroidism .................................................................................................... 40
Insomnia and Difficulty Sleeping ......................................................................... 41
Lactose Intolerance .............................................................................................. 43
Loss of Appetite .................................................................................................... 44
Lymphedema ......................................................................................................... 46
Nausea .................................................................................................................. 48
Pain ....................................................................................................................... 50
Reflux, Heartburn, and GERD ............................................................................... 52
Sexual Dysfunction .............................................................................................. 54
  Female Sexual Dysfunction ............................................................................... 54
  Male Sexual Dysfunction .................................................................................. 58
Sore Mouth, Throat, and Tongue ......................................................................... 62
Weight Gain .......................................................................................................... 63
Weight Loss .......................................................................................................... 64

Nutrition ................................................................................................................ 66
  I Have Lymphoma. What Should I Eat? ............................................................ 66
  Anemia During Cancer Treatment ..................................................................... 67
  Food Safety ......................................................................................................... 70
  Must Have Grocery List ..................................................................................... 73

Practical Concerns ............................................................................................... 76
  Financial Concerns and Cancer ........................................................................ 76
  10 Financial Assistance Tips for Cancer Patients ............................................. 78
  Understanding and Managing My Health Insurance ....................................... 79
  The Basics of Medicare .................................................................................... 80
  I Am Uninsured. What Are My Options? ......................................................... 81
  Finding Transportation ..................................................................................... 83
Finding Lodging .................................................................................................................. 84
What Do I Need To Know About Social Security Disability Benefits and Cancer? .......... 85
Advanced Directives ......................................................................................................... 86
Palliative and Hospice Care ............................................................................................... 87
Emotional Support Programs ............................................................................................ 88

Survivorship ....................................................................................................................... 90
  Screening Recommendations and Follow-Up Care .......................................................... 90
  Survivorship Nutrition ....................................................................................................... 90
  Fear of Recurrence ........................................................................................................... 93
  Immunizations for Cancer Survivors ................................................................................. 95
  Smoking Cessation ........................................................................................................... 97

Worksheets ......................................................................................................................... 100
  Questions for Your Healthcare Team ................................................................................ 101
  My Medical History .......................................................................................................... 103
  Appointment Notes .......................................................................................................... 109
  My Healthcare Team Contact List .................................................................................... 110
  Treatments and Side Effects Log ...................................................................................... 113
  Budgeting Worksheets ..................................................................................................... 116
  Calendar ............................................................................................................................. 119

Additional Resources ........................................................................................................ 122
If you or someone you know has just been diagnosed with non-Hodgkin lymphoma, you may have a lot of questions. In the next few pages, you will find basic information about non-Hodgkin lymphoma and questions to ask your healthcare team.


To understand non-Hodgkin lymphoma, it’s first important to understand what cancer is: basically, the production of abnormal cells.

The body is programmed to routinely replenish cells in different organs. As normal cells age or get damaged, they die off. New cells take their place. This is what’s supposed to happen. Abnormal cell growth refers to a buildup of extra cells. This happens when:

- New cells form even though the body doesn’t need them or
- Old, damaged cells don’t die off.

These extra cells slowly accumulate to form a tissue mass, lump, or growth called a tumor. These abnormal cells can destroy normal body tissue and spread through the bloodstream and lymphatic system.

About Non-Hodgkin Lymphoma

Non-Hodgkin lymphoma is not one cancer but a large group of cancers. In non-Hodgkin lymphoma, the cancer is a type of white blood cell called the lymphocyte. These cells play a major role in your immune system, roaming around in your body ready to fight off infection. To understand this form of cancer, it’s helpful to understand how your immune system works.

Your immune system is complex. It consists of many interacting parts, including:

- white blood cells called lymphocytes
- a network of lymph nodes and connecting vessels called the lymphatic system

and lymphoid organs like the tonsils, thymus, and spleen. Lymph nodes, which are composed almost entirely of lymphocytes, exist throughout the entire body. They play a critical role in ‘educating’ lymphocytes on how to fight infection. There is also lymphatic tissue in other parts of your body, like your stomach, skin and small intestine.
Because lymphatic tissue is in many parts of the body, Non-Hodgkin lymphoma can start almost anywhere. Usually, it's first found in a lymph node above your diaphragm. This is the thin muscle between your chest and your abdomen. Non-Hodgkin lymphoma can also be found in a group of lymph nodes or in other parts of the lymphatic system.

In 2012, there were around 70,000 new cases of Non-Hodgkin lymphoma. It is also called NHL.

**Difference in Lymphomas**

The main difference between Hodgkin and non-Hodgkin lymphoma is the type of lymphocyte each involves.

A specialized kind of doctor, called a pathologist, can examine the cancer cells under a microscope to tell the difference. If the pathologist sees a Reed-Sternberg cell, the lymphoma is classified as Hodgkin lymphoma. If the pathologist does not see the Reed-Sternberg, but rather sheets or clusters of abnormally accumulating lymphocytes, the lymphoma is non-Hodgkin lymphoma. Diagnosing the kind of lymphoma you have is a very complicated process, that requires pathologists who are very familiar with the disease. It is far more complicated than just looking under the microscope, and involves many other kinds of tests.

It's very important to know which type of lymphoma you have. The treatment and outcomes for each type are very different.

**Types of Non-Hodgkin lymphoma**

There are many types of lymphoma. The two most common kinds are diffuse large B-cell lymphoma and follicular lymphoma. If you are diagnosed with non-Hodgkin lymphoma, your doctor will specify which kind you have.

Lymphomas typically come in two big groups: Indolent lymphomas grow slowly. Doctors think of them as chronic diseases that often time do not even need to be treated. They are usually treated when there is a need for treatment. Your doctor can tell if you need to be treated.

- Aggressive lymphomas, which have the potential to grow very quickly, and can produce symptoms related to their accumulation. These symptoms can include fever, chills, and sweating at night (also called nocturnal diaphoresis). These lymphomas almost always require treatment with chemotherapy. Depending on the type of lymphoma, these diseases can be cured with the right treatment.
- Sometimes, the slower growing indolent lymphomas can transform from indolent to aggressive. When this happens, it is often associated with some symptoms like those noted above. It usually requires chemotherapy when it happens.

Your treatment plan will depend on what type of lymphoma you have. It's often a good idea to get a second opinion about the type of lymphoma that you have. Because there are 70 different types, sometimes the treatment for different diseases can be dramatically different.
For this reason, it’s usually a good idea to get an opinion from someone who specializes in treating these often rare diseases.

**The Diagnosis**

If you have symptoms that might suggest Non-Hodgkin lymphoma, your doctor will first probably want you to have one or more of the following tests:

**Physical exam:** Your doctor will check for swollen lymph nodes in your neck, underarms, and groin. Your doctor will also check to see if your spleen or liver are swollen.

**Blood tests:** The lab does a complete blood count (CBC). This checks your blood for the number of white blood cells. It also checks for other cells and substances, such as lactate dehydrogenase (LDH). Lymphoma may cause a high level of LDH.

**Chest X-rays:** These are used to reveal swollen lymph nodes or other signs of disease in your chest.

**Biopsy:** The only definite way to diagnose Non-Hodgkin lymphoma is through a biopsy.

Your doctor may want to biopsy your lymph node or tumor if there is one. There are 3 different kinds of biopsies:

- An excisional biopsy removes an entire lymph node.
- An incisional biopsy removes just part of a lymph node
- A needle core biopsy. This type of biopsy is not preferred because it only removes a very tiny piece of tissue. Because NHL contains mostly normal cells, this procedure can sometimes not lead to the correct diagnosis

There is a fourth way to sample a lymph node or tumor, called a fine needle aspiration. Under no circumstances should this method be used to diagnosis any form of lymphoma. You should know what kind of biopsy your surgeon wants to obtain. When diagnosing non-Hodgkin lymphoma, it’s best to remove the entire lymph node. Then the tissue is checked for the presence of abnormal Reed-Sternberg cells. If these cells are there, then your doctor can make the diagnosis of Non-Hodgkin lymphoma.

Non-Hodgkin lymphoma usually spreads from one group of lymph nodes to another. For example, if non-Hodgkin lymphoma starts in the lymph nodes in your neck, it might spread to the lymph nodes above your collarbone. From there, it could spread to the lymph nodes under your arms.

Over time, the non-Hodgkin lymphoma cells can invade your blood vessels. This allows them to spread to almost any other part of your body. For example, it can spread to your liver, lungs, bone, and bone marrow. To know the extent of non-Hodgkin lymphoma, your doctor will probably order one or more of these tests:
**CT scan (CAT scan or computed tomography):** The CT scan is an X-ray test that produces detailed pictures of your body. Instead of taking one picture, like a regular X-ray does, a CT scanner takes many pictures. It does this by rotating around you while you lie on a table. Then a computer combines all these images. That produces 3-dimensional pictures. CT scans can help find tumors in your bladder, kidneys, and other organs. It can also show any swollen lymph nodes that might have cancer.

Before any pictures are taken, you may have to drink 1 to 2 pints of a liquid. It is called oral contrast. This fluid helps outline your intestine. This helps the doctor see the differences between your normal body and any potential tumors. You may also receive an IV (intravenous line) in your arm or hand. A different type of contrast dye can be injected through the IV. Its purpose is also to outline blood vessels in your body, which helps the radiologist (doctors who read x-ary films and CT scans) see your anatomy more clearly.

The injection may make you feel flushed or warm. It is a little uncomfortable, but not painful. Many patients say that having to lie still is difficult.

**MRI scan (magnetic resonance imaging):** MRIs are similar to CT scans. An MRI scan provides detailed pictures like CT scans. The difference is that MRI scans use radio waves and strong magnets instead of X-rays. The energy from the radio waves produces patterns. A computer takes these and turns them into detailed images of specific parts of your body.

MRI scans are often little more uncomfortable than CT scans. For one thing, an MRI takes up to an hour. You may be placed inside a narrow tube. This can feel confining. There are newer, open MRI machines in many hospitals and clinics around the country.

**PET scan (positron emission tomography):** For this test, a special kind of radioactive sugar is put into your vein. The sugar then collects in places that have cancer. A scanner can then identify these places. Lymphoma cells use sugar faster than normal cells, so areas with lymphoma show up brighter in the pictures.

**Bone marrow biopsy.**

Your doctor may need to perform a bone marrow biopsy, though many patients with NHL will not need one. Early stage NHL rarely goes to the bone marrow. If necessary, your doctor will use a thick needle to remove a small sample of bone and bone marrow. These are taken from your hipbone or another large bone. You will be given local anesthesia to control the pain.

**Ultrasound.** In an ultrasound, a small, hand-held device is held against your body. This device sends out sound waves that humans cannot hear. These waves bounce off nearby tissues. Tumors produce echoes that are different from the echoes that healthy tissues make. A computer then uses the echoes to create a picture. This picture can show possible tumors.

**Spinal tap.** In a spinal tap, your doctor uses a long, thin needle to take fluid from your spinal column. You’ll probably be given local anesthesia to control pain. The fluid is then checked for
lymphoma cells or other problems. With a spinal tap, it’s important to lie flat for a few hours afterward to keep from getting a headache.

The Stages

Once non-Hodgkin lymphoma has been diagnosed, it’s important to know what stage of cancer you have. Knowing what stage your cancer is tells you how serious it is. The stage of non-Hodgkin lymphoma cancer depends on the size of the cancer, lymph node involvement and if there is any distal spread of the tumor. It helps your doctor plan the right course of treatment. Because these disease are blood cancers, and blood is supposed to travel around your body, stage does not carry the same prognostic information that it carries for other disease like lung or breast cancer.

To determine the stage of non-Hodgkin lymphoma, your doctor will consider:

- Whether the lymph nodes are on one or both sides of your diaphragm.
- Whether the disease has spread to your bone marrow, spleen, liver, or lung.

The stages of non-Hodgkin lymphoma are:

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>This is a very early stage. The lymphoma cells are in one lymph node group (such as the neck or underarm). Or the lymphoma cells may be in only one part of a tissue or organ (like the lungs).</td>
</tr>
<tr>
<td>2</td>
<td>The lymphoma cells are in at least 2 lymph node groups on the same side of the diaphragm. They may be either above or below the diaphragm but must be on the same side. Stage II also applies to lymphoma cells that are in one part of an organ or tissue and the lymph nodes near that organ.</td>
</tr>
<tr>
<td>3</td>
<td>In Stage 3, the lymphoma cells are in lymph nodes above and below the diaphragm. Lymphoma may also be found in one part of a tissue or organ (such as the liver or lungs) that is near these lymph node groups.</td>
</tr>
<tr>
<td>4</td>
<td>In Stage 4, lymphoma cells are found in several parts of one or more organs or tissues.</td>
</tr>
<tr>
<td>Recurrent</td>
<td>The disease returns after treatment.</td>
</tr>
</tbody>
</table>
Besides using these staging numbers, your doctor may also classify your non-Hodgkin lymphoma as either A or B:

- **A**: You have not had weight loss, drenching night sweats, or fevers.
- **B**: You have had weight loss, drenching night sweats, or fevers.

The International Prognostic Index (or IPI) is a score that can give you and the doctor some insight into the aggressiveness of your disease. It consists of 5 factors, including:

- Age: good prognosis if age 60 or younger
- Performance status: good prognosis if able to do most normal activities
- Lactate dehydrogenase level (or LDH, is an enzyme found in high levels inside lymphoma cells: good prognosis if blood level is normal
- Number of extranodal sites (that is, is the lymphoma growing in non-lymph node structures like your bone marrow, liver, and lung, for example: good prognosis if no lymphoma outside lymph nodes, or only 1 area outside of lymph nodes.

Stage: good prognosis if Stage 1 or 2 only. To determine your IPI, you just add up how many factors you have that are abnormal, and get the score. The lower the number, the better. Your doctor may choose to be more aggressive if your IPI score is very high, though this is still controversial.

**Explore Your Treatment Options**

If you’ve been diagnosed with non-Hodgkin lymphoma, it’s important to explore all options related to non-Hodgkin lymphoma treatment. Below, learn what’s next, what questions to ask the doctor, and what treatments are available.

**Finding an Oncologist**

The first step on the non-Hodgkin lymphoma journey is to find an oncologist (medical or surgical) who inspires trust. It may seem overwhelming to choose an oncologist. First, start with referrals from your primary care physician, specialist, or insurance carrier. Talk to family and friends who may have recommendations.

Here are some things to consider when choosing an oncologist:

- Is the oncologist board certified?
- How much experience does he or she have in treating non-Hodgkin lymphoma?
- Do you feel comfortable talking with this doctor? Does he or she listen well?
- Is the staff compassionate? Is the environment a good one or do you feel rushed?
- What hospital(s) does this oncologist see patients in?
- What are the office hours?
- What if you have an emergency? Can you call?
- Can this doctor be contacted after hours?
You will be spending a lot of time with the oncologist and staff nurses and technicians, so it’s important to feel comfortable with them.

As you and your doctor explore the treatment options open to you, make sure you find out the answers to the following:

- What are the chances my cancer will come back after this treatment?
- What do we do if the cancer comes back or the treatment doesn’t work?
- Will I lose my hair?
- Will it hurt?
- Will there be scars?

Choosing a Cancer Center

Choosing where to receive treatment is just as important as selecting an oncologist. It’s good to know the differences between hospitals. Here are some guidelines:

- Academic cancer centers: These are affiliated with medical schools. At these locations, high priority is put on research. They are usually located in large cities.
- Community cancer centers: The main focus is on patient care.
- Cancer centers: These are noted for a high quality of science and research.

Some questions to ask before choosing where to get your treatment include:

- Volume: How many non-Hodgkin lymphoma patients do you see annually?
- Travel: How far do you want to travel? Would there be extra costs?
- Cost: Is the hospital covered by your insurance plan?
- Accreditations: What accreditations does the hospital hold?

Treatment Options

It’s helpful to understand the possible treatments for non-Hodgkin lymphoma. Following are overviews of the most common treatments. Reading these should help you know what to expect, what the potential side effects are, and what the advantages are to each.

The common treatments for non-Hodgkin lymphoma are:

- Chemotherapy
- Biological Therapy
- Radiation Therapy
- Stem Cell Transplant

Your doctor can describe your treatment options. While your doctor will work with you to develop a treatment plan that meets your needs, you must be aware that to cure the disease, you doctor may not have a lot of flexibility. The treatments known to cure your disease may be few, and as such, you certainly want to listen carefully, and not compromise that chance.
Your doctor may refer you to a specialist, or you may ask for a referral. There are several different specialists who treat non-Hodgkin lymphoma:

- Hematologists
- Medical oncologists
- Radiation oncologists

You may also need to be treated by an oncology nurse and a registered dietician.

The choice of treatment depends mainly on the following:

- The type of non-Hodgkin lymphoma (for example, follicular lymphoma)
- Its stage (where the lymphoma is found)
- How quickly the cancer is growing (whether it is indolent or aggressive lymphoma)
- Your age
- Whether you have other health problems
- The IPI

If you have indolent (slow growing) non-Hodgkin lymphoma without symptoms, you may not need treatment for the disease right away. Your doctor will watch you closely. In this way, you can begin treatment when you begin to have symptoms, or the CT scan shows that the disease is growing. This process is called watchful waiting. Typically, your doctor will treat the disease if you experience any of the following:

- Bulky disease, defined as over 10 cm or 4 inches
- A gradual trend in growing disease
- Disease causing symptoms (pain, fever, chills, sweating)
- Low blood counts (like low white blood cells, red blood cells [anemia] or platelets
- If you have indolent (slow growing) non-Hodgkin lymphoma and require treatment, you have a lot of treatment options. These can include biological therapy with new drugs called monoclonal antibodies (drugs like rituximab), or chemotherapy,

If you have Stage I or II lymphoma, there is some chance you could be cured with radiation therapy. This however will depend where the disease is located. If you need the criteria noted above for treatment, you may get rituximab with or without chemotherapy. Sometimes non-Hodgkin lymphoma comes back after treatment. This is called a relapse. If this happens, you may need high doses of chemotherapy, radiation therapy, or both. In some cases, you may need stem cell transplantation. The details on how to manage the disease at this point varies dramatically from one form of NHL to another. In many cases, you may be a candidate for a clinical trial evaluating a new treatment concept. Clinical trials represent a wonderful option if it’s right for you. This requires a long discussion with you physician, and finding a place experienced in conducting clinical research.
Specific Questions to Ask Your Doctor

Before starting any treatment, you may want to ask your doctor:

- What type of lymphoma do I have? Can I have a copy of the pathologist’s report?
- What is the stage of my disease? Where are the tumors?
- What are my treatment choices? Which do you recommend for me? Why?
- Will I have more than one kind of treatment?
- What are the expected benefits of each kind of treatment? How will we know the treatment is working? What tests will be used to check its effectiveness? How often will I get these tests?
- What are the risks and possible side effects of each treatment? What can we do to control the side effects?
- How long will treatment last?
- Will I have to stay in the hospital? If so, for how long?
- What can I do to take care of myself during treatment?
- What is the treatment likely to cost? Will my insurance cover the cost?
- How will treatment affect my normal activities?
- Would a clinical trial be right for me?
- How often will I need checkups?

Chemotherapy

Chemotherapy treatment (usually called “chemo”) uses medicines that kill cancer cells. Often rapidly. Chemotherapy medicines do this by inhibiting the processes the cancer cell uses to divide, or to resist dying. Chemo affects your whole body because it goes through your bloodstream. The drugs can reach the lymphoma cells in almost all parts of your body.

Chemo usually doesn’t refer to one drug but many, because there are lots of different chemotherapy medicines. Typically, combination chemotherapy is the optimal approach for patients with non-Hodgkin lymphoma.

When is chemotherapy used?

Chemotherapy may be given either alone or along with radiation therapy. When given alone, it is given in a higher dose designed to kill off cancer cells.

Chemotherapy is usually given by vein, but some forms can be given by mouth. Your medical oncologist will tell you how many cycles or courses of chemotherapy are best for you.

The number of cycles of chemotherapy needed vary. It is relatively common for chemo treatment to begin a week or two after the biopsy. Most chemo treatments for Hodgkin lymphoma can be administered over about 6 months, assuming there are no delays administering the treatment.
What to Expect

Chemotherapy not only weakens and destroys cancer cells at the site of the tumor, but throughout the body as well. Unfortunately, this means that chemo can unintentionally harm the development of normal cells like your hair, nails, mouth, and digestive tract.

The side effects chemo causes depend on the type of chemotherapy you receive and how many cycles you receive. The most common side effects of chemo are:

- Nausea and vomiting
- Fatigue or tiredness
- Confusion, forgetfulness (“chemo brain”)
- Decreased blood counts, sometimes with bruising, bleeding, or infection
- Sores inside your mouth
- Numbness in your hands and feet
- Diarrhea, loose stool
- Increased urgency to have a bowel movement or urinate

Make sure to tell your doctor if you have these conditions before starting chemo. There may be drugs available that can help with these side effects.

The drugs used for non-Hodgkin lymphoma also may cause:

- Skin rashes or blisters
- Headaches
- Body aches
- Darkened skin tone
- Ridges in your nails

How You Receive Chemo

Chemo medicines come in different forms and can be given in different ways:

- Intravenously (IV): As an infusion, the medicine comes through a thin needle (IV) in a vein in your hand or lower arm. An oncology nurse will insert the needle before each infusion and take it out afterwards.
- Injection: As a single shot into a muscle in your leg, arm, hip, or under the skin in the fatty part of your stomach, leg or arm.
- By mouth: As a pill or capsule. You may take this yourself at home.
- Through a port: This is inserted in your chest during a short outpatient surgery. It is about the size of a quarter and sit right under your skin. A port is a small disc made of plastic or metal. A catheter (soft thin tube) connects the port to a large vein. The chemo medicines are delivered through a thin needle right into the port. You can also get your blood drawn through the port. Once you have finished chemo, the port is removed in a brief outpatient procedure.
• Through a catheter in your chest or arm. This is a soft thin tube that is inserted into a large vein. This is done in a short outpatient surgery. The other end of the catheter stays outside your body. This is similar to having a port.

If you have a catheter or port, your medical team will tell you signs of infection to look for.

Port vs. Catheter

Many doctors recommend getting a catheter or port. It makes chemotherapy easier and more comfortable each time, as you don’t have to be restuck each time, like with an IV or injection.

Setting Your Schedule

Your oncologist will set your treatment regimen. Every chemotherapy regimen is made up of cycles. This means a period of treatment followed by a period of recovery. For example, you may get chemo one day and then have a few weeks of recovery with no treatment. That would be one cycle. Or you may get chemo for several days in a row and then have a recovery period. Several cycles make up a complete chemotherapy regimen.

The number of cycles in a regimen and the length of each regimen varies from patient to patient. A lot depends on the medicines used. However, most regimens take 3 to 6 months to complete. A typical routine is treatment every 3 weeks.

You can get chemotherapy in a variety of settings: at a hospital, in a doctor’s office, or in a clinic. You may even get chemo at home if you are taking chemo in a pill form or you have a portable pump.

If you take chemo in a clinic, hospital or doctor’s office, you usually go home between treatments. In some cases, you may stay in the hospital to be monitored. This is especially true if your immune system isn’t working as well as it should be. Your doctor will explain where you’ll be getting your treatment.

Passing Time During Chemotherapy

A chemotherapy treatment at a hospital or clinic can take anywhere from one to several hours. Although many chemo treatment areas have televisions and magazines, you may want to bring something to help pass the time. Ideas include:

• A laptop
• Knitting, needlepoint or crochet
• A good novel
• Crossword or other puzzle book
• Sketchbook and pencils
• Cards or board games (if you have someone to play with)
• Ipod or portable CD player to listen to music
• Paper and pens to keep a journal or write letters
Planning Ahead for Chemotherapy

Chemotherapy treatment can drain most of your energy. This is a major process your body is going through. There are some things you should take care of before you start chemo:

- Get your teeth cleaned and get a dental check-up. Chemotherapy weakens your immune system, so you may be more vulnerable to infections caused by bacteria that are dislodged during teeth cleaning.
- Get any heart tests (like an EKG) that your doctor recommends.
- If you’re a woman, get a Pap smear, if you’re overdue. Chemo can alter the results of your Pap smear, so get one beforehand.
- Find someone to help around the house. Chemotherapy can cause fatigue. Line up someone to help with your daily chores: cleaning, grocery shopping, carpooling, and cooking to name a few. Don’t be too proud or stoic to ask for help. Friends and family members will be happy to do something that helps you during this treatment phase. Ask yourself: wouldn’t you be willing to do it for someone else?
- Be sure to have a back-up plan should you get sick at home, or in the middle of the night. While rare, if you develop fever or signs of infection, you may need to go to the hospital at inconvenient times. Identify family or friends who are able and willing to help you, and drive you to the hospital.
- Join a support group if that sounds helpful.
- Find out ahead of time what you should and shouldn’t eat or drink on treatment days.
- Tell your doctor all the vitamins, supplements, over-the-counter and prescription medicines you take.
- Talk to your doctor about hair loss. Most chemo medicines cause some amount of hair loss. If you plan on wearing a wig, you might want to go ahead and get it so you can match it to your hair color and style.

Questions to Ask About Chemotherapy

You may want to ask your doctor these questions before having chemotherapy:

- Which drugs will I have? What are the expected benefits?
- When will treatment start? When will it end? How often will I have treatments?
- Where will I go for treatment? Will I be able to drive home afterward?
- What can I do to take care of myself during treatment?
- How will we know the treatment is working?
- What side effects should I tell you about? Can I prevent or treat any of these side effects?
- Will there be lasting side effects?
**Biological Therapy**

Certain types of non-Hodgkin lymphoma (usually B-cell lymphomas) may benefit from the use of a biological agent. This type of treatment helps your immune system fight cancer.

Monoclonal antibodies are an example of a biological therapy. These antibodies are proteins made in highly specialized laboratories that can bind directly to cancer cells. They help your immune system destroy lymphoma cells. As such, they often do not carry the same toxicities seen with chemotherapy, certainly you won’t lose your hair. These antibodies are injected through your vein. You may receive this treatment at your doctor’s office, clinic, or hospital.

The major side effects of biological agents are infusion related reactions. These often include the development of flu-like symptoms such as:

- Fever
- Chills
- Headache
- Weakness
- Nausea

Most side effects are easy to treat.

**Questions to Ask About Biological Therapy**

You may want to ask the doctor these questions before having biological therapy:

- How will the treatment help my disease?
- Will I have to stay in the hospital?
- How will we know if the treatment is working?
- How long will I be on biological therapy?
- Will I have side effects during treatment? How long will they last? What can we do about them?
- Are there any long term side effects

**Radiation Therapy**

Radiation therapy is also called radiotherapy or radiation. This is a very effective way to destroy lymphoma cells.

Your doctor may recommend radiation in combination with chemotherapy. Radiation can pinpoint the lymphoma cells very well. In addition, radiation therapy is relatively easy to tolerate, because its side effects are limited to the treated area.
A radiation oncologist will oversee your radiation treatments. There are 2 major types of radiation used for non-Hodgkin lymphoma:

- **External radiation:** A large machine aims the rays at the part of the body where lymphoma cells have collected. This is called local therapy because it affects cells in the treated area only. Most people go to a hospital or clinic for treatment 5 days a week for several weeks.

- **Systemic radiation:** In this type of radiation, you receive an injection of radioactive material that travels throughout your body. This radioactive material is bound to monoclonal antibodies that seek out lymphoma cells. The radiation destroys the lymphoma cells.

**What to Expect**

The goal of radiation is to kill as much lymphoma as possible while preserving normal tissue. Your radiation oncologist will determine how many treatments you will receive. Sometimes treatments are given once a day and sometimes twice a day. A treatment usually takes a few minutes. The total treatment time can take between 3 and 5 weeks, depending on the total dose required.

The side effects of radiation therapy depend on:

- The type of radiation therapy
- The dose of radiation
- The part of the body that is being treated

For instance, external radiation to your abdomen can cause nausea, vomiting, and diarrhea. When your chest and neck are treated, you may have a dry, sore throat and some trouble swallowing. In addition, your skin in the treated area may become red, dry, and tender. You also may lose your hair in the treated area, which is usually temporary.

You are likely to become very tired during external radiation therapy, especially in the later weeks of treatment. Resting is important, but doctors usually advise people to try to stay as active as they can.

People who get systemic radiation also may feel very tired. They may be more likely to get infections.

**Questions to Ask Before Radiation Therapy**

You may want to ask your doctor these questions before having radiation therapy:

- Why do I need this treatment?
- When will the treatments begin? When will they end?
Stem Cell Transplantation

If lymphoma returns after treatment, you may require stem cell transplantation. This means your own blood-forming stem cells are transplanted. Why is stem cell transplantation necessary? If you are receiving chemotherapy, radiation therapy, or both, the high doses destroy not only the lymphoma cells but the healthy blood cells in your bone marrow. That’s why you may need a transplant of healthy stem cells.

What to Expect

Stem cell transplants take place in the hospital. Healthy blood-forming stem cells are given to you through a flexible tube placed in a large vein in your neck or chest area. New blood cells develop from the transplanted stem cells.

The stem cells may come from your own body or from a donor. There are 3 main types of stem cell transplants:

**Autologous stem cell transplantation**: This process uses your own stem cells. These are removed before you have any chemotherapy or radiation. Your healthy stem cells will be frozen and stored. Then, once the chemotherapy and/or radiation are done, the stored stem cells are thawed and put back in you.

**Allogenic stem cell transplantation**: In this process, healthy stem cells come from a donor. Doctors use blood tests to make sure the donor’s cells match yours. Often the donor is a close relative—parent, brother or sister.

Umbilical cord stem cell transplant - Umbilical cord blood, like bone marrow and peripheral blood, is a rich source of stem cells for transplantation. There may be advantages for certain patients to have cord blood stem cell transplants instead of transplants with marrow or peripheral blood stem cells (PBSCs).

Questions to Ask About a Stem Cell Transplant

You may want to ask the doctor these questions before having a stem cell transplant:

- What are the possible benefits and risks of different types of transplants?
- What kind of stem cell transplant will I have? If I need a donor, how will we find one?
- How long will I need to be in the hospital? Will I need special care? How will I be protected from germs?
- How will we know if the treatment is working?
• What can we do about side effects?
• How will treatment affect my normal activities?
• What is my chance of a full recovery?

For sure, should it come time to consider a stem transplant, it will be imperative that you go to a highly specialized center that performs these procedures. Because the experience with different types of stem cell transplant with different kinds of lymphoma may be in the early stages of study, it may be important to get more than one opinion about whether this is right for you. These are complicated treatments that should only be performed by those centers with substantial experience in the field.

Questions for Your Healthcare Team

If you’ve just been diagnosed with cancer, you may be confused and overwhelmed. You probably want answers, but you may not even know what questions to ask. As a cancer patient, being able to talk openly and honestly with your healthcare team is very important. Use these must-ask questions as a guide to start talking with your healthcare team.

What is my diagnosis?
This question may seem like a no-brainer, but in the rush of appointments, you may not receive a clear answer. If you are unsure of your diagnosis, ask your oncologist. Sometimes more specific tests are needed to make an exact diagnosis.

What is my prognosis? What stage is my cancer?
Knowing your prognosis can help you better prepare for the future and select your best treatment plan. In order to know the stage of your cancer, your doctor will need to do tests. These may include scans, genetic testing, and/or a biopsy. The answer to these questions may be difficult to hear. You may consider having a family member or friend with you at this appointment.

What are my treatment options? What would you recommend?
Ask your oncologist to explain all your treatment options, including possible side effects and cost. Ask your oncologist which treatment he or she recommends. If you are unsatisfied with your options, do not be afraid to seek a second opinion.

Am I eligible for a clinical trial?
Clinical trials help improve the standard of care for all cancer patients. Based on your situation, a clinical trial may also be your best treatment option. Each trial has its own eligibility requirements.

What are the possible short-term and long-term side effects of treatment? How will these affect my normal activities?
Always ask about short-term and long-term side effects before beginning treatment so you are prepared. You should also consider short-term and long-term side effects when deciding which treatment plan is best for you.
How can I manage these side effects?  
Some side effects can be easily managed through diet, exercise, or over-the-counter medication. Other side effects may require prescription medication, occupational therapy, or physical therapy which your oncologist can prescribe as needed.

Will my ability to have children be affected? Is there anything I can do to preserve my fertility?  
Some cancers and cancer treatments can affect your fertility, but you do have options. Before treatment, you may be able to freeze eggs or bank sperm. There may be steps you can take during treatment to protect your reproductive system as well. For more information, visit Fertile Hope at http://www.fertilehope.org/.

How can I keep myself as healthy as possible during treatment?  
Your own immune system plays a big part in your fight against cancer. It is important to stay as healthy as possible while undergoing cancer treatment.

Where can I find help with financial concerns?  
Evaluate your financial situation as soon as possible. You will not want to deal with financial stress in the middle of treatment when you may not feel well.

Where can I find help with lodging or transportation?  
When beginning cancer treatment, planning ahead is key. Some treatment centers have lodging coordinators or social workers to help you with the logistics of treatment.

What will my follow-up care plan include?  
After you finish treatment, make sure you and your oncologist create a follow-up care plan. You will need to check for recurrence. You may also need follow-up care for long term side effects.

When can I call myself a survivor?  
According to the National Cancer Institute’s definition of a cancer survivor, “a person is considered to be a survivor from the time of diagnosis until the end of life.”
Clinical trials are medical research studies that test new ways to prevent, screen, diagnose, or treat a disease. Cancer clinical trials determine if a treatment shows an improved way of caring for patients. Clinical trials improve cancer care for all. Talk to your doctor about clinical trials. Depending on your specific diagnosis, a clinical trial may be your best treatment option.

All About Cancer Research

Cancer research involves very highly trained doctors and scientists trying to figure out how cancer works. Research is always done by a set of rules, called the “scientific method” that ensures the information will be valid. Researchers begin by looking for answers to questions like these:

- What causes cancer?
- What makes cancer cells keep growing?
- What destroys cancer cells?
- What stops cancer cells from growing?

By studying how cancer cells behave in animals, researchers can develop theories, or ideas, about potential treatments for humans with cancer. Once a treatment is ready to be tested on humans, researchers conduct clinical trials.

What are clinical trials?

A clinical trial is a medical research study that tests new ways to prevent, screen, diagnose, or treat a disease. The word “clinical” means related to examining and treating patients.

Cancer clinical trials help to determine if a treatment, drug, or procedure shows a better way of treating a particular cancer, or provides a way to treat a condition for which there wasn’t a treatment before.

It takes years of thought and planning to have a clinical trial accepted by the U.S. Food and Drug Administration (FDA). The FDA must approve the trial before researchers can recruit patients. Clinical trials allow patients access to the latest research treatments before they are available to the public.

Who sponsors clinical trials?

Medical or research institutions, pharmaceutical and biotechnology companies, the government, and nonprofit groups who want to improve current cancer treatment can all sponsor clinical trials. Some trials are "investigator initiated," which means a researcher or doctor created the trial, but these trials face the same strict requirements.

What do the phases of clinical trials mean?

Phase I trials answer the questions: Is the drug or treatment safe? What is a safe dose? What are the side effects? Phase I trials are small, each only involving 20-80 participants. These trials are usually the first time a drug or treatment has been tested in humans.
Phase II trials tell researchers if the drug or treatment is effective in a larger group (100-300 participants) and help identify safety concerns.

Phase III trials determine within a large group (1,000 – 3,000 participants) if the experimental drug or treatment works better than what is currently used and if there are additional side effects. Most Phase III trials are randomized, meaning some participants will receive the experimental drug or treatment while others will receive the standard drug or treatment currently accepted by the medical community as best for their cancer type (standard of care).

Phase IV trials allow researchers to learn more about the drug or treatment and its risks, benefits, and best use.

Usually FDA approval comes after large phase III trials. However, sometimes special consideration is given to treatments that show great promise in early trials.

After enough data is gathered to prove that the new treatment is effective or more effective than current treatments, the FDA will investigate the findings and approve the treatment for use. After FDA approval, doctors can prescribe treatments to their patients without enrolling patients in clinical trials.

For a participant, what happens in a clinical trial?

Each clinical trial recruits and screens participants through participating treatment centers. In order to learn if a drug is effective, the participants must be similar in the type of diagnosis and other factors. Trials are designed to be very specific so researchers can know that the drug or treatment being studied is causing changes. For example, a clinical trial may be designed to answer a specific question, such as this: “Is this treatment effective for BRCA positive breast cancer in patients who have not received previous treatment?”

Participants must be eligible in order to qualify for the trial. Some possible requirements for eligibility include:

- Cancer type
- Stage
- Specific tumor types or genetic markers
- Treatment history
- Age
- Other medical conditions

If you qualify for a trial, your healthcare team will provide you with all the information about the trial. They will tell you, in a process called informed consent, how the trial will be conducted and the possible risks and benefits of the trial. You will then sign a document stating that you understand the details of the trial and that you are willing to participate. Even after signing the document of informed consent, you may withdraw from the trial at any time for any reason.

The way you receive treatment depends on the specific clinical trial. Clinical trial treatments can come in many forms. These include but are not limited to the following:

- Intravenous (IV) medications given through a port or IV line
- Shots
- Oral medications
• Surgery
• Radiation

As with any cancer treatment, clinical trial treatments may come with side effects. Your healthcare team will help you manage these side effects. It is very important to report to your healthcare team any side effects that you experience. Part of what researchers are studying is how the treatment affects the whole body, not just the cancer cells.

**How is a clinical trial treatment different from other treatments?**
Patients who decide to participate in clinical trials receive excellent care and attention. Throughout the trial, your healthcare team will closely monitor you for improvements and adverse side effects.

Researchers want to control as much about your care as they can to make sure it is the treatment that is helping your cancer improve, and not something else. Because of this, you may have restrictions on what you can eat and what other medicines you can take.

Although you should always follow your treatment plan and not miss appointments, doing so is especially important with a clinical trial. Clinical trials must have consistency among the participants to know if the treatment really is working.

**Are clinical trials a “last resort” for cancer patients?**
Patients who are no longer helped by existing standard of care treatments may find that a clinical trial provides hope, but many patients begin their treatment program with a clinical trial because the treatment best suited to their situation is still being tested. Some clinical trials even exclude patients who have already received another form of treatment.

When participating in a clinical trial that evaluates if a new treatment is better than the current standard treatment for your cancer type, you will always receive treatment – either the standard of care or the new treatment being studied. By being in a clinical trial, you may receive the added benefits of a new treatment before it is available to the public.

In many cases, cancer research moves at a faster pace than the FDA treatment approval process. Researchers have made important discoveries about biomarkers and mutations that affect how cancers respond to treatment. Because of the long time it takes for a treatment to be tested through the clinical trials process, many of these breakthrough treatments are still only available through participating in a clinical trial.

**Why Should I Consider A Clinical Trial?**

A clinical trial is a medical research study that tests new ways to prevent, screen, diagnose, or treat a disease. The first step is to speak with your oncologist to find out if a clinical trial is right for your cancer journey. The National Comprehensive Cancer Network (NCCN), an alliance of 21 leading cancer centers, believes that “the best management for any patient with cancer is in a clinical trial.”
Why should I consider a clinical trial?
Here are the top reasons why you should consider a clinical trial:

**Complete care**
The "standard of care" is what the medical community agrees is the treatment for a specific type of cancer given the patient's overall health. Clinical trials ALWAYS provide treatment that is the standard of care or better. For example, in a randomized Phase III trial for a promising new chemotherapy drug, some patients would get the treatment under study while others get the standard of care. Or some patients would get the current standard of care plus the treatment under study while others get just the current standard of care.

**Personalized Medicine**
Many of the newest clinical trials focus on very specific tumor types such as tumors that carry specific genetic mutations, markers, or DNA sequencing. Basically, these treatments are tailored to individual cancer diagnoses. Many of these treatments are only available through clinical trials.

**Careful monitoring**
Because the promising new treatment is being carefully studied, patients are also carefully monitored by health care professionals to see how they are doing and to watch for side effects. So, patients enrolled in clinical trials tend to talk with their health care professionals more often and are watched more carefully than patients not involved in a trial.

**Safety first**
Requirements for clinical trials are strictly managed by the Food and Drug Administration. Before a drug is approved for testing in humans, the FDA ensures that it has gone through strict testing protocols in laboratory animals.

**Close to home**
Most people are familiar with the tremendous research being conducted all over the country at research institutions, but in fact, many community cancer centers offer opportunities for their patients to participate in clinical trials. Depending on the type of clinical trial you seek, you may have many options that do not require you to travel.

**Scientific advancement**
Without clinical trials, there is no progress toward cures for cancer. By participating in scientific research through a clinical trial, you can help future cancer patients access new, better treatments. You can play a more active role in your own health care. People who are treated through clinical trials have access to the best new treatments before the general public.

**Now that I know the benefits of clinical trials, what are the risks?**
There are risks involved with the treatment for any life-threatening illness, including treatment offered through clinical trials:

- There may be difficult side effects from medications or treatments.
- The treatment may not be effective.
- The clinical trial may require extra time for trips to the study site, treatments, hospital stays, or complex dosage requirements.

However, through the process of "informed consent," your medical team will make sure you understand all the risks and benefits.

**How can I find a clinical trial?**

If you are interested in participating in clinical research, your first conversation should be with your doctor. She or he may be able to suggest trials or help you search for appropriate options.

*My PearlPoint's Clinical Trial Locator* (my.pearlpoint.org/clinical-trials/search) uses clinicaltrials.gov for our search data, as all clinical trials have to be registered with them. Be aware that the information may not be up-to-date. Your best source of information will be with the facility that is conducting the clinical trial. Their contact information will be clearly noted.

**How To Talk to Your Doctor About the Latest Cancer Research**

If you are interested in participating in a clinical trial, the first step is to talk to your healthcare team.

**How To Start the Conversation**

Here are some tips for talking to your doctor about clinical trials:

- Don't be afraid to ask. Your doctor may not bring up clinical trials, but you are the person being treated so you should be involved in planning your treatment.
- Do not feel that you are second-guessing your doctor. Your doctor should be willing to discuss options with you and answer all your questions without feeling insulted.
- Do not be afraid to seek a second opinion if necessary.
- If possible, talk to your doctor about clinical trials before you begin treatment. Some trials require that participants have not received any other treatments.
- Write down your questions and what you want to talk about before your appointment. Organize your thoughts and your notes so you don't forget anything.
- You may wish to have your caregiver go with you to your appointments. Your caregiver can take notes or ask any additional questions if you happen to forget.
- Search *My PearlPoint's Clinical Trial Locator* (my.pearlpoint.org/clinical-trials/search) to find possible trials on your own. If you've done some research, beginning the conversation with your doctor may be easier, especially if your treatment location is not a large research center.
- Keep in mind that while a clinical trial may be one patient's best option, there may not be a clinical trial option for your diagnosis. You should discuss ALL your treatment options with your healthcare team to create the best treatment plan for you.

**What To Ask Before Starting a Trial**

Once you find a trial and meet the eligibility requirements, you will go through a process called informed consent. During this process, your healthcare team and members of the research team conducting the trial will tell you all you need to know about the trial. Make sure you receive answers to the questions below:
• What is the purpose of the trial?
• How will the trial treatment be better for me than other treatment options?
• How will the healthcare team learn if I am eligible for the trial?
• Where will I receive treatment?
• What type of treatment will the trial involve?
• What will happen at my appointments? (For example, will I have scans, blood tests, and/or examinations?)
• During the treatment, who should I contact with questions and concerns?
• What are the risks and benefits of this trial?
• Will my insurance cover the cost of the trial?
• Will I receive any financial assistance for travel and lodging?
• What will my follow-up care be?
Most cancer patients experience some side effects as a result of their diagnosis or treatment. The type of side effects depends on your diagnosis, treatment type, and overall health. Some of the most common side effects for non-Hodgkin lymphoma patients include: fatigue, loss of appetite, nausea, pain, and weight loss. Talk to your healthcare team about your risk for side effects—which side effects are you most likely to experience?

Side effects can be managed a variety of ways with lifestyle changes, nutrition, exercise, and medication. Read through the following sections to learn tips for managing your side effects to help improve your cancer journey.

Changes in Taste and Smell

Changes in taste and smell can interfere with maintaining good nutrition during treatment. Here are some ways to manage changes in taste and smell.

- Note which foods and liquids taste and smell different.
  - Any or all of the four tastes — salty, sweet, bitter, and sour — may be affected.
  - It is common for meats to taste especially bitter.
  - Sometimes one taste is specifically more pronounced. For example, everything may taste really salty, or sweets may taste so sweet they are not appealing.
  - Pay attention to changes in taste to be able to apply these tips appropriately.
- Take care of your mouth and teeth.
  - Dental issues may affect taste, so visit your dentist prior to treatment.
  - Rinse mouth thoroughly before eating using plain water or a baking soda/salt water mixture (1/4 tsp. baking soda, 1/8 tsp. salt, and 1 cup warm water).
  - Sometimes medications, chemotherapy drugs, and radiation cause a film to form inside the mouth, affecting the taste buds. Rinsing may help to clean away this film.
  - After meals, rinse with an alcohol-free mouthwash or the baking soda/salt water mixture.
- If meats taste bitter or are not appealing, try alternative protein sources such as eggs, beans, cheese, or nuts.
  - If beef tastes bitter, try chicken, turkey, or fish.
  - Marinades that are sweet are often able to counter the bitter flavor of some meats.
  - Other sources of protein to try are eggs, cheese, nuts, or beans.
  - It is important to find high protein foods that are palatable to best meet the body’s protein needs.
- Try to keep odors to a minimum.
• Do not cook anything with a long cooking time in the house where the person who is in treatment spends most of his/her time.
• Use cups that have lids and use straws to limit the odor of any liquids that are not appealing.
• Serve foods at room temperature. Hot foods tend to have a stronger smell than cold foods.

• Limit exposure to metal.
  • Eat using plastic utensils instead of metal.
  • Prepare and store food in glass pans and containers.
  • Between meals, sour flavors such as lemonade or candy may help. Mint candy or gum may also give some relief.
  • Tart or bitter flavors may be more palatable. Try citrus and vinegar based foods. Seasoning food differently and more heavily may help to mask the metallic flavor. Try barbeque sauce, salad dressings, ketchup, mustard, relish, onion, garlic, rosemary, ginger, chili powder, basil, oregano, tarragon, curry, and cumin.

• Don’t be afraid to try some new foods.
  • Sometimes foods you didn’t like before cancer treatment become more appealing as tastes change.
  • Do not be surprised if favorite foods do not taste the same as they did before.
  • Be patient as these changes are usually temporary.
  • Try to make good nutrition a priority and stock your home with a variety of healthy foods.

“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. There are some things you can do to 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 yourself to do things.
- Track your medications and use a weekly pill box.
- Lay out everything you need for the 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:
  o Deep breathing
  o Meditation
  o 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.
  o 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.
Constipation

Constipation is common during cancer treatment. It can be caused by many factors such as cancer type, food and liquid intake, surgery, or medications. Follow these tips to manage constipation and promote regularity.

- Soluble and insoluble fiber are both important for overall health and nutrition.
  - Soluble fiber is found in oats, beans, sweet potatoes, and fruits.
  - Soluble fiber is completely digested by the body. Soluble fiber reduces cholesterol, stabilizes blood sugar, and rids the body of toxins.
  - Insoluble fiber is found in wheat, nuts, seeds, and fruit and vegetable skins.
  - Insoluble fiber is not digested by the body and is excreted as waste. Insoluble fiber promotes regularity.

- 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 first before taking anything.

Diarrhea

Diarrhea occurs when foods pass through the body too quickly. The body cannot absorb enough nutrients, vitamins, minerals, and water. Follow these tips to carefully manage diarrhea and prevent dehydration and malnutrition.

- 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 first 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.

Difficulty Swallowing

Treatment to the head and neck 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.
  o Higher doses of radiation can cause more discomfort.
  o Chemotherapy and radiation treatment at the same time may make side effects worse.
  o Drinking alcohol or using tobacco can make side effects worse.

Use mealtime tactics to make swallowing easier.
  o 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.
  o Cook foods until they are soft and tender.
  o Moisten and soften foods with gravy, sauces, broth, or yogurt.
  o Consume liquids with meals.
  o Sip drinks through a straw; this may make them easier to swallow.

Avoid foods that are hard to swallow or irritating.
  o Avoid coarse foods that do not soften in the mouth.
  o Avoid sharp and crunchy foods like potato and tortilla chips.
  o Avoid spicy foods.
  o Avoid acidic foods like lemons, lime, oranges, and tomatoes.
  o Be careful eating hot foods to reduce the risk of burning your mouth. Cold foods may be soothing.
  o Avoid alcohol.

Choose foods that are easy to swallow.
  o Try breakfast foods like instant oatmeal, grits, pancakes, waffles, and cold cereal that has been softened in milk.
  o For a main dish, try chicken, tuna or egg salad, soups and stews, soft cooked fish, tofu, and meatloaf.
  o Pick side dishes like cottage or ricotta cheese, macaroni and cheese, mashed white or sweet potatoes, and rice or risotto.
  o Try desserts like custard, tapioca pudding, ice cream, milkshakes, and sherbet.
  o Choose snacks like creamy nut butters, applesauce, gelatin, smoothies, and yogurt.

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 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:

<table>
<thead>
<tr>
<th>Drug</th>
<th>Type of Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erlotinib, Gefitinib, Cetuximab, Panitumumab</td>
<td>Colorectal, Head and Neck, Lung, Pancreatic</td>
</tr>
<tr>
<td>Sorafenib, Sunitinib</td>
<td>Kidney, GIST, Liver</td>
</tr>
<tr>
<td>Ipilimumab</td>
<td>Melanoma</td>
</tr>
<tr>
<td>Vemurafenib</td>
<td>Melanoma</td>
</tr>
<tr>
<td>Everolimus and Temsirolimus</td>
<td>Kidney, Pancreatic</td>
</tr>
</tbody>
</table>

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 while undergoing cancer treatment:

**Avoid irritants.**

- Use unscented bath and household products including soap, shampoo, lotion, 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. You may need an antibiotic. If left untreated, infections can become very serious and spread to other parts of the body.

**Dry Mouth**

Dry mouth is common during and following cancer treatment. Symptoms of dry mouth are thirst, sore mouth or throat, difficulty swallowing, and changes in taste. Follow these tips to manage dry mouth.

• Chew gum or suck on ice chips, hard candy, or popsicles to help relieve dry mouth.
- Keeping gum, ice chips, candy, or popsicles in the mouth helps keep the mouth moist.
- Choose sugar-free or low-sugar gum or candy for prevention of cavities.
- In place of ice chips, try frozen grapes.
- Use lip balm if your lips become dry.
- **Choose foods that are easier to chew and swallow.**
  - Choose soft foods like scrambled eggs, puddings, and ice cream.
  - Avoid dry foods.
  - Cut your food into small pieces to make it easier to chew and swallow.
  - Soups and stews are good options, as long as meats are soft or cut into small pieces.
  - Try mashed potatoes and rice instead of crackers or breads.
  - Choose canned fruits or applesauce instead of raw fruits.
  - Puddings, ice cream, and sorbet are also good options.
  - Serve foods with gravy, broths, or sauces. This will make them easier to chew and swallow.
  - Season your food with citrus and herbs instead of salt or hot spices.
- **Drink at least eight to ten 8-ounce cups of liquid each day.**
  - Drinking liquids with meals can make it easier to swallow foods.
  - Sip cool drinks in between meals to ensure adequate fluid intake.
  - Tart drinks in small amounts, such as lemonade, may help your mouth produce more saliva.
  - Keep a glass of water next to your bed at night. Drink when you wake during the night.
- **Eat small meals, and eat more often.**
  - Eating small, frequent meals will ensure that you are meeting your nutritional needs.
  - Try to have a good source of protein with meals and snacks. Eggs, cottage cheese, yogurt, beans, lentils, and smoothies are good soft food choices that also provide protein.
- **Promote a moist mouth.**
  - Rinse your mouth every 1-2 hours.
  - Mix ¼ tsp. of baking soda and 1/8 tsp. salt with 1 cup warm water. Rinse with plain water after using this mixture.
  - Do not use a mouthwash that has alcohol. Alcohol makes a dry mouth worse.
  - Ask your doctor if an artificial saliva product might help. **Radiation and some medications can decrease saliva production.**
- **Avoid things that make dry mouth worse.**
  - Alcoholic drinks can worsen dry mouth.
  - Do not smoke or use other tobacco products.
  - If you do smoke, talk to your healthcare team about quitting.
- **Tell a doctor or nurse if you have white patches in your mouth.**
  - White patches can be evidence of an infection.
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 protein, iron, B vitamins, and vitamin D.
  - Talk to your healthcare team about other side effects such as anemia, pain, or vomiting.

Feeling Full Quickly

Feeling full too quickly is a common side effect, especially after abdominal surgery. This can cause weight loss. Not eating enough weakens the body and delays healing. Below are some tips to ensure proper nutrition.

- Eat small, frequent meals throughout the day.
  - Smaller meals are easier to digest and will allow you to better meet your needs throughout the day.
  - Keep healthy snacks on hand to eat between scheduled meals.
- Avoid foods and actions that may cause gas or bloating.
High-fat foods take longer to digest. They can make you feel fuller between meals. Avoid fried or greasy foods.

Gas-forming foods include: broccoli, cauliflower, Brussels sprouts, cabbage, corn, turnips, onions, peas, garlic, cantaloupe, watermelon, apples, avocado, beans, lentils, and nuts.

Stop behaviors that involve swallowing extra air. Do not suck on ice or candy, chew gum, drink carbonated drinks, or drink through a straw.

- Drink liquids between meals rather than during meals.
  - Drinking with your meals and snacks can fill you up more quickly.
  - Avoid carbonated drinks. Carbonated drinks can make you feel fuller.
- Keep your head up after meals.
  - Lying down after meals will only make your discomfort worse.
- If you are underweight or losing weight too quickly, choose foods that are rich in nutrients and calories.
  - Try to have a source of protein with each meal and snack. Some examples of protein-rich foods include eggs, chicken, fish, meat, milk, yogurt, cheese, beans, nuts, and peanut butter.
  - Add extra calories, protein, and healthy fats to foods you already eat to help prevent weight loss. Try adding olive oil, nuts, nut butters, seeds, non-fat powdered milk, or protein powder to recipes.
  - Drinking nutrient-rich liquids like smoothies or milkshakes can provide nutrition without making you feel full. Liquids leave the stomach more quickly than solid foods.
  - Ask a registered dietitian if drinking a liquid nutrition supplement is needed to provide necessary calories and protein. If needed, a specific liquid nutrition supplement can be recommended that meets your needs.

Gas and Bloating

Excess gas is a common side effect, especially for colorectal and stomach cancer patients. Foods, drinks, behaviors, and medications contribute to gas. These tips may help with the pain, bloating, and discomfort that come with excess gas.

- Avoid gas-forming foods.
  - Avoid broccoli, cauliflower, Brussels sprouts, cabbage, corn, turnips, onions, peas, peppers, radishes, garlic, cantaloupe, watermelon, apples, avocados, beans, lentils, and nuts.
  - Avoid dairy products such as milk cheese or yogurt.
  - Avoid carbonated beverages.
- Avoid behaviors that cause you to swallow extra air.
  - Eat slowly.
  - Do not suck on ice or candy.
  - Do not chew gum.
  - Do not drink through a straw.
  - Drink liquids slowly with small sips.
Hypothyroidism

What is hypothyroidism?
Hypothyroidism means your body is not making enough of the thyroid hormone. The thyroid hormone regulates your metabolism. Metabolism is the internal process that allows your body to use food and nutrients and produce and use energy. Hypothyroidism may occur for many reasons, including as a result of cancer treatment or surgery that affects or removes the thyroid gland.

What are the side effects of hypothyroidism?
The side effects of hypothyroidism include:

- Fatigue
- Difficulty sleeping
- Sleeping too much
- Puffiness (often in the face) and bloating
- Loss of concentration, memory loss, absentmindedness.
- Weight gain
- Anxiety, irritability, mood swings
- Depression
- Dry eyes and mouth
- Dry or flaky skin
- Inability to process nutrients used by the body, such as calcium
- Hair loss or thinning
- Changes or interruptions to menstrual cycle
- Joint pains and stiffness
- Muscle cramps
- Intolerance to cold
- Constipation
- Nausea
- Tingling or numbness in fingers or toes (neuropathy)

Remember, these side effects are temporary. Once you begin taking a thyroid hormone (levothyroxine, sold under the brand names Synthroid and Levoxyl), your side effects will gradually improve. Your doctor will need your help to know if you are getting the right dosage; use the Treatments and Side Effects Log later in this handbook to keep track of your symptoms and side effects.

What can I do to manage hypothyroidism?

- Take your medication as directed.
  
  o It is important to take your thyroid hormone as directed by your doctor, usually on an empty stomach at the same time every day.
  
  o It is usually recommended that you not take supplements for a period of time after taking thyroid hormone. Antacids, iron, and calcium supplements, dietary
fiber, soy, and even walnuts can affect your body’s absorption of the hormone. Check with your doctor or pharmacist for more specific recommendations.

- Eat a healthy diet.
  - Proper nutrition will help you fight fatigue, prevent unwanted weight gain, and promote healthy hair and skin.
  - Your calorie needs may change as your thyroid hormone levels change, and therefore you may find it helpful to talk with a Registered Dietitian for guidance.

- Get active.
  - Physical activity can improve quality of sleep, increase energy, treat constipation, prevent unwanted weight gain, and alleviate feelings of depression or anxiety.
  - Ask your healthcare team before starting any exercise program.

- Go easy on yourself.
  - You may feel frustrated by fatigue and absentmindedness, but remind yourself that these side effects won’t last forever.
  - Once you begin taking levothyroxine, it may take months for the body to re-regulate itself; try not to get discouraged.

**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.
• 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.
• Silence all call, email, and text alerts on your phone.

Tips for sleeping through the night:

• Try to go bed and wake up at the same time each day.
• Choose a small snack, not a large meal, before bed.
  o 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.

Lactose Intolerance
Lactose intolerance occurs when the body cannot digest milk sugar (lactose). Some patients experience lactose intolerance, with symptoms like diarrhea, gas, and stomach cramps after having dairy. These tips may help to relieve symptoms.

• Avoid dairy products and foods containing lactose and instead choose lactose-free or reduced lactose milk products.
  o Most grocery stores sell lactose-free milk and ice cream.
  o After checking with your doctor, consider trying products made with soy or rice instead. Soy milk, rice milk, and almond milk are available at most grocery stores.
  o Yogurt with live active cultures and hard cheeses such as parmesan and aged cheddar are lower in lactose. You may find these to be better tolerated and less likely to cause symptoms
  o Avoid using butter, margarine, cream, or soft cheeses when cooking or preparing foods.
• Read labels carefully.
- Avoid foods that have been prepared with milk, butter, milk solids, cream, casein, or whey.
- Avoid products with ingredient lists that say “May contain milk”.
- Talk to your doctor about using over-the-counter enzymes.
  - Lactase enzyme products are available in capsule, liquid, or pill form.
  - Taking these enzymes with your meal may help you to digest the lactose in milk and prevent symptoms.
- Choose other calcium-fortified or high-calcium foods.
  - Read labels to find foods that have been fortified with calcium to ensure you are meeting your calcium needs.
  - There are many ways to meet your calcium needs from foods other than dairy products. Other good sources of calcium include leafy green vegetables, broccoli, fortified orange juice, fortified cereals, canned salmon, tofu, almonds soy beans, and white beans.
  - Talk with your physician or a registered dietitian about whether you could benefit from taking a calcium supplement.
- Symptoms of lactose intolerance may improve overtime after treatment ends, but sometimes it can be a long-term problem.

**Loss of Appetite**

Loss of appetite interferes with good nutrition before, during, and after treatment and can contribute to dangerous weight loss. The following are some tips to optimize nutrition while dealing with appetite loss.

- Manage any other nutrition related side effects that may contribute to appetite loss.
  - Nausea, vomiting, diarrhea, constipation, dry mouth, sore mouth, swallowing difficulty, and heartburn may lead to loss of appetite.
  - Talk to a registered dietitian and your healthcare team for assistance with any of these side effects. It is important to get help managing any of these side effects to increase appetite.
- Take note of when your appetite is best.
  - For some people this is in the morning and appetite diminishes throughout the day. For other people it may be the opposite.
  - When you feel well, eat as much nutritious food as possible in case you do not feel well later.
  - Do not limit or restrict food intake when appetite is good.
- Eat 5-6 small meals per day and snack anytime.
  - Small amounts of food are typically easier to digest and are easier on the stomach. It is often easier to better meet nutrition needs while battling appetite loss with smaller amounts of food more frequently.
- Keep healthy snacks around, and do not go more than three hours without eating.
  - Pack a cooler or insulated lunch bag to take on longer trips or to appointments when the wait time is variable.
Keep small containers of fruit, dried fruit, trail mix, small bottles of juice, yogurt, cheese, whole grain crackers, cereal, granola bars, and other portable food items that are easy to eat and require little to no preparation.

Always keep snacks visible and available as a reminder that it is important to eat to get the body the nutrients it needs.

- If food is not appealing, have a nutritious beverage instead.
  - A high-protein shake or smoothie can have as many calories as a small meal or large snack.
  - Have a ready-to-drink liquid nutrition supplement when food is not appealing.
  - Milkshakes, smoothies, or protein shakes can be made with yogurt, milk, ice cream, protein powder, fruit, and other ingredients using a blender. Have these ingredients available for times when a drink sounds better than a meal.

- Drink liquids between meals.
  - Sometimes drinking liquids with meals causes the stomach to get full faster. This prevents eating enough and maximizing nutrition from food sources.
  - If an early feeling of fullness is a problem, try waiting to drink any liquids until after a meal and do not drink any liquids for at least 30 minutes before a meal.

- Add calories and protein to foods to give their nutrient content a boost.
  - There are ways to add protein and calories to foods that are already eaten regularly.
  - Add a scoop of protein powder to a shake or smoothie.
  - Add healthy fat such as olive oil, nuts, or nut butter to recipes and other dishes to boost the calorie content.
  - Ask a registered dietitian for other suggestions on how to increase the protein and calorie content of foods.

- Exercise or do some physical activity at least an hour before a meal.
  - Regular exercise may help increase appetite.
  - Go for a 20-minute walk before sitting down to a meal.

- Get in the habit of having a bedtime snack.
  - An easy-to-digest snack such as yogurt and fruit, cheese and crackers, or peanut butter and crackers is an easy way to get some additional nutrition and will not impact appetite for the next meal.
  - If reflux or heartburn is an issue, have this snack at least one hour before lying down.

- Emotions are often related to appetite. Talk to your healthcare team about managing your emotional well-being.
  - Depression, anxiety, fear, and stress can all affect appetite.
  - Trained health professionals such as social workers and psychologists can assist in managing these emotions.
  - Support groups are another resource that may help in processing these emotions.
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.

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.
- No new tattoos in 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 though 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 recommend 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
    - Skin care
    - Special exercises
    - Compression bandages
  - The massage is called manual lymphatic drainage (MLD). This massage style helps move lymph fluid through the system to decrease pain and swelling.
  - 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.
- Lymphedema can make it easier 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

**Nausea**

Nausea and vomiting are common side effects of cancer treatment that can cause dehydration, poor nutrition, and weight loss. Follow these tips to control nausea and vomiting.

- 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 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 other foods that require slow cooking.
  - 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.
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 blister. 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. Amputations and mastectomies can lead to “phantom” pains where the removed limb or breast used to be.

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.

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.

**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.

### Reflux, Heartburn, and GERD

Heartburn, reflux, and GERD (gastroesophageal reflux disease) may occur during cancer treatment. Cancer treatments or medications may affect parts of your digestive tract and cause the food and liquids in your stomach to reflux (travel back) into your esophagus (food pipe). Patients with reflux may have symptoms such as swallowing difficulty, a sore throat, sour taste in your mouth, heartburn and painful digestion.

Talk with your healthcare team for the best care for reflux. Here are some tips and guidelines to help control reflux:

**Go small.**
- Eat 5-6 small meals or snacks throughout the day. Smaller amounts of food are easier for the body to digest and absorb.
- Smaller amounts of food also mean there is less food that can travel back up the food pipe.

**Choose lean.**
- Avoid fried and fatty foods. These foods are hard to digest and stay in your stomach for a long time. Time increases risk for reflux.
- Choose baked, broiled, or grilled foods instead.

**Dress for comfort.**
- Wear loose-fitting clothes, especially clothes that are not tight around your stomach.
- Clothes that are tight around the stomach can trigger reflux.

**Avoid smoking and alcohol.**
- Smoking cigarettes (including e-cigarettes) and drinking alcohol can trigger reflux.
- Instead of after-dinner drinks and cigarettes, chew sugarless non-mint gum for 30 minutes after meals. This encourages food to move through your digestive system.
Sit up.

- Pay attention to your posture.
- Sit up at least 1 hour after eating.
- Good posture helps your breathing and may reduce fatigue during eating.
- Raise the head of your bed 6 to 9 inches by putting wooden blocks under the legs of the head of your bed.

Slow down.

- Eat slowly and chew food really well. Digestion begins in the mouth.
- Smaller food pieces are much easier to digest and are less likely to cause discomfort.
- Meals eaten in calm, relaxed place seems to be better digested.
- Added stress from treatment can also trigger reflux; try to eat when you are feeling most relaxed.

Choose well.

- Some specific foods and drinks may cause reflux symptoms.
- Some common problem foods and drinks may be: chocolate, cocoa, mint, whole milk, caffeine, pepper, some fruits/juices, pastries and other high-fat desserts.

Write it down.

- Record in a log the times you eat, the foods and drinks you consume, and any reflux symptoms.
- If you eat a large portion of a problem food, you may have symptoms. Try a small portion and take notes in your log. Use your log to eliminate items that cause reflux symptoms.
- Avoid “problem foods” for a couple of days to see if symptoms disappear.

Avoid eating before bed.

- Avoid eating too close to bedtime.
- Have your last food or drink 1-3 hours before you recline.
- If still having trouble sleeping due to reflux, you may need to raise the head of the bed so that gravity helps keep food down in the stomach.

Ask for help.

- Consult a local registered dietitian for specific recommendations based on your level of food tolerance.
- Talk to your healthcare team if symptoms persist or get worse.
Sexual Side Effects

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.

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 article such as pain, lack of desire, and emotional issues can also make achieving orgasm difficult.

- Work on managing all of 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. Read the other side effects managements sections of this handbook to get all your side effects under control.
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.

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.

Surgery

Surgery to the pelvic area including surgery for prostate, anal, bladder, or testicular cancer can lead to the following:

- Damage to blood vessels or nerve endings resulting in difficulty having and keeping an erection, known as erectile dysfunction or impotence
- Loss or damage of sexual organs
- Infertility
- Orgasms that do not result in ejaculation

After surgery, ask your doctor if and when it is safe to have sex.

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 Nutrition Tips for Managing Weight Gain.

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.
  o Both 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.
  o 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.
  o 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?
Sore Mouth, Throat, and Tongue

Some cancer treatments can cause mouth sores, ulcers, and tender gums, leading to dehydration, poor eating, and weight loss. Follow these tips to manage sore throat, mouth, and tongue.

- Choose soft, bland foods.
  - Softer foods will be easier to chew and swallow.
  - Soups and stews are good options, as long as meats are soft and tender.
  - Try breakfast foods like instant oatmeal, grits, pancakes, waffles, and cold cereal that has been softened in milk.
  - 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 applesauce, gelatin, smoothies, and yogurt.

- Prepare foods in ways that make them easier to eat.
  - Cut foods into small pieces. You may consider using a blender or food processor to puree foods.
  - Cook foods until they are soft and tender.
  - Serve foods with gravy, broths, or sauces.
  - Choose soft or canned fruits or applesauce instead of raw fruits with tough skins.

- Avoid foods and drinks that make mouth sores worse.
  - Avoid citrus fruits and juices, salty or spicy foods, and acidic foods like tomatoes.
  - Do not drink carbonated or caffeinated drinks.
  - Refrain from having beer, wine, liquor, or any other type of alcohol.

- Avoid very hot foods.
  - Hot foods can cause mouth and throat discomfort.
  - Choose room temperature or cold foods that are soothing.
  - Allow soups and hot foods to cool to room temperature before serving.
  - Try freezing fruits, and suck on frozen fruit pops, fruit ices, or ice chips.

- Choose foods that are good sources of protein to combat weight loss.
  - Aim to have a good source of protein with meals and snacks.
  - Ground meats, eggs, cottage cheese, yogurt, custard, beans, lentils, and smoothies are good soft food choices that also provide protein.
  - Eat small, frequent meals. You may find it easier to eat smaller amounts at a time.

- Drink at least 8-10 eight-ounce glasses of water each day.
  - Drink liquids with your meals as this will make it easier to swallow foods.
  - Sip cool drinks in between your meals.
  - Drink with a straw. This can help push the foods past the painful sores in your mouth.
  - Avoid caffeinated or and carbonated beverages.
  - Avoid alcohol. Alcohol can irritate the mouth.

- Use good mouth care.
  - Rinse your mouth several times a day. Mix 1/4 tsp. baking soda, 1/8 tsp. salt, and 1 cup warm water to make a rinse that removes food and promotes healing.
Do not use a mouthwash that has alcohol. Alcohol makes a sore mouth worse.
Use a toothbrush with soft bristles.
Remove dentures (except during eating) if your gums are sore. Keep dentures clean.
Avoid cigarettes, cigars, and tobacco products.
Ask your doctor about special mouthwashes and sprays that can numb the mouth and throat.
Tell your doctor if your gums are bleeding or if you have white patches in your mouth. Both can be signs of infection.

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 before, during, and 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 regular 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 for 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 less 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.
  - Drink smoothies, shakes, and nutrition supplements with or in place of a meal.

- 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.
  - Peanut butter crackers, half a sandwich, yogurt, and cereal are good bedtime snacks.
When you are faced with a cancer diagnosis, nutrition can be an important part of your journey. Eating a well-balanced diet before, during, and after cancer treatment can help you feel better, maintain your strength, and speed your recovery. Use these tips about nutrition written by our registered dietitians.

I Have Lymphoma. What Should I Eat?

How do I make the best food choices throughout cancer treatment?

When you are faced with lymphoma, nutrition can be an important part of your journey. Lymphoma is cancer of the lymph nodes which are a mass of tissue that helps protect the body against infection. Eating a well-balanced diet before, during, and after cancer treatment can help you feel better, maintain your strength, and speed your recovery.

- **Maintain a healthy weight.** Aim to avoid losing or gaining much weight during treatment. Strict dieting is not recommended during cancer treatment. Losing weight can lower your energy level and decrease your body’s ability to fight infection.

- **Eat small, frequent meals throughout the day.** Eating frequent small meals will ensure your body is getting enough calories, protein, and nutrients to tolerate treatment. Smaller meals may also help to reduce treatment-related side effects such as nausea. Try eating 5-6 small meals or “mini” meals about every three hours.

- **Choose protein-rich foods.** Protein helps the body to repair cells and tissues. It also helps your immune system recover from illness. Include a source of lean protein at all meals and snacks. Good sources of lean protein include:
  - Lean meats such as chicken, fish, or turkey
  - Eggs
  - Low fat dairy products such as milk, yogurt, and cheese or dairy substitutes
  - Nuts and nut butters
  - Beans
  - Soy foods

- **Include whole grain foods.** Whole grain foods provide a good source of carbohydrate and fiber, which help keep your energy levels up. Good sources of whole grain foods include:
  - Oatmeal
  - Whole wheat breads
  - Brown rice
  - Whole grain pastas

- **Eat a variety of fruits and vegetables every day.** Fruits and vegetables offer the body antioxidants, which can help fight against cancer. Choose a variety of colorful fruits and
vegetables to get the greatest benefit. Aim to eat a minimum of 5 servings of whole fruits and vegetables daily.

- **Choose sources of healthy fat.** Avoid fried, greasy, and fatty foods, Choose baked, broiled, or grilled foods instead. Healthy fats include:
  - Olive oil
  - Avocados
  - Nuts
  - Seeds

- **Limit sweets and added sugars.** Foods high in added sugars like desserts and sweets provide little nutritional benefit and often take the place of other foods that are better for you.

- **Stay hydrated.** Drinking enough fluids during cancer treatment is important for preventing dehydration. Aim to drink 64 ounces of fluid daily. Avoid drinking large amounts of caffeinated beverages. Too much caffeine can lead to dehydration.

- **Practice good food safety.** Wash your hands often while preparing food. Use different knives and cutting boards for raw meat and raw vegetables. Be sure to cook all foods to their proper temperature and refrigerate leftovers right away.

- **Talk to your healthcare team before taking any vitamins or supplements.** Some medications and cancer treatments may interact with vitamins and supplements. Choose food first as the main source for nutrients.

- **Drink alcohol in moderation, if at all.** Alcohol may contribute to dehydration, can lower the abilities of your immune system, and provides no beneficial nutrients.

- **Most importantly, know that your cancer journey is unique to you and your treatment.** You may experience side effects that affect your ability to follow these suggestions. If you are struggling with any side effects, such as loss of appetite, nausea, diarrhea, vomiting, or any other nutrition concerns, your needs may be different. A registered dietitian can suggest nutrition guidelines that will be appropriate for your cancer journey.

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**Anemia During Cancer Treatment**

Anemia is a condition that occurs when the body does not have an adequate amount of red blood cells. There are several types of anemia with a variety of causes. Causes can include poor production of red blood cells, destruction of red blood cells, or bleeding that depletes red blood cells. If possible, it is best to determine the cause of the anemia to treat or improve anemia-related symptoms. There are several types of anemia with a variety of causes. Below are the specific types of anemia and their cause:
**Iron-deficiency anemia** is caused by blood loss or not eating enough iron-rich foods. This results in the body not being able to make enough red blood cells.

**Pernicious anemia** is caused by the body not being able to absorb vitamin B12 properly, causing a B12 deficiency. Vitamin B12 deficiency can lead to the body not being able to make enough red blood cells.

**Folic acid-deficiency anemia** is caused by not eating enough foods rich in folic acid or the body’s inability to absorb enough folic acid. It also can be related to illness. Again, the result is the body is not able to make enough red blood cells.

**Hemolytic anemia** is an acquired or inherited disease that causes red blood cells to be deformed. The result of this disease is that the body destroys red blood cells too quickly.

**Sickle cell anemia** is an inherited disease that is most common among African Americans. Sickle cell anemia causes red blood cell to be deformed and sickle shaped. Sickle shaped blood cells do not carry oxygen properly, break down easily, and clog blood vessels.

The first four types of anemia are the most common anemia that occurs during cancer treatment. Anemia can be related to poor nutrition, the body not functioning optimally, or some of the medications that are being given to treat the cancer. The following are some tips and suggestions to help manage anemia:

**Choose iron rich foods to incorporate into meals and snacks.**

The recommended daily iron intake for men is 8 mg/d. The recommended daily intake for women ages 19-50 is 18mg/d. The recommended daily intake for women over the age of 50 is 8/mg/d. Pregnant and lactating women have increased needs. There are two types of iron in food: heme and non-heme. Heme iron is more easily absorbed and is found only in meat, fish and poultry. Non-heme iron is found in vegetables, fruits, dried beans, grains, and nuts. Here is a chart showing some iron rich foods and their iron content:

<table>
<thead>
<tr>
<th>Heme Iron Sources</th>
<th>Amount of Food</th>
<th>Iron Content (mg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clams</td>
<td>3 ounces</td>
<td>23.8</td>
</tr>
<tr>
<td>Oysters</td>
<td>3 ounces</td>
<td>7.8 mg</td>
</tr>
<tr>
<td>Chicken Liver</td>
<td>3 ounces</td>
<td>8.0 mg</td>
</tr>
<tr>
<td>Beef Liver</td>
<td>3 ounces</td>
<td>5.8 mg</td>
</tr>
<tr>
<td>Beef Sirloin</td>
<td>3 ounces</td>
<td>2.9 mg</td>
</tr>
<tr>
<td>Ground Beef</td>
<td>3 ounces</td>
<td>1.8 mg</td>
</tr>
<tr>
<td>Chicken (dark meat)</td>
<td>3 ounces</td>
<td>1.1mg</td>
</tr>
<tr>
<td>Non-Heme Iron Source</td>
<td>Amount of Food</td>
<td>Iron Content (mg)</td>
</tr>
<tr>
<td>---------------------------</td>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Chicken (white meat)</td>
<td>3 ounces</td>
<td>0.9 mg</td>
</tr>
<tr>
<td>Pork loin</td>
<td>3 ounces</td>
<td>0.9 mg</td>
</tr>
<tr>
<td>Salmon</td>
<td>3 ounces</td>
<td>0.7 mg</td>
</tr>
</tbody>
</table>

Eat iron-containing foods with foods containing vitamin C.

Vitamin C enhances the absorption of iron. Here is a list of foods containing vitamin C.

<table>
<thead>
<tr>
<th>Fruit</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cantaloupe</td>
<td>Citrus Fruit</td>
</tr>
<tr>
<td>Papaya</td>
<td>Pineapple</td>
</tr>
<tr>
<td>Cranberries</td>
<td>Watermelon</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vegetables</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Broccoli</td>
<td>Brussel Sprouts</td>
</tr>
<tr>
<td>Spinach</td>
<td>Cabbage</td>
</tr>
<tr>
<td>Potatoes</td>
<td>Tomatoes</td>
</tr>
</tbody>
</table>

Avoid foods, beverages and behaviors that may reduce iron absorption.
Tannins found in tea can block iron absorption. Limit tea consumption and drink between meals instead of with meals and snacks or when not eating iron-containing foods. Do not drink alcohol if you are anemic or if you are taking medications or supplements to treat anemia.

**Only begin taking an iron supplement if blood work shows an iron deficiency.**

Your healthcare team or a Registered Dietitian can provide direction on which supplement(s) to take. Do not begin any supplements without consulting with a healthcare provider first. If you are instructed to take an iron supplement, take it on an empty stomach if tolerated. Iron is absorbed best on an empty stomach.

**Be sure to eat enough protein.**

Foods high in protein are very important to include during cancer treatment because they help support the immune system. Many of these protein containing foods also contain iron. Protein is found in the highest amount in meat, eggs, fish, dairy products, beans, tofu, and nuts.

**Eat foods containing folate.**

Folate is a B vitamin that supports the production of red blood cells. Eating enough folate-containing foods may help to prevent anemia. The best sources of folate are lentils, pinto beans, garbanzo beans, spinach, black beans, navy beans, kidney beans, collard greens, turnip greens, and lima beans.

**Eat foods containing vitamin B 12.**

Although vitamin B 12 deficiency is rare, poor nutrition over a long period of time may result in a deficiency. Since vitamin B 12 also plays a role in the production of red blood cells, consuming foods containing vitamin B 12 is important. The best sources of vitamin B 12 are eggs, sardines, salmon, venison, lamb, beef, shrimp, halibut, scallops, yogurt, and milk. Your healthcare provider may check your blood level of vitamin B 12 to determine if you have a deficiency.

**Be aware of anemia symptoms.**

It is common not to have any symptoms at all. However, the most commonly reported symptoms are excessive fatigue, shortness of breath, general weakness, and in some cases heart palpitations. If any signs of blood loss are present such as blood in the stool or urine or frequent nose bleeds, alert your health care provider immediately.

**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 of this is that 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 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 handling any food as well as after. 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 a separate cutting board 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 meat 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:

<table>
<thead>
<tr>
<th>Meat</th>
<th>Internal Minimum Temperature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ground Beef</td>
<td>165° F</td>
</tr>
<tr>
<td>Turkey</td>
<td>165° F</td>
</tr>
<tr>
<td>Chicken</td>
<td>165° F</td>
</tr>
<tr>
<td>Steak or other cuts of beef</td>
<td>160° F</td>
</tr>
<tr>
<td>Whole chicken, turkey, duck, or goose</td>
<td>180° F</td>
</tr>
<tr>
<td>Pork</td>
<td>170° F</td>
</tr>
<tr>
<td>Egg dishes</td>
<td>160° F</td>
</tr>
<tr>
<td>Casseroles</td>
<td>165° F</td>
</tr>
<tr>
<td>Reheated leftovers</td>
<td>165° F</td>
</tr>
</tbody>
</table>
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 of 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 health care team for regular updates on your blood counts and the status of your immune system.
Must Have Grocery List

It’s always important to have good, healthy foods on hand, especially if you are fighting cancer or are a cancer patient. Eating well during cancer treatment can help to improve your overall health, improve your response to treatment, and maintain good health during treatment and recovery. Having a well-stocked pantry can assure that you are getting the calories and nutrition your body needs. Below are some suggested items that are healthy kitchen staples.

Pantry

Grains
- Whole grain breads, English muffins, pita bread, flour or corn tortillas
- Crackers: saltines, club crackers, whole wheat crackers, graham crackers
- Whole grain brown rice or white rice
- Whole wheat and refined pastas such as, penne, bowtie, macaroni, egg noodles, etc.
- Quick cooking oats and steel cut oatmeal
- Couscous, bulgur, or quinoa
- Cream of wheat
- Grits
- Dry cereal
- Natural popcorn
- Flour, cornmeal, breadcrumbs

Fruit/ Vegetables
- Canned fruit
- Dried fruit
- Individual fruit cups
- Applesauce, no sugar added
- Potatoes and sweet potatoes
- Onions
- Garlic
- Canned tomatoes (diced, whole), tomato sauce, marinara sauce
- Canned no salt added vegetables
- Instant mashed potatoes

Dairy
- Nonfat dry milk powder or whey protein powder
☐ Evaporated milk

**Proteins**
- ☐ Canned tuna, salmon, or chicken (Choose those packed in water, not oil.)
- ☐ Natural peanut and almond butter
- ☐ Unsalted nuts and seeds
- ☐ Canned or dried beans, vegetarian refried beans, lentils.
- ☐ Protein bars

**Fats and Oils**
- ☐ Oil, olive, canola, cooking spray

**Other**
- ☐ Canned low sodium soups
- ☐ Low sodium chicken, beef, or vegetable stock
- ☐ Dried herbs and spices
- ☐ Vinegars such as red wine and balsamic
- ☐ Decaffeinated teas
- ☐ Flavored drink mixes, lemonade
- ☐ Pudding or gelatin mixes
- ☐ Individual pudding or gelatin cups
- ☐ Honey, sugar, stevia

**Refrigerator:**

**Fruits/Vegetables**
- ☐ Fresh and jarred fruits and vegetables
- ☐ Packaged salad mixes such as spinach, romaine and arugula

**Dairy**
- ☐ Low-fat milk,
- ☐ Low-fat plain or Greek yogurt
- ☐ Cheese slices, cheese sticks, shredded or crumbled cheese
- ☐ Reduced fat cottage or ricotta cheese
- ☐ Fortified soy, almond, or rice milk

**Proteins**
- ☐ Eggs
☐ Skinless chicken breasts or ground chicken breast  
☐ Lean pork  
☐ Lean cuts or lean ground beef  
☐ Ground turkey or turkey breast  
☐ Nitrate and nitrite-free deli meats  
☐ Hummus  

**Fats and Oils**  
☐ Mayonnaise  
☐ Salad Dressings  
☐ Reduced  

**Other**  
☐ Beverages- 100% juices, tea, sports drinks, liquid nutrition supplements  
☐ Fat-free sour cream  
☐ Lemon juice, lime juice  
☐ Sauces and condiments like low sodium soy sauce  

**Freezer:**  

**Grains**  
☐ Frozen whole grain waffles  
☐ Whole grain breads, rolls, English muffins, bagels, etc.  

**Fruits/ Vegetables**  
☐ Frozen vegetables and fruits  
☐ Frozen juice concentrate (100% juice)  

**Dairy**  
☐ Frozen desserts: sherbet, frozen yogurt, ice cream  

**Proteins**  
☐ Chicken breasts  
☐ Fish such as tilapia, salmon, flounder  
☐ Shrimp  

**Other**  
☐ Popsicles
A cancer diagnosis brings with it practical concerns such as financial, emotional, and legal issues. If possible, it is best to address these concerns before you begin treatment because you may not want to deal with these issues when you are not feeling well. In the next few sections, you will find information on the following:

- Preparing financially for cancer
- Legal considerations
- Hospice and palliative care
- Finding emotional support

Financial Concerns and Cancer

A cancer diagnosis can cause financial concerns. Even if you have insurance, there are things you need to think about. Here are the questions you need to ask before you start treatment:

**Am I insured? Is my insurance going to cover the cost of treatment?**

- Before you begin treatment, take a look at your insurance plan to see what starting treatment will cost you.
- A portion of costs will be "out of pocket" with any insurance plan.
  - See if you can get this cost automatically taken out of your bank account or pay check or paid with a credit card.
- You have to meet your deductible before your insurance company will pay for care.
- As soon as possible, determine what your co-payment will be for each appointment and treatment.
  - Use this to make a budget for future treatments and doctor appointments
- Most insurance plans have the option for cancer patient to be assigned a case manager.
  - Be sure to ask for this service.
  - This person will be able to answer all your questions.
  - If your insurance company does not have a case manager service, ask to speak to the same representative each time you call.
  - If your insurance is through your employer, someone in HR will be able to answer questions about your coverage.
- You may need to find a supplemental program to cover fees that your primary insurance does not.

**What if I don’t have insurance?**
- State Medicaid: www.cms.gov
- Affordable Care Act: www.healthcare.gov/law/
- Your Local Health Department and Local Free Clinics: http://freeclinics.us/clinics/search

Can I afford treatment? What other expenses can I expect?

- Before you begin treatment, ask the billing department for the expected cost.
  - When you begin, your doctor will give you a treatment plan.
    - For example, you will do a certain number of rounds of chemotherapy or a certain number of weeks of radiation.
  - Take this plan to the billing department to get an estimate of the cost of your prescribed treatment plan.
  - The more information you get the better you can prepare.
- Ask the billing department if there are any ways you might be able to save money.
  - Many providers will give you a discount if you pay in full.
  - Ask if you can set up a payment plan where you pay a certain amount each month towards your bill.
- You will need to change your current budget to include costs related to your cancer diagnosis and care.

Are there options for treatment that are less expensive? Are these options just as effective? Am I eligible for a clinical trial?

- Ask your doctor and healthcare team these questions.
- Be sure to discuss all your treatment options with your healthcare team.
- Clinical trials are not more or less expensive than other treatments. Many insurance plans cover clinical trial treatments. Ask your doctor and healthcare team for more information.

Does my hospital or treatment center have options for financial assistance? Is there assistance I can apply for? Does my hospital have a reduced cost program? If so, what are the eligibility requirements?

- Many hospitals have options for financial assistance.
- Ask if there is someone you can talk to about your options.

What other costs should I expect?

- Additional expenses you need to consider include:
10 Financial Assistance Tips for Cancer Patients

Whatever your financial situation, a diagnosis of cancer can complicate your budget. Review these tips for greater financial peace of mind.

- **Understand your current and upcoming financial situation.**
  - Use the budgeting worksheets in this handbook to help you understand your regular income and expenses. Doing so can ensure that you are not blindsided by the impact of any extra expenses.
  - Learn about the costs of your treatment plan. Before you begin treatment, your doctor will prescribe a certain treatment plan; for example, a certain number of weeks of chemotherapy. The billing department of your doctor’s office or treatment facility may be able to give you an estimate.

- **Ask your doctor if there are more affordable options for treatment.**
  - Start with these questions: Are there less expensive treatment options? Would these options be as effective?

- **If you do not already have a system for handling your finances, now is the time to develop one.**
  - Decide how you will keep track of your finances moving forward. Will you keep handwritten records? Will you use a computer program? 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 have a customer service agent who is helpful.

- **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 track of everything in one place.

- **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.

- **When contacting the billing department, ask to speak with the same representative each time.**
• 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.

• Working with your insurance company and understanding your coverage will help you know all your options.
  o Many insurance companies offer case managers for diagnoses like cancer.

• Look to nonprofit organizations for help.
  o 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.
  o Examples of organizations include: churches, American Cancer Society, CancerCare, Salvation Army, and the United Way.
    • American Cancer Society: (800) 227-2345
    • CancerCare: (800) 813-HOPE (4673)
    • United Way: Dial 211 or visit www.211.org or www.unitedway.org.

• If you realize you are going to be late making a payment, be sure to call your creditors as soon as you can and let them know of your situation.
  o Some companies like your credit card or mortgage company might temporarily change your payment requirements or interest rate.

Managing My Health Insurance

Even with insurance, the cost of cancer is high and often requires lots of visits with primary care doctors and specialists for labs, tests, and treatment. Your insurance may not cover the cost of everything. You will 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 you start treatment, take a look at your insurance plan and see what is covered and what additional costs you will need to pay.
• 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 companies have a deductible. A deductible is the certain amount that you will have to pay before the insurance plan will start paying. Even with the deductible met, you may have to make co-payments.
• Always look in advance into what your co-payment will be for each appointment and treatment.

Make a budget.

Use coverage, co-pay, and deductible information to make a budget for future treatments and doctor’s appointments. This is also a good way to plan your new budget and not be surprised by the additional costs.

• Use the budgeting worksheets provided at the end of this handbook.

Submit everything to your insurance company.

Submit all of your medical expenses, regardless if 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.

Look for financial assistance.

If you are still having trouble managing costs, look to financial assistance programs. Forms of assistance include co-pay as well as premium assistance and prescription assistance programs. All financial assistance is usually dependent on income and cancer type.

The Basics of Medicare

Medicare is an insurance program run by the United States government. Medicare is for people who

• Are 65 years and older and are eligible for Social Security benefits
• Are receiving Social Security Disability Insurance and have completed a 2-year waiting period for Medicare
• Have Railroad Retirement/Disability benefits
• Have end-stage renal disease or Amyotrophic Lateral Sclerosis

Medicare has 4 types of possible coverage.

Part A (Hospital Insurance): Part A covers inpatient care. It is free for most Medicare recipients. The services covered by Part A include hospital care, skilled nursing facility care, nursing home care, hospice, and home health services.

Part B (Medical Insurance): Part B covers medically necessary services, meaning services or supplies that are needed to diagnose or treat your medical condition and meet accepted
standards of medical practice. Part B also covers preventive services such as healthcare to prevent illness or detect it at an early stage when treatment is most likely to work best. These services include clinical research, ambulance services, durable medical equipment, mental health, second opinion, and limited outpatient prescription drugs. Part B of Medicare does come at a cost. In most cases, participants pay a premium of about $105 a month.

Note: Part A and B usually cover 80% of costs for individuals, leaving 20% left for the individual to pay. (For example, if your bill is $4,000, Medicare would pay $3,200 and you would pay $800.) With this type of Medicare, there are Medigap programs to cover the additional 20%. These programs have a limited enrollment period; if that period is missed, you may lose access.

Part C (Medicare Advantage Plans): Part C plans are offered through private companies approved by Medicare. These plans cover all the services provided by Medicare Part A and Part B. These plans vary depending on location and have their own set premiums, deductibles, and co-pays.

Part D (Prescription Drugs): Part D may be covered by your premium if your income is below a certain amount. Otherwise, you will pay according to your income (no more than $69.30 a month).

If the cost of Medicare is too much, look to Medicare.gov for options to help pay your costs. Medicare.gov is also a great resource to look up what is specifically covered by Medicare.

I Am Uninsured. What Are My Options?

If you are uninsured or underinsured and have been diagnosed with cancer, you should know your 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 government.

- 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, you may qualify.

For the most up-to-date information on these expansions, visit healthcare.gov and the Kaiser Family Foundation at kff.org.

**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 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 COBRA.
- If you are eligible but have not signed up for COBRA, you may be able to pay past premiums and obtain COBRA coverage.

**Affordable Care Act:**

The Affordable Care Act (ACA) was signed into law in 2010. 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 the government-run healthcare marketplace if they do not have insurance through their employers or another source.

- Now that the March 31, 2014, enrollment deadline has passed, the only way to apply for coverage through the ACA marketplace is to see if you qualify for a special enrollment period.
- The enrollment period for 2015 will begin on November 15, 2014. In the meantime, you can look to healthcare.gov to see if you might qualify for a subsidy and what your deductible and premiums might be.
- 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, 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 at www.nafcclinics.org/clinics/search.
- 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 admissions office of the participating hospital to determine if you meet eligibility requirements.
- For more information, visit the US Department of Health and Human Services at www.hrsa.gov.

Finding Transportation

Transportation to and from treatment can be difficult to find and maintain. Some first steps to finding reliable transportation include the following:

- Always begin by asking your healthcare team if your treatment center provides transportation assistance.
- Try calling your insurance provider. Some insurance plans also provide help with transportation to and from treatment.

If neither of these options is helpful, try some of these resources:

The American Cancer Society's Road to Recovery

The American Cancer Society offers a volunteer-run service called Road to Recovery. This service provides transportation to and from treatment for people who have cancer and do not have a ride or are unable to drive themselves. Because this service is run by volunteers who donate their time and use their own cars, the drivers cannot usually drive long distances. Call (800) 227-2345 to learn how to schedule a ride in your area.

Public Transportation

Bus systems and local public transportation are good options. Most public transportation systems have door-to-door service options for medically needy and handicapped individuals. Note, however, that your healthcare team may advise you not to use public transportation if you have a weakened immune system.

Financial Assistance to Cover Gas Costs

If you are able to drive and have to travel a long distance, you may be able to find financial assistance to cover the gas costs of transporting yourself. There are multiple resources for this assistance including the American Cancer Society, CancerCare, and Grind for Life. These resources can provide a limited amount of financial assistance for the cost of gas or other costs of travelling, such as bus passes or the cost of medical transport. Also check with your
treatment center. Sometimes local organizations provide gas cards directly to treatment centers to distribute.

You can contact the organizations listed above using the following information:

- American Cancer Society: (800) 227-2345 or cancer.org.
- CancerCare: (800) 813-HOPE (4673) or www.cancercare.org.
- Grind for Life: (561) 252-3839 or www.grindforlife.org.

**Free or Reduced-Cost Flights**

Sometimes getting to treatment also includes having to fly for treatment. Angel Flight is an organization that provides free air transportation for medically necessary trips. They are a nonprofit of pilots and volunteers. You can contact Angel Flight by calling (918) 749-8992 or visiting www.angelflight.com.

**Finding Lodging**

A cancer diagnosis may require you to travel for doctor appointments and treatment. Some forms of treatment require you to visit a treatment center for multiple days in a row for weeks at a time. There are a couple of options to consider when having to make these kinds of extensive trips.

**Checking with Your Treatment Center**

If you need assistance finding or paying for lodging, tell your healthcare team as soon as possible. Some treatment centers have lodging coordinators especially if the center treats a lot of patients from out of town. Treatment centers may also have their own lodging such as a hospitality house. Ask your healthcare team if your treatment center has resources to help with lodging.

**American Cancer Society's Hope Lodge**

The American Cancer Society (ACS) sponsors Hope Lodges in most major cities throughout the country. It is free to stay at all the Hope Lodge locations. If you have an ACS Hope Lodge in your area, your oncology nurse or social worker should be able to help with the application process. This resource is not for those who are homeless. ACS will check to make sure you have somewhere to stay once you have checked out. To contact the American Cancer Society, call (800) 227-2345 or visit www.cancer.org.

**Hotels with Medical Rates**

For discount lodging, hotels with medical rates are a great option. Most major hotel chains offer medical rates for those who are travelling for medical treatment. Make sure you book your rooms in advance. The hotel may require proof from your doctor that you are traveling for medical reasons.

**Joe’s House**
The nonprofit Joe’s House provides an online nationwide database of places that offer lodging for cancer patients. Check out their website to determine options in your area. You can search by state, city, and even treatment center. The search results include nonprofit lodging as well as hotels that provide medical discounts. Visit Joe’s House at www.joeshouse.org.

**What Do I Need To Know About Social Security Disability Benefits and Cancer?**

Do you have a cancer diagnosis? Are you 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.
- Apply as soon as possible. The SAA denies most disability claims at first. You can 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.

- 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.
- 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.

**Advanced Directives**

Advanced directives or an advance care plan are legal papers. These papers tell your family and healthcare team your medical wishes. They are used in case you cannot make a medical decision. For example, if you are unconscious, your healthcare team and family will follow your advanced directives.

Advanced directives may differ by state. Your hospital or treatment center can give you the forms. Be sure to give your family members and healthcare team a copy of your advanced directives. If you change your mind about the kind of treatment you prefer, you can change your advanced directives.

Advanced directives may include living wills, medical power of attorney, or DNR orders. Here is a list of things to consider for your advance care plan:

- **Life support or use of equipment such as dialysis machines, ventilators, and respirators**
- **DNR (Do Not Resuscitate)**
  - DNR orders tell your healthcare team not to do CPR if your heart or breathing stops.
    - CPR (cardiopulmonary resuscitation)
      - First aid used when your heart or breathing stops. CPR can include chest compressions, electric shock, or medication.
- **DNI (Do Not Intubate) orders**
  - DNI orders tell your healthcare team not to put a tube through your nose or mouth to help you breathe.
- **Artificial nutrition and hydration**
  - If you are unable to eat or drink, your healthcare team will provide you with nutrition and fluids through an IV or feeding tube.
- **Treatment of new conditions**
- **Organ and tissue donation**
- **Medical Power of Attorney**
  - Medical power of attorney lets you name another person, such as a family member or close friend, who can make decisions about your medical care if you cannot.
  - This may also be called a healthcare proxy, appointment of healthcare agent, or durable power of attorney.
Most states will not allow anyone on your healthcare team to be your medical power of attorney.

A cancer diagnosis can be a stressful time. It may be scary to consider these issues before you are very sick. However, it is important to think about these issues early. You will not want to deal with them when you are feeling very ill.

Palliative and Hospice Care

At some point in your cancer journey, you may need to consider palliative care or hospice. Palliative care is a treatment that helps relieve pain and symptoms but does not provide a cure. Palliative care can be used along with your prescribed cancer treatment. Hospice is a type of palliative care. Specifically, hospice is end-of-life care. Both palliative care and hospice aim to improve quality of life. Talk with your healthcare team about what is best for you. Below you will find more information about hospice and palliative care. Use the questions at the end to guide talks with your healthcare team.

- Palliative care
  - Palliative care helps relieve pain and symptoms but does not provide a cure.
  - You may use palliative care at any point during your cancer journey. A patient does not have to be terminal to receive palliative care.
  - Palliative care can be combined with other forms of treatment.
  - You may use palliative care to manage side effects from treatment.
  - Some forms of palliative care may be covered by Medicare, Medicaid, or other insurance plans. Often, costs for palliative care fall on the individual.

- Hospice
  - Hospice is a type of palliative care.
  - Hospice is end-of-life care. Terminal patients with a life expectancy of six months or less often use hospice.
  - Hospice care is not usually given at the same time as other curative treatments. Hospice is given after treatment options have been exhausted.
  - Medicare pays for all hospice costs. In most states, Medicaid pays for hospice costs. Most other insurance plans have hospice benefits.

- Questions to Ask Your Healthcare Team
  - Should I consider palliative care now or in the near future?
  - Will my insurance cover my palliative care?
  - How long can I get palliative care?
  - Where will I get my palliative care?
  - Can I still do treatment for my illness while doing palliative care?
  - Should I consider hospice care now or in the near future?
  - Will insurance cover my hospice care?
  - If my life expectancy is longer than six months, can I still get hospice care?
o Can I get hospice care in my home?
o Who will be caring for me? Will they be doctors, nurses, social workers, or home health aides?
o What legal issues such as advanced directives, living wills, or medical power of attorney should I think about?

Emotional Support Programs

A cancer diagnosis can make you feel anxious and depressed. This is normal. It may help to talk to someone. It can be especially helpful to connect with other survivors and patients. 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

  o Connects you with a group of people in a similar situation
  o Support groups meet on a regular basis.
  o Support groups meet online, over the phone, or face-to-face.
  o Ask your healthcare team about local support groups.
  o Licensed social workers or other medical professionals facilitate most support groups.
  o Support groups can be for current cancer patients, survivors, or family members.
  o Some groups are defined by diagnosis, age, or sex.
  o 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.
  o Where can you find support groups?
    o Your hospital or treatment center
    o Your local American Cancer Society chapter
      ▪ Visit cancer.org or call (800) 227-2345.
    o Cancer Support Community
      ▪ This includes The Wellness Community and Gilda’s Club.
      ▪ Visit cancersupportcommunity.org or call (888) 793-9355.
    o CancerCare
      ▪ Visit cancercare.org or call (800) 813- HOPE (4673).

• Connect with a Fellow Survivor

  o One-on-one partnering programs will match you with a fellow cancer survivor. This person may have a similar diagnosis and may be finished with treatment.
  o These allow for a more personal connection.
  o Most programs are for family members as well as patients.
  o Usually these programs are run through phone or email.
  o How can you connect with a fellow survivor?
    o 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.
Even after treatment ends, your cancer journey continues. Many cancer survivors refer to the time after treatment ends as the “new normal.” 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.

Screening Recommendations and Follow-Up Care

Follow-up care after completing non-Hodgkin Lymphoma 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 may need follow-up exams every few months for several years so your healthcare team can closely monitor your health.
  - Your follow-up care will depend on your type of lymphoma as well as what treatments you received.
  - Be sure you tell your doctor about any symptoms or changes in your well-being.
- Follow your recommended screening schedule.
  - You may need blood work or computerized tomography (CT) scans or positron emission tomography (PET) scans to check for signs of recurrence.
- If you change your primary care physician, make sure your new doctor has all your medical records and history.
- Tell your doctor about any side effects.
  - Some side effects occur after treatment ends. Let you healthcare team know of any and all changes so they can help you manage them effectively.
- Keep your health insurance if at all possible.
  - Follow-up care, especially imaging, can be very expensive if you do not have health insurance.

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 against 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).
- A 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 64 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.

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

Achieve and maintain a healthy body weight for your height.

1. Eat healthy by following the guidelines on this handout.
2. Consult with a registered dietitian to determine individual energy needs and a realistic goal weight.
3. Monitor food intake and measure portion sizes.
4. Begin to track food intake in a journal.

Exercise

- If not currently exercising, gradually work toward 45-60 minutes daily. This can be split up into 10 or more minute increments 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 first 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 not any nutrients.
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? Education, the environment, animals. 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.
- **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 equal.

**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.

**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 and 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 immunizations schedule recommended by the CDC for people with weakened immune systems, such as cancer survivors.

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

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: PVV13 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.

**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.

**Why should I quit?**

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

<table>
<thead>
<tr>
<th>Time Since Quitting</th>
<th>Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 minutes</td>
<td>Blood pressure and heart rate drop</td>
</tr>
<tr>
<td>12 hours</td>
<td>CO2 levels in blood stream return to normal*</td>
</tr>
<tr>
<td>3 months – 9 months</td>
<td>Circulation and lung function improve</td>
</tr>
<tr>
<td>1 year</td>
<td>Risk of heart disease cut in half</td>
</tr>
<tr>
<td>---------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>5 years</td>
<td>Risk of mouth, throat, esophageal, and bladder cancer cut in half</td>
</tr>
<tr>
<td>10 years</td>
<td>One-half as likely to die from lung cancer, and risk of laryngeal and pancreatic cancer decreases</td>
</tr>
<tr>
<td>15 years</td>
<td>Risk of heart disease is the same as a non-smoker's</td>
</tr>
</tbody>
</table>

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 dependency 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.
  o 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.
  o What triggers your cravings—stress, food, other people smoking?
  o Avoid triggers if at all possible.
  o 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.
  o Other tobacco products can also increase your risk for cancer and diseases.
  o 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

Call (800) Quit-Now to connect with your state’s helpline.
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.

- About My Cancer
- Questions for Your Healthcare Team
- My Medical History
- Appointment Notes
- My Healthcare Team Contact List
- Treatments and Side Effects Logs
- Budgeting Worksheets
- Calendars
Questions for Your Healthcare Team

When you are diagnosed with cancer, you may feel overwhelmed with information. Ask your oncologist the following questions to make sure you have the answers you need.

What is my diagnosis?
__________________________________________________________________________________________
__________________________________________________________________________________________

What stage is my cancer? What is my prognosis?
__________________________________________________________________________________________
__________________________________________________________________________________________

What are my treatment options? What would you recommend?
__________________________________________________________________________________________
__________________________________________________________________________________________

Am I eligible for a clinical trial?
__________________________________________________________________________________________
__________________________________________________________________________________________

What are the long-term and short-term side effects of treatment? How will these affect my normal activities?
__________________________________________________________________________________________
__________________________________________________________________________________________

How can I manage these side effects?
__________________________________________________________________________________________
__________________________________________________________________________________________

How can I keep myself as healthy as possible during treatment?
__________________________________________________________________________________________
__________________________________________________________________________________________
Will I be able to have children? What are my options to preserve fertility?
________________________________________________________________________
________________________________________________________________________

Where can I find help with financial concerns?
________________________________________________________________________
________________________________________________________________________

Where can I find help with lodging or transportation?
________________________________________________________________________
________________________________________________________________________

What will my follow-up care plan include?
________________________________________________________________________
________________________________________________________________________
My Medical History

Your healthcare 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 in the past.

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Description</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
My Medical History (continued)

Family Medical History

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

<table>
<thead>
<tr>
<th>Condition</th>
<th>Relation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td></td>
</tr>
<tr>
<td>Blood Clots</td>
<td></td>
</tr>
<tr>
<td>Cancer (List Cancer Type)</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
</tr>
<tr>
<td>Heart Disease</td>
<td></td>
</tr>
<tr>
<td>High Blood Pressure</td>
<td></td>
</tr>
<tr>
<td>High Cholesterol</td>
<td></td>
</tr>
<tr>
<td>Blood Clots</td>
<td></td>
</tr>
<tr>
<td>Low Blood Pressure</td>
<td></td>
</tr>
<tr>
<td>Kidney Disease</td>
<td></td>
</tr>
<tr>
<td>Lung Disease</td>
<td></td>
</tr>
<tr>
<td>Irritable Bowel Syndrome</td>
<td></td>
</tr>
<tr>
<td>Liver Disease</td>
<td></td>
</tr>
<tr>
<td>Colitis</td>
<td></td>
</tr>
<tr>
<td>AIDS/HIV</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

Do you know any other pertinent family medical history?

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

PearlPoint Cancer Support
My Medical History (continued)

Current Medications and Allergies

Please list all current medications, including any vitamins, supplements, or over-the-counter medications.

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Dosage and Time</th>
<th>Reason Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
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</tbody>
</table>

List all allergies.

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
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:
Account Number:
Policy Holder’s Name:
Patient’s Relation to Insured:

Secondary Insurance Provider:
Account Number:
Policy Holder’s Name:
Patient’s Relation to Insured:
Appointment Notes

Take notes on all the new information your healthcare team provides at appointments. Write down any new instructions, medications, treatment plans, etc., so you can reference them later.

Date: ______________  Doctor: __________________

________________________________________________________________________

List lab work, imaging, or other tests.

<table>
<thead>
<tr>
<th>Test &amp; Date</th>
<th>Purpose</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Test:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
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</tr>
</tbody>
</table>

Next Appointment: ________________________________________________
### 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.

<table>
<thead>
<tr>
<th>Name</th>
<th>Contact Info</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver</td>
<td>Phone: Phone: Fax: Email: Address:</td>
</tr>
<tr>
<td>Primary Care Doctor</td>
<td>Phone: Phone: Fax: Email: Address:</td>
</tr>
<tr>
<td>Oncologist</td>
<td>Phone: Phone: Fax: Email: Address:</td>
</tr>
<tr>
<td>Nurse</td>
<td>Phone: Phone: Fax: Email: Address:</td>
</tr>
<tr>
<td>Name</td>
<td>Contact Info</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>Radiation Oncologist</td>
<td>Phone: Phone: Fax: Email: Address:</td>
</tr>
<tr>
<td>Surgeon</td>
<td>Phone: Phone: Fax: Email: Address:</td>
</tr>
<tr>
<td>Hospital</td>
<td>Phone: Phone: Fax: Email: Address:</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Phone: Phone: Fax: Email: Address:</td>
</tr>
<tr>
<td>Name</td>
<td>Contact Info</td>
</tr>
<tr>
<td>------</td>
<td>--------------</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
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<td>Phone:</td>
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<td>Fax:</td>
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<td>Email:</td>
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<td>Email:</td>
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<td>Address:</td>
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</tbody>
</table>
Treatments and Side Effects Log

Keeping track of your treatments, medications, side effects, and overall well-being is very important during your cancer journey. How your nutrition, activities, and medications affect the way you feel can provide insight for you and your healthcare team.

Date(s)/Week: ____________

**Treatments or procedures:**
Include specific dates, descriptions, and medications given.

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

**Foods Eaten:**

<table>
<thead>
<tr>
<th></th>
<th>Breakfast</th>
<th>Lunch</th>
<th>Dinner</th>
<th>Snacks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

**Activity or Exercise:**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
## Treatments and Side Effects Log (continued)

### Medications:

<table>
<thead>
<tr>
<th>Name</th>
<th>Dosage &amp; Time</th>
<th>Reason Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Current Weight: _______  Physical Well-Being*: _______  Emotional Well-Being*: _______

*On a scale of 1-10. 10 = feeling your best. 1 = feeling your worst.
## Treatments and Side Effects Log (continued)

### Side Effects:
Record all side effects experienced by checking mild, moderate, or severe. If none, leave blank.

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in taste and smell</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty swallowing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dry mouth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling full quickly</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gas and bloating</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hair loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lactose intolerance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of appetite</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphedema</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuropathy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin changes (blisters, rashes, itchy, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sore mouth, throat, or tongue</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight gain</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For help managing side effects, visit [Nutrition Tips for Managing Side Effects](#), or download PearlPoint’s new Cancer Side Effects Helper app to your smart phone.

### Notes:

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

To keep track of this information online, visit *My PearlPoint* (my.pearlpoint.org) to create a personalized dashboard. On your dashboard, you can virtually track your well-being and save notes on your progress.
Budgeting Worksheets

<table>
<thead>
<tr>
<th>Sources of Income</th>
<th>Expected:</th>
<th>Actual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSI/SSDI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment Benefits: Short-Term Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Have you had to stop working due to your diagnosis? Have you considered applying for Social Security Disability Insurance?

<table>
<thead>
<tr>
<th>Monthly Expenses</th>
<th>Expected:</th>
<th>Actual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortgage/Rent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Energy Bill/ Gas Bill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water Bill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Groceries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Credit Cards</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Car Payment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gasoline</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loans</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home/Cell Phone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housecleaning/Landscaping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance Premiums (health, life, home, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clothing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Fees</td>
<td></td>
<td></td>
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<tr>
<td>Total</td>
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</table>

To reduce these costs, have you considered:

- Are you eligible for Food Stamps?
- Are you able to get assistance with your electric bill from Low Income Heating Energy Assistance Program (LIHEAP)?
- Is there a local free cleaning service in your area? (For example, Cleaning for a Reason)
- Do you qualify for government assistance for housing, child care, or cell phone?
Budgeting Worksheets (continued)

<table>
<thead>
<tr>
<th>Medical Expenses:</th>
<th>Expected:</th>
<th>Actual:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance Deductible</td>
<td></td>
<td></td>
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<tr>
<td>Co-Payments</td>
<td></td>
<td></td>
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<tr>
<td>Prescriptions</td>
<td></td>
<td></td>
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<tr>
<td>Transportation (parking fees, flights, etc.)</td>
<td></td>
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<tr>
<td>Medical Supplies</td>
<td></td>
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<tr>
<td>Caregiving/Home Care</td>
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<tr>
<td>Supplements</td>
<td></td>
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<tr>
<td>Mental Health Care</td>
<td></td>
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<tr>
<td>Legal Services</td>
<td></td>
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<tr>
<td>Travel</td>
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<tr>
<td>Assistance Received:</td>
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</tbody>
</table>

Possible sources of assistance:

- Have you considered a prescription assistance resource like NeedyMeds to reduce costs of prescriptions? Call (800) 530-6987 or visit www.needymeds.org.
- Are you eligible for co-pay assistance based on cancer type?
- Can you reduce transportation and gas costs through resources like Road to Recovery or CancerCare?
  - For Read to Recovery call the American Cancer society at (800) 227-2345 or visit www.cancer.org.
  - Call CancerCare at (800) 813-HOPE (4673) or visit www.cancercare.org.
- Is there a sliding scale resource in your area for mental health services?

<table>
<thead>
<tr>
<th></th>
<th>Expected:</th>
<th>Actual:</th>
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</thead>
<tbody>
<tr>
<td>Total Income:</td>
<td></td>
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<tr>
<td>Total Expenses (Monthly/Medical):</td>
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<tr>
<td>After Expenses: (Total Income – Total Expenses = After Expenses)</td>
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</table>
Budgeting Worksheets (continued)

Financial Assistance

When applying for financial assistance, keep track of your applications (as outlined in the chart below) to make sure you submit everything and hear back from the programs in a timely manner. You may have to follow up with some programs. If a program provides reoccurring support, you will want to make note of that in the frequency column.

<table>
<thead>
<tr>
<th>Assistance Organization:</th>
<th>Date Applied:</th>
<th>Status:</th>
<th>Frequency:</th>
<th>Amount:</th>
<th>Need:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ex: CancerCare</td>
<td>2/11/14</td>
<td>Applied</td>
<td>One-Time</td>
<td>$125</td>
<td>Gas</td>
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Calendars

Month: ________________

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<tr>
<th>Sunday</th>
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<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
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Notes:
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PearlPoint Cancer Support
## Calendars (continued)

**Week:** ______________________________________

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<th>Friday</th>
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<table>
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<tr>
<th>Saturday/Sunday</th>
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</table>

**Notes:**

___________________________________________________________________________

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___________________________________________________________________________

___________________________________________________________________________
Appointment Details

Use this sheet to plan the details of your appointments in advance.

Date:
Time:
Location:

Provider:
Reason:
- Office visit
- Imaging
- Lab work
- Surgery
- Treatment
- Other _____________

Transportation:
________________________________________________________________
_________________________________________________________________

Lodging:
_________________________________________________________________
_________________________________________________________________

Notes:
_________________________________________________________________
_________________________________________________________________
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.
my.pearlpoint.org
(877) 467-1936 X 101
guidance@pearlpoint.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, we 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.
www.cancer.org
(800) 4-CANCER

Leukemia & Lymphoma Society
The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health agency dedicated to blood cancer. The LLS mission: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. LLS funds lifesaving blood cancer research around the world and provides free information and support services.
www.lls.org
(888) LLS-7177